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Younger onset dementia: a literature review

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Abstract

Evidence underpinning services and supports for people with younger onset dementia is an emerging field. Much of the information available to date has been descriptive or based on expert opinion, with limited empirical studies regarding the efficacy of particular approaches. However, this is changing in response to the increasing recognition of the different aetiologies, trajectories and implications of the diagnosis for people who are aged less than 65 years at onset. This Literature Review is the first part of a two - stage project funded by the Australian Government to inform the development of services and supports for people with younger onset dementia and their families. Preliminary findings have been used to shape the national consultations that were conducted as part of the needs and feasibility analysis.

Keywords

literature, dementia, review, onset, younger

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CHSD
centre for health service development

Younger Onset Dementia: A Literature Review

January 2014

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australian health services research institute
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Glossary of Abbreviations

AA	Alzheimer's Association - usually followed by the notation for the country
ABS	Australian Bureau of Statistics
ACAT	Aged Care Assessment Team
ACAP	Aged Care Assessment Program
ACON	AIDS Council of NSW
AD	Alzheimer's disease
ADAHPS	AIDS Dementia and HIV Psychiatry Service
ADI	Alzheimer's disease International
ADHC	Ageing, Disability and Home Care
ADL	Activity of Daily Living
AHSRI	Australian Health Services Research Institute
AIHW	Australian Institute of Health and Welfare
AlzNSW	Alzheimer's Australia NSW
APP	Amyloid Precursor Protein
ARBD	Alcohol related dementia or alcohol related brain damage
BPSD	Behavioural and psychological symptoms of dementia
bvFTD	Behavioural variant fronto temporal dementia
CACP	Community Aged Care Package
CADASIL	Cerebral autosomal dominant ateriopathy with subcortical infarcts
CALD	Culturally and Linguistically Diverse
CANDID	Counselling and Diagnosis in Dementia
cART	Combination antiretroviral treatment
CANE	Camberwell Need Assessment for the Elderly
CI	Confidence interval
CIRCA	Cultural & Indigenous Research Centre Australia
CDC	Consumer Directed Care
CLAN	Care Leavers Australia Network
CLBD	Dementia with Cortical Lewy Bodies
CNC	Clinical Nurse Consultant
COAG	Council of Australian Governments
COTA	Council on The Ageing
DAC	Disability Ageing and Carers
DADHC	NSW Department of Ageing, Disability and Home Care
DAE	Deloitte Access Economics
DAS	Dementia Advisory Service
DBMAS	Dementia Behaviour Management Advisory Service
DCRC	Dementia Collaborative Research Centre
DLB	Dementia with Cortical Lewy Bodies
DoHA	Department of Health and Ageing (Australian Government)
DS	Down Syndrome
DVD	Digital Versatile Disc
DYNOPTA	Dynamic Analysis to Optimise Ageing
EACH	Extended Aged Care at Home
EACHD	Extended Aged Care at Home Dementia

EOAD	Early onset Alzheimer's disease
EOD	Early onset dementia
EOFTD	Early Onset Fronto Temporal Dementia
ESD	Early Stage Dementia
FaHCSIA	Australian Government Department of Housing, Community Services and Indigenous Affairs
FINALEX	Finnish Alzheimer's Disease Exercise Trial
FTD	Fronto Temporal Dementia
GP	General Practitioner
HAART	Highly active antiretroviral treatment
HACC	Home and Community Care
HAD/ADC	HIV Associated Dementia/AIDS dementia complex
HADS	Hospital Anxiety Depression Scale
HAND	HIV associated neuro-cognitive disorder
HIV/AIDS	Human Immunodeficiency Virus/Acquired Immune Deficiency Syndrome
HD	Huntington's disease
HRQOL	Health Related Quality of Life
IADL	Instrumental activities of daily living
IPA	Interpretive Phenomenological Analysis
KGOWS	Koori Growing Older Well Study
KICA-Cog	Kimberley Indigenous Cognitive Assessment
LGBTI	Lesbian Gay Bisexual Transgender Intersex
LHD	Local Health District
LWML	Living With Memory Loss
GP	General Practitioner
LOAD	Late Onset Alzheimer's disease
LOD	Late onset dementia
MCCI	Multicultural Communities Council Illawarra
MID	Multi-infarct dementia
MND	Motor Neuron disease
MS	Multiple Sclerosis
NDIS	National Disability Insurance Scheme
NPI	Neuropsychiatric Inventory
NRCP	National Respite for Carers Program
NYODCP	Netherlands Younger Onset Dementia Care Program
OAP	Old Age Psychiatry
PD	Parkinson's disease
PLWD	People Living with Dementia
PNFA	Progressive Non Fluent Aphasia
PPA	Primary Progressive Aphasia
PWFTD	People with Fronto-temporal dementia
RACF	Residential Aged Care Facility
RACPG	Royal Australian College of General Practitioners
RUDAS	Rowland Universal Dementia Assessment Scale
RUD	Resource Utilisation in Dementia
SD	Semantic dementia
SPRC	Social Policy Research Centre
SPSS	Statistics Package for Social Sciences

TBI	Traumatic brain injury
UK	United Kingdom
UNSW	University of New South Wales
VaD	Vascular dementia
YOAD	Young onset Alzheimer's disease
YOD	Younger Onset Dementia
YPWD	Young people with dementia
ZBI	Zarit Burden Interview

Executive Summary

Evidence underpinning services and supports for people with younger onset dementia is an emerging field. Much of the information available to date has been descriptive or based on expert opinion, with limited empirical studies regarding the efficacy of particular approaches. However, this is changing in response to the increasing recognition of the different aetiologies, trajectories and implications of the diagnosis for people who are aged less than 65 years at onset.

This Literature Review is the first part of a two-stage project funded by the Australian Government to inform the development of services and supports for people with younger onset dementia and their families. Preliminary findings have been used to shape the national consultations that were conducted as part of the needs and feasibility analysis.

Research methods

The review employed a rigorous search strategy to identify literature related to services and needs of people with younger onset dementia. It included a broad conceptualisation of 'younger onset dementia', and considered literature from within the disability, chronic health, business and volunteer sectors as well as the traditional aged care and mental health paradigms where the majority of dementia literature currently resides. Included for consideration have been the social, economic and environmental factors that enable and support people with younger onset dementia. The rationale for this approach was the potential of these other sectors to have developed models of care and support that could inform service development for people with younger onset dementia.

Likewise, we have broadened the definition of the term 'younger onset dementia' in our search terms, given the reviews to date have predominantly focused on Alzheimer's disease and, to some extent, fronto-temporal dementia. Our search included groups that have neuro-cognitive deficits associated with illnesses such as HIV/AIDS, Parkinson's disease, alcohol or drug abuse, Huntington's chorea, Down syndrome and Multiple Sclerosis. The rationale for their inclusion was the potential for these groups to have developed service models that could also be appropriate for the broader younger onset dementia cohort. We have also included contextual factors such as living arrangements, with a particular search for information on those living alone.

This review was conducted between September and December 2013, including over 300 journal articles, reports, presentations and websites out of the 425 yielded from the search strategy. Further details of the search strategy are provided in Section 2.

Overview of Younger Onset Dementia

The introductory overview (Section 3) describes the different types of younger onset dementia and has noted the similarities and differences in the range of symptoms for these subtypes.

The overlapping of some symptoms across younger onset dementia types has made differential diagnosis complex and difficult. Problems experienced by people with younger onset dementia in obtaining a diagnosis, including the lengthy time to diagnosis and frequent initial misdiagnosis, is a common theme in this literature. Although this issue has been reported for

many years it still remains a major issue for service improvement. Some studies have reported a greater presence of behavioural and psychological symptoms (BPSD) for some sub-types such as fronto-temporal dementia (FTD) but the evidence is as yet equivocal; however, BPSD appear to be relatively common for most types which adds to the needs and care requirements for people with younger onset dementia.

As the onset of younger onset dementia commonly occurs in people aged between 40 – 65 years it occurs at an earlier period in the life cycle stage. This earlier onset raises a number of issues for people with younger onset dementia including loss or diminishment in roles such as provider, parent and spouse and the significant adjustment to those changes that is required. Many people consequently experience financial difficulties arising from the loss of income and additional care costs.

As people with younger onset dementia are younger they are often physically healthy and active and may not experience the co-morbidities that are associated with later onset dementia. Another common theme in this literature is the need for access to individually tailored, person centred services and the need for existing services to provide programs/services that are more age-appropriate for people with younger onset dementia.

Some types of younger onset dementia are more preventable. These include alcohol related brain damage or alcohol related dementias (ARBD), which recent prevalence studies indicate is more common in Australia than elsewhere. Recent findings concerning potent combination antiretroviral treatments for HIV/AIDS appear to be reducing the incidence of this form of younger onset dementia, reminding us that new treatments have the potential to affect both the incidence and the prevalence of younger onset dementia, highlighting the importance of ongoing biomedical research.

Huntington's disease (HD), Down's syndrome and some forms of Alzheimer's disease (AD) are more strongly associated with genetic risk factors. Obviously for groups so affected provision of genetic counselling and clear information is of prime importance.

The limited literature available indicates there is quite a long period from onset of symptoms to permanent residential care placement for people with younger onset dementia (e.g. 6-9 years) and that the level of informal care provided is high which places a significant burden on these families. Although some studies indicate a relatively high use of institutional services for this group (e.g. hospital admissions, nursing home respite etc.) authors also report that community service use is relatively low for this group. Many authors suggest the need for a central gateway to services for people with younger onset dementia or the adoption of case-management and key worker approaches.

Research gaps

There are significant research issues and gaps relating to prevalence, incidence, life expectancy and the proportions of people that are diagnosed with the various sub-types of younger onset dementia. More accurate and up to date Australian estimates will be critical for service planning purposes. There are few studies that comprehensively examine service utilisation and the costs of illness for the younger onset dementia group or that include consideration of social and informal care costs. Likewise, there are relatively few studies that examine the cost

effectiveness of both pharmacological and non-pharmacological for dementia overall, let alone for people with younger onset dementia.

Living with younger onset dementia

The experience, issues and stated need of people with younger onset dementia, their carers and families are explored in Section 4. There were quite a few studies reviewed that interviewed people with younger onset dementia directly about their own experience of living with dementia. Many could be characterised as qualitative thematic analyses of interviews usually based on very small sample sizes. The challenges faced were of both a personal and systemic nature.

Personal challenges related to adjusting to dementia and coping with role changes, such as loss of independence, loss of employment, loss of empowerment, and needing to rebuild and restructure one's life. Loss of empowerment was associated with the feeling that involvement in decision making was being denied to people with younger onset dementia, often by well-meaning carers or service staff. There was a desire expressed by many to remain involved and to get on with their lives as best they could.

Systemic challenges were problems associated with obtaining a diagnosis (length of time taken, earlier misdiagnoses), feeling stigmatised because of the dementia 'label', a lack of referrals to support services, falling between the cracks of service systems, a lack of access to age appropriate services and programs, and financial problems.

While some authors recommend further research on the 'experience' of people with younger onset dementia, we believe that 'more of the same' research is actually not required. What is required are a few well-funded studies with better research designs, larger sample sizes, a triangulation of methods of outcome assessment, and consideration of the control of extraneous variables/ confounding factors. The previous studies have provided valuable insights but the level of evidence is 'weak'. However, what is clear from the research is that the involvement and participation of people with younger onset dementia in service design, development and evaluation should become part of routine practice.

Despite explicit searching, no studies were found that considered the needs of people with younger onset dementia who lived alone or those that have no familial carer. Although it has been estimated that approximately one third of people with dementia live alone there is little data available in the younger onset dementia research literature and yet this is a group that is likely to have high service needs. It might well be that premature placement in residential care facilities may be an issue for this group and this needs to be further explored. Similarly the issue of parental carers for people with younger onset dementia does not appear to have been explored.

The experience of spouses revealed similar themes to that of the person with younger onset dementia, along with some additional challenges. The familiar theme was the long quest to obtain a diagnosis and adjusting to that diagnosis. This is particularly important as spouses often report deterioration in their relationship arising from changed behaviours in the lead-up to the formal diagnosis.

In addition, issues included managing BPSD, changing roles, grief associated with the 'loss' of spouse (as they were) and their future plans, juggling the caring role with other family and daily life responsibilities including employment, and difficulties in making new plans for the future. Other studies report that social isolation may be quite common amongst spousal carers. These issues also need to be addressed by support services.

Some authors note there are different phases of the couple's relationship which can be characterised as progressing from sustaining their 'couplehood', through maintaining their involvement and in the end stages to 'moving on' (e.g. moving from a 'we' focus to an 'I' focus) which may actually be a necessary developmental step. Although many of the studies report negative effects on the spouse such as carer burden, many couples have a positive focus on their predicament and try to maximise their quality of life and to maintain their relationship. Some carers have reported developing higher self-esteem and assertiveness as a function of undertaking their caring role. Factors that need further investigation concern the nature of the couple's relationship at symptom onset and through the illness progression, the effectiveness of the coping strategies that spouses use and the identification of precursors of poor coping strategies in spousal carers.

Some carer studies have included mixed groups of carers in their studies (spouses, children, other relatives, formal carers, ex carers) although most of these studies include a large number of spouses/partners. However, studies that use mixed carer groups or combine both the person with younger onset dementia and carer feedback run the risk of ignoring particular issues for these groups. As noted above, although some of the issues raised are in common, each group is likely to have its own, slightly different perspective on each issue. An example of this is the area of unmet needs where people with younger onset dementia rate psychological distress as a more common unmet need than do carers or professionals.

A number of these studies have used more quantitative approaches, such as including the use of standardised scales to assess carer burden, stress, carer and patient unmet needs, the presence of psychiatric symptoms amongst carers, and health related quality of life and well-being. Generally these studies indicate high levels of stress and burden for carers, poorer quality of life, and unmet needs including social isolation, depression and anxiety.

Some recent studies have used person with younger onset dementia - carer dyads to explore these themes and the value of dyad studies is that data relating to the person (e.g. severity, presence of BPSD etc.) can be directly related to carer findings and vice versa, which provides for a somewhat higher level of evidence. Similarly, some studies are now using comparator groups where the younger onset dementia group is compared to a later onset dementia group. Unfortunately many of these initial studies have poor control of confounding factors such as the duration of the caring period, age and the diagnostic composition of the comparator groups. Many studies are cross-sectional so do not address the course of the dementia and while recent studies from the Netherlands are addressing this research gap, there is a clear need for further longitudinal research.

Relatively fewer studies have interviewed or surveyed children of people with younger onset dementia with regard to their experience and in most cases the sample sizes are again very small which limits the degree to which these findings can be generalised. The literature on the effect on children having a parent with dementia makes mention of perceived stigma and

associated shame/ embarrassment, bewilderment, family conflict, high care burden, the physical challenge of caring, psychological issues and problems at school. Many of these children are undertaking a demanding caring role (sometimes becoming a 'parent' to a parent) while also facing the usual development challenges of growing up. Coping strategies, family cohesion and security of attachment are raised as issues but little research has been conducted directly on these topics. Some children reported there positive effects of their caring role, such as maturation and the experience they have gained, despite the challenges. However, it is clear these children have substantial needs for support and due to the care burden placed upon them may have a potential for psychological and social disadvantage that needs to be further explored.

A few studies have focussed on issues concerning rarer forms of younger onset dementia. Some comparative studies have suggested that carer burden may be higher for carers of people with FTD but it is not directly related to the number of BPSD as these have been found to be similar across comparator groups. The issue might not be the total number of BPSD symptoms the person displays but the type of BPSD symptoms and their frequency. These factors might also interact with carer and other socio-demographic variables and multivariate techniques might be required to gain a further understanding of these elements.

Some forms of younger onset dementia also have quite a different presentation as occurs with Down syndrome and dementia where the carer has experienced the caring role often since the childhood of the client. Although one study noted the provision of informal care was much greater for people with Down syndrome and dementia, another study suggested these carers were more settled in their caring roles and less prone to experience issues such as 'burn-out' or health related issues than for other younger onset dementia groups. This may require further exploration as the literature is sparse.

Despite the numerous attempts by organisations such as the Alzheimer's Association to provide comprehensive information across a range of forums, including the internet, the need for clear information and advice is still mentioned as an unmet need for carers and patients.

Service design

Issues concerning service design and development are addressed in Section 5. It provides both a policy context and an evidence base regarding how service providers, regardless of the source of funding, can build their capacity to deliver services to people with younger onset dementia. The fundamental premise for service provision for younger onset dementia is that services must be individually tailored due to the significant diversity across the younger onset dementia population. This section also explores the current, changing policy context for younger onset dementia service delivery in Australia.

A set of overarching principles for service design and development for delivering services to people with younger onset dementia have been described that can be applied to service provision for people with younger onset dementia in a variety of contexts such as health care, disability or aged care and community based services. These have been grouped into three main categories of principles of service design:

Individualised model of service:

- Listening to people with younger onset dementia and their carers
- Individualised service planning / a person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognition of the diversity among the many younger onset dementia diagnostic groups and the special needs of individuals.

Staff attributes:

- Appropriately skilled and suitable staff
- An holistic approach
- An enabling and consumer centred approach
- Case management skills
- Effective communication
- Flexibility.

Organisational attributes:

- Access to integrated specialist diagnostic and ongoing symptom management services
- Capacity for organisational change
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Ability to cater for needs of people in rural and remote communities
- Individualised service planning / person centred approach
- Respect and consideration for clients and carers
- Effective risk management strategies
- Appropriate exit policies relating to the suspension and withdrawal of services.

A range of programs were identified in Section 6 for people with dementia, their carers and family members. The majority of programs were aimed at the person with dementia and/or their carer and only a few programs were aimed at other family members. The majority of studies that evaluated programs generally provided only a low level of evidence. However, there are some types of programs that were identified that can be considered helpful or that may warrant further research.

Programs that have been shown to be helpful include:

- tailored physical activity programs;
- Support programs such as peer support and carer support groups, as well as those that include both the person with dementia and the carer. While studies usually involved support programs that were face to face, the facilitation of support groups through communication technology, such as email and videoconferencing, showed promise;
- Information and education services such as the Living with Memory Loss program provided through Alzheimer's Australia and,
- Cognitive stimulation programs.

Likewise, programs that provide active meaningful participation, including horticulture, volunteering or supported workplaces and creative expression programs also warrant further study with people who have younger onset dementia.

While the need individually tailored support programs such as case management and key workers is clear, their mode of operation and purported outcomes require further research.

In Section 7 the service needs of special needs groups are discussed. Australian Commonwealth legislation (Aged Care Act 1997, as amended 2013) recognises a range of people as having special needs with regard to access and equity which must be considered as an integral part of service planning, development and delivery. These include people from:

- Aboriginal and Torres Strait Islander communities
- non-English speaking backgrounds
- rural and remote areas;

and people who are:

- financially or socially disadvantaged
- veterans
- homeless or at risk of becoming homeless
- care leavers (people who had been raised in care homes), or
- Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI).

When considering these groups it is imperative to acknowledge that there are people living with dementia that may be classified under multiple special needs groups and therefore may experience disadvantage on a number of fronts (Saunders, 2013).

In summary, the literature in relation to dementia and special needs groups was sparse and generally not specific to people with younger onset dementia. The identified literature ranged from emerging practice and expert opinion to mainly qualitative research with small sample sizes. While the issues identified are similar to those of the general population, the key messages for these groups is to ensure the cultural, linguistic and geographic factors are adequately identified and addressed in the planning, funding and delivery of services. Barriers identified included: access to culturally appropriate diagnostic services; denial of dementia within some cultural groups; privacy and confidentiality concerns - including the use of personal

information; transport - especially in rural and remote areas; and, having suitably qualified staff in some cultural and linguistic specific services, e.g., translation services.

Additionally, the literature identified particular needs for some of these groups. From a service provision perspective living in a rural or remote region is likely to be disadvantageous across the board because mainstream services may be scarce or non-existent, restricting both choice and access. Since there is very small number of people living with younger onset dementia it is highly unlikely that appropriate services for this group with special needs would be available, particularly in rural and remote areas (Blackstock et al, 2006; Tyson, 2007; Saunders, 2013).

Although the research literature about younger onset dementia relating to the defined special needs groups is scant the available literature, including grey literature, emphasises that the needs of these groups are complex, multifaceted and dynamic and become more so with the onset of dementia, reinforcing the call for person-centred, culturally appropriate, flexible service options.

Next steps

Throughout the report a large number of research gaps have been identified and a number of recommendations for future research have been identified. Likewise recommendations concerning service provision and service delivery have also been identified for further consideration by government. Despite the limitations regarding strength of evidence for many of the programs and services reviewed, there are some clear lessons emerging about optimal service system design. These are summarised in the following three key points:

Focus on the person with younger onset dementia
Fundamental is a person-centred focus with people with younger onset dementia involved in the development, design and the evaluation of services and supports they may need. This is important to ensure services are tailored to the individual needs, goals and aspirations, and relationships of the person with young onset dementia, and their surrounding support network.

Service attributes
At the individual service level, the focus needs to be on practices that are delivered with respect and consideration, by staff who are appropriately skilled, in an environment that is enabling and 'dementia friendly' in its design.

The delivery of services needs to be timely and responsive to the progression and complexities of young onset dementia, within the context of a risk management framework that appropriately balances the likelihood that younger people with dementia may want to take part in activities where there is a higher level of risk involved.

Integration of services
To improve the coherence of what can be an extremely fragmented service system, the focus needs to be on policies and models that facilitate service integration, such as multi-disciplinary teams, service linkages, care pathways and case management and coordination.

1 Introduction

This Literature Review is the first part of a two-stage project funded by the Australian Government to inform the development of services and supports for people with younger onset dementia and their families. Preliminary findings were used to shape the national consultations that were conducted as part of the needs and feasibility analysis. The final report will report on the key themes emerging from the consultations and seek to elucidate the issues arising in the literature with practical examples of how the service system can be adapted and modified to better meet the needs of people with younger onset dementia, their families and networks that support them.

1.1 Literature Review Methods

A rigorous search strategy was employed to identify literature related to services and needs of people with younger onset dementia. The review also included a needs and feasibility analysis of existing services with the view to identifying their capacity to deliver services to people with younger onset dementia.

The domains for inclusion were broader than those traditionally provided for people with dementia that have arisen from within a mental health and/or aged care service paradigm. Included for consideration were social, economic and environmental factors that enable and support people with younger onset dementia, through drawing on information available within the disability and chronic health care sectors, and community organisations and businesses that employ volunteers.

Likewise, we broadened the definition of the term 'younger onset dementia' in our search terms, given the reviews to date have predominantly focused on Alzheimer's disease and, to some extent, fronto-temporal dementia (Thompson, 2011). Our search included groups that have neuro-cognitive deficits associated with illnesses such as HIV/AIDS, Parkinson's disease, alcohol or drug abuse, Huntington's chorea/disease, Down syndrome and Multiple Sclerosis. These groups may not identify with the term 'dementia' (given its association with aged care) but may exhibit symptoms and have care and support needs that are similar; the rationale for their inclusion was the potential for these groups to have developed service models that could also be appropriate for the broader younger onset dementia cohort. We also included contextual factors such as living arrangements, with a particular search for information on those living alone.

Given the relatively tight timeframe for the literature review (four months), only articles written in English were reviewed.

1.1.1 Academic literature search

The literature search included both peer reviewed Australian and international academic literature as well as material outside the academic literature such as government reports and web based information.

In relation to the academic literature, established methods of conducting literature reviews (such as the Cochrane Collaboration approach) were used that included the following key search elements:

- Determine a clear focus for the review that included a specific research question that was reviewed. The research question was 'broad' rather than 'narrow' to incorporate the possibilities provided by sectors outside the health and aged care sector, such as the disability and community sectors;
- Develop search and indexing terms that reflected the research question and were specific to the database being searched. Whilst it was relatively straightforward to initially identify key terms related to the subject area, we ensured that our search strategy was robust enough to identify differences in the interpretation or application of particular terms between different countries or time periods. A detailed outline of the search terms and search strategy used appears in Appendix 1;
- Search of multiple relevant bibliographic databases including EBSCO databases (e.g. Medline, Cinahl, Academic Research Complete), Scopus, Proquest Central, Informa Healthcare, Cochrane Collaboration, Biomed Central, Summons and Google Scholar;
- Hand search of specific journals that appeared to contain relevant information pertaining to the project. The *Alzheimer's Care Today* journal and the *Dementia* journal were hand searched;
- Development of clear criteria for the inclusion or exclusion of each study/report. We recognised that the underlying objective of this literature review was to provide an evidence base to inform policy, rather than to provide definitive answers to a specific question. In this context, selection criteria was broader than those often adopted in reviews with an explicit focus;
- Review of identified study/report titles and abstracts and retrieve full text of all potentially relevant study/reports;
- A final decision on the inclusion or exclusion of each identified study/report was made.

It is well recognised that even systematic reviews of the literature cannot rely solely on protocol-driven search strategies (Greenhalgh & Peacock, 2005). For this reason, we supplemented the above search strategies with what is commonly referred to as 'snowballing' methods where we searched:

- Backwards in time - scanning reference lists of full text papers and making a judgement about which references to pursue;
- Forwards in time - using Google Scholar to review citations of key papers;
- Searching by key authors in the field.

1.1.2 Non-academic / 'grey' literature search

In addition to reviewing the academic literature, we applied an equally rigorous approach to identify and access information from non-academic sources (grey literature). As expected this was a useful source of information for the needs and feasibility assessment of services for people with younger onset dementia. This was also a useful source of information in identifying the capacity of specific types of service providers, community groups and organisations to build their capacity to deliver services to this client group.

A variety of strategies were employed to ensure that relevant material was identified. Once identified, the criteria described above were applied to determine the inclusion of this

information into the literature review. The searching process included, but was not limited to the following components:

- Surface WEB (e.g. GOOGLE [advanced] & [scholar]);
- Country by country searches (e.g. Health Departments, Community Services Departments, National libraries, key universities);
- Personal communications with individuals from key organisations;
- Specific site searches (e.g. Fightdementia.org.au, pwd.org.au);
- Commercial web sites (e.g. AMAZON.com);
- Other areas such as international conferences and professional associations.

We utilised the specialist skills of the AHSRI librarian, Ms Rebecca Cook throughout the searching process. A more detailed outline of sources of grey literature appears in Appendix 1.

1.1.3 Search results

Our search identified 448 documents of which 304 have been included in this review. Academic literature identified included 201 journal articles, 13 books/book sections and seven theses. Grey Literature identified included 83 documents including reports, web pages, conference presentations and other presentations, government documents and pamphlets.

The country of origin of the documents that were obtained primarily focussed on the United Kingdom, the United States of America (USA), The Netherlands, Canada and Australia. There were a number of documents from other European countries such as Ireland, France, Spain, Sweden, Norway and Finland. There were also some documents from Japan, Israel and New Zealand.

The majority of documents identified were published in more recent years with 149 documents published from 2010 onwards, 118 documents published between 2000 and 2009 and 37 articles published before 2000.

Documents were entered into an Endnote database to manage references.

2 Literature Review

2.1 Introduction

The literature has been grouped into the following sections:

- General Literature (overview articles, types of Younger Onset Dementia, characteristics and symptoms, prevalence studies)
- Experiences of People with younger onset dementia, their Carers and Families (articles concerning the experience of dementia and the effects on the patient, family and carers and how this may affect service design and implementation issues)
- Service Design and Development (articles that reflect on the design and development of service models that are relevant to people with younger onset dementia)
- Particular Programs (these articles concern particular program initiatives and their evaluation)
- Special Needs Groups (articles that focus on issues for special groups e.g. Culturally and Linguistically Diverse groups, Aboriginal and Torres Strait Islander peoples, Lesbian, Gay, Bisexual, Transgender individuals etc.).

Some papers focus on more than one of these areas, and where relevant, these have been reviewed under more than one section. For the tables that provide a summary of the literature reviewed for each article the author, date, location, topic, study design, strength of evidence, diagnosis, focus (client/ carer/ family/ other), special needs groups, study numbers and a summary have been provided.

In assessing the strength of evidence of the majority of the literature (e.g. empirical or quasi-empirical practice) the following categories have been used:

- **Well-supported practice** – evaluated with a prospective randomised controlled trial
- **Supported practice** – evaluated with a control group and reported in a peer-reviewed publication
- **Promising practice** – evaluated with a comparison group
- **Acceptable practice** – evaluated with an independent assessment of outcomes, but no comparison group (e.g., pre- and post-testing, post-testing only, or qualitative methods) or historical comparison group (e.g., normative data)
- **Emerging practice** – evaluated without an independent assessment of outcomes (e.g., formative evaluation, service evaluation conducted internally)
- **Routine practice** (e.g., routine data)
- **Expert opinion** (e.g., peak bodies; government policy; opinion pieces, editorials or summaries from health professionals)
- **Case-study (**e.g. one shot case-studies or a group of case-studies that are largely anecdotal).

There are a range of studies that do not clearly fit this paradigm (e.g. literature reviews or epidemiological estimate studies) where it would be difficult, given the emerging nature research in this field, to effectively or finely grade these studies with regard to their strength of

evidence although a critique is made in the text. In many of the literature reviews authors have not used stringent inclusion/exclusion criteria as per meta-analytic approaches given the scarcity of the literature detected but have chosen instead to make comment about the studies found and to refer to the strength of evidence of the studies included using similar criteria to those above. In these cases the category of 'other' is used:

- **Other** (e.g. Literature Review; Epidemiological/ prevalence study).

As the summary tables indicate below the level of evidence for most studies in this emerging field of research is not high and there are many studies that are classified at the level of emerging practice or below.

3 The General Literature

This section included a large number of peak association reports (e.g. Alzheimer's Australia), literature reviews and overviews and articles that pertain to the diagnoses/types of younger onset dementia and that focus on patient symptoms and characteristics. Table 1 below provides a summary of the literature examined for this section. With regard to government and association reports, only the more recent reports were examined, or those that contained evidence about a particular project of relevance, as it was found that many of the earlier reports are now somewhat out of date. Government papers concerning policy issues and services are mainly addressed in Section 5 -Service Design and Development.

With regard to diagnostic groups we have used the terminology used by the authors and it should be note that some authors prefer the use of the term Early Onset Dementia (EOD) or Young People with Dementia (YWPD) to younger onset dementia but these terms are often used interchangeably.

As can be seen from Table 1, below much of the literature in this section contains overviews, literature reviews, government reports and relatively few empirical studies as might be expected in a 'general' section. Much of the empirical literature relates to studies undertaken to evaluate programs and services or to describe carer and family issues and these papers are reviewed in the later sections of this report.

It should be noted that the focus of this report is to examine literature that is relevant to the service needs of people with younger onset dementia. Thus although information concerning the prevalence, type and symptoms of these dementias is included, as this relates directly to service needs and models, no detailed analysis of the biological causes and associated pathologies of these conditions has been included as this is viewed as out of scope. Summaries/overviews are provided by Alzheimer's Australia (Hodges et al, 2009; Mocellin et al, 2013).

It should also be noted that while the search terms included the rarer subtypes of younger onset dementia relatively little academic literature was uncovered and additional searches of the grey literature and snowballing was used to supplement the literature extracted. It is felt the coverage of these areas is adequate for the purposes and scope of this report but in the future it could be supplemented by particular and dedicated searches concerning these rarer forms of younger onset dementia.

Table 1 General literature (overviews, diagnoses, types, characteristics)

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Access Economics (2005)	Australia	Dementia Estimates & Projections Australia	Prevalence study	Prevalence study	Dementia/YOD			Australian & international prevalence estimates based on meta-analyses; estimated State figures; review of other data sources e.g. self-report DAC survey data
ADAHPS (2013)	Australia/ NSW	HIV complex case management	NA –project description	NA -	HAD/ADC			A brief description of a service for the management of people with HIV associated dementia or other complex needs. There is a regional outreach service available provided through a consortium of Sydney based services which is currently being trialled
ADHC (2012)	Australia/ NSW	Forum on YOD	NA – summary /fact sheet	Expert opinion	YOD clients & carers			Outlines key principles of care re YOD, service modifications and initiatives for capacity building for services
ADHC (2013)	Australia	Roundtable with Bakker	NA - forum	Expert opinion	YOD -all			Roundtable with Bakker of NYODCP - raising awareness; integrated diagnostic services, service design and models of care; family & community support, predictors of residential placement, residential support
AIHW (2007)	Australia	Dementia in Australia	Prevalence est. based on meta-analysis	Prevalence study	Dementia/YOD			Australian prevalence estimates –2007 (Harvey et al 2003; Lobo et al 2000)
AIHW (2012)	Australia	Dementia in Australia	Prevalence est. based on meta-analysis	Prevalence study	Dementia/YOD			Australian prevalence estimates - 2012 (Harvey et al 2003; ADI 2009)
Alvarez (2012)	USA	Alzheimer's disease in Down syndrome	Literature Review	Literature review	Down S. & AD			A more recent review of Down syndrome and dementia
Alzheimer's Association USA (2013a)	USA	Traumatic brain injury	NA- summary/fact sheet	Expert opinion	Dementia			Summary information on traumatic brain injury and dementia
Alzheimer's Association USA (2013b)	USA	Down Syndrome and Alzheimer's Disease	NA- summary/fact sheet	Expert opinion	Dementia			Information sheet on Down syndrome and dementia
Alzheimer's Australia (2009)	Australia	National Consumer summit YOD	NA - summit	Expert opinion	YOD clients & carers	Yes		Key priorities for YOD in 2009 - agreed initiatives: increased awareness, timely diagnosis, increased service links/networks, access to services, address employment and financial needs

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Alzheimer's Australia (2012a)	Australia	HIV associated dementia	NA – fact sheet	Expert opinion	HIV/Dementia			Overview of HIV associated dementia (HAD) and mild cognitive impairment associated with HIV (HAND)
Alzheimer's Australia (2012b)	Australia	Down Syndrome and dementia	NA-fact sheet	Expert opinion	Down syndrome			Overview of Down syndrome and dementia
Alzheimer's Australia (2013)	Australia	YOD: A new horizon?	NA - overview	Expert opinion	YOD clients & carers			Key priorities for YOD in 2013 identified in context of NDIS - 6 priorities: awareness, timely diagnosis, model for NDIS, service redesign, participation & inclusion, program of research
Alzheimer's Society UK (2005)	UK	YOD guide to service provision & development	NA - guide	Expert opinion	YOD/Dementia all			Guide to service provision and development for people with YOD in the UK. Epidemiology of YOD UK
Alzheimer's Society UK (2008)	UK	Out of the shadows	Interviews and focus groups – qualitative analysis	Emerging practice	Dementia		32 PWD	The focus is on all dementias rather than YOD but the patient interviews reflect on the stigma associated with dementia. Themes included: improve public understanding, improve GP understanding, develop better specialist diagnostic services, provide information which is timely and accessible and develop stronger support networks to facilitate coping
Alzheimer's Society UK (2012)	UK	Multiple Sclerosis and dementia	NA – fact sheet	Expert Opinion	MS and dementia			Fact sheet concerning MS and dementia
Bakker (2013)	Netherlands	YOD care needs and service provision	Longitudinal observational studies	NA	YOD		Various	Compendium of articles by Bakker and colleagues
Bakker et al (2013a)	Netherlands	Predictors of time to institutionalisation of YOD	Longitudinal observational study	Supported practice	YOD clients		226 YOD, 120 LOD	YOD have a longer period to institutionalisation than LOD. Other predictors- presence of BPSD; carer stress and competence
Beattie et al (2004)	UK	Views of younger people about their dementia	Qualitative interviews	Emerging practice	YOD clients		14 clients	Themes-experience of dementia, diagnosis, age, risk and danger. Clients desire age-appropriate services. Need to assess patient views
Bentham & La Fontaine (2008)	UK	Services for young people with dementia	Literature review	Literature review	YOD clients	Yes		Recommends comprehensive multidisciplinary & multi-agency service that provides specialist assessment, diagnosis and interventions & provision for meaningful

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								activity relevant to YOD
Brodaty & Cumming (2010)	Australia	Dementia services in Australia	Literature review	Literature review	Dementia/ YOD	Yes		Recommends: increase awareness & carer support, reduce stigma, improve timeliness of diagnosis, support for special needs groups, age appropriate services & correct underfunding for dementia research
Brodaty et al (2012)	Australia	Dementia-time to death	Literature review	Literature review	Dementia/ YOD			Review of life expectancy and survival data for dementia in general
Broe (2013)	Australia	Koori growing older well study	Prevalence catchment study	NA - web description	YOD - Indigenous	Y	546 Indigenous people over 60 336 follow up	Study identified cases of Dementia amongst Indigenous peoples in suburban and semi-urban catchment in NSW - noted high prevalence rate
Brown et al (2012)	Australia	Service & support requirements YOD people & families	Literature review	Literature review	YOD all			Recommends: early intervention, community participation & social engagement, family & relationship support; informal support, respite, employment & financial support, CALD services
Burrell (2012)	Australia/ NSW	Types and symptoms of YOD	NA -overview	Expert opinion	YOD clients			Presentation from YOD forum that outlines types, symptoms of YOD and relates this to therapeutic approaches
Chemali et al (2012)	USA	Diagnosing EOD and then what?	Retrospective medical record & service review	Routine practice	EOD (YOD) clients		76	Review of 76 EOD (YOD) memory clinic patients - identifies lack of age-appropriate services for this group and high levels of medication use
Coppus et al (2010)	Netherlands	Early menopause and dementia risk – Down syndrome	Prospective longitudinal cohort	Acceptable practice	Down S. with dementia		85 DS females	Study suggests that age at menopause in women with Down syndrome is a determinant of age of onset of dementia and mortality
Cosgrave et al (1999)	Ireland	Age of onset of women with Down's and menopause	Part of prospective study	Acceptable practice	Down's clients		143 Down's, 12 dementia	Onset of dementia for 12 Down's women with Dementia was associated with onset of menopause. Small sample of people with Down's and dementia
De Waal et al (2013)	International	Designing and delivering dementia services	Literature Review	Literature review	Dementia/ YOD - services			An edited collection of recent articles concerning Dementia internationally. One chapter addresses YOD in particular (Koopmens and Thompson, 2013). See also Livingston and Cooper (2013) and Ratcliffe et al (2013)
Deloitte	Australia	Dementia	Prevalence	Prevalence	Dementia/YOD			Updated Australian and international prevalence

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Access Economics (2011)		across Australia 2011-2059	study	study				estimates, review of previous studies and overview of data sources
Ellis et al (2007)	US	HIV and antiretroviral treatment in the brain	Literature review	Literature review	HIV/AIDS Dementia/ ADC			Impact of antiretroviral therapy on HAD/ADC
El-Mallakh et al (1993)	US	Neuropsych program for HIV-infected individuals	Neuropsych assess of 60 HIV & 20 AIDS patients	Emerging practice	HIV/AIDS clients		60 HIV, 20 AIDS	Need for neuropsychiatric assessment of HIV and AIDS patients. Increase awareness AIDS dementia & provision appropriate service referrals
Erlich (1994)	Australia/ NSW	Planning for young adults with Brain Damage NSW	NA - overview	Expert opinion	Brain Damage -all			Different causes of Brain Damage may result in similar disabilities but diverse paths for service provision and a general under provision of services
Evers (2009)	Europe	Cognitive dysfunction in Multiple Sclerosis (MS)	NA - overview	Expert opinion	MS and dementia			Discussion sheet on MS, cognitive dysfunction and dementia
Ferran et al (1996)	UK	EOD Clinical Characteristics and Service Use	Patient follow-up memory clinic	Routine practice	EOD (YOD) clients		200	At inception 8% of clients in residential care which increases to 22% at 1 year follow-up. 49% had depressive symptoms and 27% showed aggression
Harvey (1998)	UK	Impact of YOD	Catchment survey, interviews & scales, Costs of illness	Promising practice	YOD clients & carers		185 YOD, 40 carers	Examined patient characteristics and carer burden. High level of carer burden associated with patient BPSD and low levels of community support. Presence of psychiatric symptoms for 52% of carers suggests need for carer assessment. People with YOD appear to use less community resources and more institutional care
Harvey et al (2003)	UK	Prevalence and causes for YOD	Catchment study	Prevalence study	YOD clients & carers		185 YOD identified 40 carers	UK prevalence 2003 -estimated >18,000 cases of YOD in UK based on 185 cases identified from a 500,000 catchment area in the UK
Heaton et al (2010)	US	HIV neurocognitive disorders persist.	Cross-sectional observational study	Prevalence of neurocognitive disorder	HIV/AIDS patients		1,555 HIV patients	Frequency and types of neurocognitive disorders associated with HIV/AIDS in a large sample including 6 clinics across USA – since the introduction of potent combination antiretroviral treatment
Hodges et al (2009)	Australia	Quality Dementia Care - YOD	NA - overview	Expert opinion	YOD	Yes		An overview of types and causes of YOD and practical strategies for managing YOD, the caring role & the family

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Hunt (2011)	US	YOD Lit Review and impact for clinicians	Literature review	Literature review	YOD all			Literature review YOD, implications for clinicians and service redesign including age-appropriate services
Ikejima et al (2009)	Japan	Prevalence and causes EOD - Japan	Prevalence study	Prevalence study	EOD (YOD)		617 identified	Based on a catchment sample of over 2 million; the prevalence rate is slightly lower overall than for the Harvey UK study and the proportion of cases by type is quite different to Harvey - many more cases of vascular dementia identified
Iverson et al (2012)	Canada	Mild traumatic brain injury and risk for Alzheimer's disease	Literature review	Literature review	MTBI			Review of the literature concerning the association of MTBI with AD -indicated there were conflicting findings but concluded there was only a small increased risk for AD for those experiencing severe TBIs
Jorm et al (2005)	Australia	Projections of future numbers of dementia cases	Prevalence projection study	Prevalence projection study	Dementia			Hypothetical projection study on the effect on prevalence estimates if new and more effective treatments for dementia delayed onset by 5 years
Kay et al (2000)	UK	Long term survival in presenile dementia	Survival estimate study	Epidemiological estimates	EOD (YOD)/ presenile dementia		227 EOD	Survival estimates based on follow-up study, North England 1980's – 1990s
Koopmens and Thompson (2013)	Netherlands	Services for people with YOD	Literature Review	Literature review	YOD			Discusses issues for services, types of services and a brief description of service models in some countries. (In De Waal et al)
Li et al (2013)	Australia/ NT	Dementia prevalence and incidence in NT	Prevalence study	Prevalence Study	Dementia	Y	NT population >45 years	Examines prevalence and incidence rates for Dementia in the Northern Territory in 2011 using capture-recapture methodology. Found a much higher incidence and prevalence of dementia for the Indigenous population (unpublished report)
Livingston and Cooper (2013)	UK	The need for dementia care services	Literature review	Literature review	Dementia			Examines overall prevalence and burden of disease estimates for dementia to identify the need for specialist services. The article addresses management issues that are topical in 2013. (In De Waal et al)
Lobo et al (2000)	Europe	Prevalence of dementia in Europe	Meta-analysis pooling data from 11 European	Prevalence study	Dementia/YOD		2346	Focus on those 65 years or above. Used by AIHW for their 2007 prevalence estimates

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
			studies					
Manly and Mayeux (2004)	USA	Ethnic differences in Dementia and AD	Literature Review	Literature Review	Dementia			Overview of studies on ethnic and racial differences in relation to dementia - with particular reference to USA
Maslow (2006)	USA	EOD: A National Challenge	NA-overview and survey data	NA - overview	EOD (YOD) all			Describes some US survey data: recommends dedicated EOD (YOD) research program, national education program, analysis of work environments for EOD & changes to service and insurance coverage relevant to USA
Mitchell (2012)	UK	Coping with YOD	Review and qualitative interviews	Emerging Practice	YOD couples		6 couples, 6 workers	Overview. Interviews identified needs for couples re clarity of information provided, flexible support services, participation in service planning, and increased public awareness to reduce stigma experienced. Further research is required re coping styles and for the identification of precursors to poor coping in couples
Miyamoto et al (2011)	Japan	Efforts in Japan to change designation of dementia	NA - Discussion	NA - description	YOD/ Dementia - stigma			Japanese policy initiative to change term for dementia to reduce stigmatic associations
Mocellin et al (2013)	Australia	Quality Dementia Care - Understanding YOD	NA -overview	Expert Opinion	YOD			An update of the overview of types and causes of YOD
Morhardt (2011)	US	Access to community based and long term services FTD	NA - Discussion	Expert opinion	FTD clients & carers			Issues for people with FTD: difficulty being diagnosed, financial issues, social security insurance access issues, poor access to community and long term services
Newens et al (1995)	UK	Dependency and community care in presenile Alzheimer's disease	Retrospective follow up over 5 years	Acceptable practice	Presenile dementia Alzheimer's type (EOAD)		109	Five years after confirmed diagnosis 57% of EOAD patients remained at home. Time to institutionalisation was estimated as a median of 8.4 years from symptom onset and 5.5 years from dementia diagnosis. The average period of survival was estimated at 9.5 years
Phillips et al (2011)	Australia	Timely diagnosis – can we do better	Literature review re time to diagnosis	Literature Review	Dementia			Examines barriers to timely diagnosis though an examination of Australian and international studies and recommends a range of service initiatives to address this

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								issue
Prince and Jackson (2009)	International	World Alzheimer Report	Prevalence est. based on meta-analysis	Prevalence study	Dementia/YOD			Provides background re latest international prevalence estimates based on meta-analysis
Ratcliffe et al (2013)	Australia	Health economic, healthcare funding and service evaluation - Dementia	Literature review	Literature review	Dementia			An overview of health economic evaluation studies applying to pharmacological and non pharmacological interventions for the treatment of dementia. Provides an example of the evaluation of the Australian dementia initiatives. (In De Waal et al)
Reed & Bluethmann (2008)	USA	Voices of Alzheimer's disease	NA - forums	Emerging Practice	Early AD clients		301 participants	Town Hall and virtual forums -57% EOD (YOD). Themes - stigma, dissatisfying interaction medical community- untimely diagnosis, uncertainty re support services, retaining independence, desire for continuing involvement
Roach et al (2008)	UK	Subjective experiences of younger people with dementia	Literature review of qualitative studies	Literature review	YOD/EOD clients			Three major experience categories identified -1 recognizing -diagnosis & information 2) relating - impact on feelings & family 3) restructuring -adjusting to living with dementia. Issues - inadequate referrals & supports, a need to review service provision
Rossor et al (2010)	UK	Diagnosis of early onset dementia	Literature review diagnosis, biological features	Literature review	YOD clients			Review of diagnostic issues and care required re differential diagnosis as emerging findings re molecular pathology may lead to new treatments. Higher rates of genetic disease were noted for YOD
Rota-Bartelink (2009)	Australia	Consider Robert – Homeless, ARBD	NA – forum	NA - overview	ARBD			Provides a brief overview related to homelessness and alcohol related brain damage (ARBD) and cognitive impairment
Sait et al (2013)	Australia	Living alone with dementia	Review, interviews, on-line provider survey	Acceptable practice	Dementia		6 patients, 101 case managers	Using AIHW (2012) prevalence estimates, census and ACAP data as a base it is estimated that up to a third of people with dementia may be living alone – no specific estimates for the YOD group. Those living alone will require additional service support to navigate the service system and to avoid potential adverse outcomes
Sampson et al (2004)	UK	Young onset dementia - diagnosis,	Literature review - diagnosis,	Literature review	YOD clients, services			Presents an approach to diagnosis, investigation and the management of YOD

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
		intervention, management	biological features					
Saunders (2013)	Australia	Get your voice heard: Living with dementia in country SA	Focus groups and survey	Acceptable practice	Dementia		145 clients & carers; 176 providers	Focus groups with a) carers and patients and b) providers in rural SA. Issues identified included the diagnostic process, lack of support post diagnosis and the need for support in linking to services. Rural issues concerned the limited availability & scope of services and need for additional travel and transport allowances to support people with dementia in rural and remote regions
Silverman (2010)	USA	Dementia among adults with Down syndrome.	NA –overview	Literature review	Down syndrome/Dementia (AD)			Provides an overview of DS and AD, examines the connection between them, reviews individual differences in risk & progression, identifies knowledge gaps
Smith et al (2008)	Australia	High prevalence of dementia and cognitive impairment in Indigenous Australian	Cognitive assessments of rural & remote Indigenous Australians	Acceptable practice	Dementia	Y	363 Indigenous people (remote)	Undertook cognitive screening of 363 rural and remote Indigenous Australians 45 years and above and estimated the prevalence rate to be 12% - about 5* higher than for other Australian prevalence estimates provided by Jorm et al (2005) at 2.4%. Includes both YOD and LOD cases
Stern et al (2011)	USA	Long-term consequences of repetitive brain trauma	Neuropathological analysis at autopsy	Acceptable practice	TBI		50	Autopsy analysis of brain damage (Chronic traumatic encephalopathy) associated with individuals who had experienced repetitive brain traumas associated with sport or military activities –implications for public health
Thompson (2011)	Australia/ NSW	Service & support requirements- people with YOD & families	Literature review - community based best practice models	Literature review	YOD all			Literature review of community based best practice and good practice dementia services across Australia
Tindal & Manthorpe (1997)	UK	EOD: A case of ill-timing	NA- review	Literature review	EOD (YOD) all			Examines literature on experience & impact of YOD. Argues for specialist service provision for YOD and the development of new research agendas
Tolhurst et al (2012)	UK	YOD impact of emergent age based factors on personhood	NA - theoretical discussion	NA -discussion	YOD clients			Examines age based factors that may affect the experience of YOD personhood - need for further research
van Vliet et al (2012)	Netherlands	Prevalence of neuropsychiatri	longitudinal observational	Supported practice	YO-AD and LO-AD dyads		98 YO-AD & 128 LO-AD	The prevalence of neuropsychiatric symptoms (NPI) comparing YO-AD and LO-AD patients over a 2 year

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
		c symptoms YOD	study				and carers	period. Prevalence of NPI symptoms lower in the young onset AD group throughout the period. Apathy the most common symptom for YO-AD
Vieira et al (2013)	USA	Epidemiology of EOD: A review of the literature	Literature review	Literature review	EOD (YOD)			Reports the differences in EOD (YOD) prevalence rates across a range of studies and also reports the differing proportions of diagnoses by type within EOD. Indicates the need for further studies to clarify incidence and prevalence
Werner et al (2009)	Israel	EOD: clinical and social aspects	NA-review	Literature review	EOD (YOD)			Summary of research on EOD (YOD) - particular focus on social aspects - cost of care, challenges for clients & carers, services available and their appropriateness
Withall & Draper (2010)	Australia	Alcohol related dementia…	NA - summary	Summary related to prevalence study	YOD/ARBD		136 YOD cases identified	Refers to eastern Sydney prevalence study where 22% of the YOD cases were identified as ARBD – a much higher estimate than for previous studies
Withall (2013)	Australia	The challenges of service provision in YOD	NA-editorial	Editorial	YOD			Briefly refers to current and ongoing Australian prevalence study (Inspired) in eastern suburbs of Sydney and discuses psychosocial aspects and the issues raised for service provision
Woolley, (2013)	Australia	YOD Key Worker Program	Hope Newsletter	NA - description	YOD			An October 2013 update on the YOD Key Worker Program

Note: A list of abbreviations used is provided in the glossary. Some articles with a primary focus on patient and carer issues will be found in Table 2

3.1 Types and Symptoms of Younger Onset Dementia

Harvey (1998) and Harvey et al (2003) estimated from a prevalence study based on catchment areas within the UK that the major types of younger onset dementia are early onset Alzheimer's disease (AD; 34%), vascular dementia (VaD;18%), fronto-temporal dementia (FTD; 12%), alcohol related dementias (ARBD; 10%), Dementia with Lewy bodies (DLB;7%) and other dementias (19%). Other dementias may include dementias associated with other primary conditions such as Huntington's disease (HD), Multiple Sclerosis (MS), Parkinson's disease (PD), Motor–Neuron disease (MND), Prion disease, HIV/AIDS dementias, Down syndrome and other intellectual disability syndromes with dementia and metabolic and brain injury syndromes. Within the 'other dementias' Huntington's disease (5%) and Multiple Sclerosis with dementia (4%) were the largest diagnostic groups. Harvey et al (2003) note that their prevalence estimates underestimate those with Down syndrome and HIV/AIDS dementia was not included in these studies.

A later study in Japan by Ikejima et al (2009) had lower prevalence estimates and found quite different proportions of the clinical subtypes: Alzheimer's disease (26%), vascular dementia (42%), dementia following brain injury (TBI; 7%) and Lewy body/Parkinson disease dementia (6%). Although it is thought the Harvey estimates may be the more applicable to Australia the initial estimates from a current prevalence study (Withall, 2013) in Australia (Eastern Sydney and surrounds) has also found different proportions for these clinical subtypes: Alzheimer's disease (16%), vascular dementia (10%) fronto-temporal dementia (13%) and a much higher estimate for alcohol related dementia (22%). The recent systematic literature review by Vieira et al (2013) also notes that quite different proportions of diagnostic types within the younger onset dementia group are reported across studies. Some of these differences might be explained by differences in methodology between the studies and these issues are discussed further in the following section concerning prevalence. It has also been reported from a retrospective review of medical records that AD, DLB and VaD make up a smaller proportion of young onset dementia cases and the younger the onset the more likely it is that there is a genetic or metabolic cause for the disorder (Kelley et al, 2008; Koopmens and Thompson, 2013; Rossor et al, 2010).

Bentham and La Fontaine (2008) note that accurate differential diagnosis is difficult for younger onset dementia with incorrect or uncertain diagnoses reported in 30%-50% of cases. Diagnosis may be particularly difficult in people with a history of psychological disorder due to masking of dementia symptoms and for those from ethnic minority groups where cultural and linguistic issues may impinge on the accuracy of cognitive and behavioural assessments. This may have implications for service planning as it would suggest there may be a significant number of undiagnosed younger onset dementia cases amongst such special needs groups. Bentham and La Fontaine (2008) also note that as 1% of younger onset dementias may be partly or fully reversible it is essential that they are thoroughly investigated in specialist units with neuro-imaging being a mandatory requirement.

Dr James Burrell (2012) at a presentation for the Forum on Younger Onset Dementia (ADHC, 2012) briefly described the major forms of younger onset dementia as does the Alzheimer's Australia *Younger Onset Dementia: A Practical Guide* and the *Understanding Young Onset Dementia* report (Hodges et al, 2009; Mocellin et al, 2013). The major symptoms associated with the major types of younger onset dementia are briefly summarised below as a discussion

of the symptoms is related to understanding the service needs and issues for younger onset dementia clients.

Early onset Alzheimer's disease is the most common type of younger onset dementia and is associated with the development of senile plaques and neurofibrillary tangles in the brain. The pathology of Alzheimer's disease is related to the abnormal build up of two proteins (amyloid and tau) that are normally present in the brain and these cause the development of plaques and tangles respectively (Hodges et al, 2009; Mocellin et al, 2013; Sampson et al, 2004). Most Alzheimer cases are not genetic but familial Alzheimer's can be inherited through gene mutations directly or through the inheritance of genes that increase the risk of developing Alzheimer's disease and these forms are more common in younger onset dementia (Rossor et al, 2010). For the genetic mutations these people will develop the disease and they will have a 50% chance of passing the gene on to each offspring making genetic counselling an important issue for the affected families. The age of onset of these forms of familial Alzheimer's is usually under the age of 65 years and these genetic mutations are responsible for approximately 25% of early onset Alzheimer's cases although they are only responsible for 5-10% of Alzheimer's disease cases overall (Mocellin et al, 2013).

AD is usually characterised by memory problems (particularly short-term memory), difficulty learning new information, problems with attention, executive dysfunction (planning, organising, and withdrawal) and navigational problems/spatial orientation (Burrell, 2012). Behavioural problems may sometimes be present and these can include agitation, wandering, poor sleep, apathy and mood disorder (Mocellin et al, 2013; van Vliet et al, 2012). Severe behavioural symptoms such as delusions, hallucinations and aggression can occur but usually later in the illness (Sampson et al, 2004) and may be more associated with a LOD presentation. For a more atypical presentation memory problems may not be the main issue initially and patients may experience prominent language disturbance (e.g. word finding difficulties) prominent visual symptoms (e.g. difficulty locating things) and prominent motor symptoms (e.g. slowness/stiffness and walking difficulties and/or falls) (Burrell, 2012). Rossor et al (2010) note that early onset AD is associated with fewer co-morbidities such as renal and heart disease, and lower medication use, whereas there is frequent co-existence of AD with vascular disease in the older population.

Vascular dementia. Progressive cognitive decline caused by stroke or vascular lesions in the brain characterises vascular dementia/ vascular cognitive disease (Mocellin et al, 2013; Rossor et al, 2010). Vascular dementia is associated with blood circulation in the brain and 2 major types are Multi-infarct dementia (MID) and Binswanger's disease (Alzheimer's Australia, 2009; 2013). MID is characterised as an accumulation of damage from mini-strokes and Binswanger's is associated with damage to deep layers of white matter in the brain. CADASIL (cerebral autosomal dominant ateriopathy with subcortical infarcts and leukoencephalopathy) is a rarer young onset form (e.g. @ 45 years) associated with migraine and psychiatric symptoms (Sampson et al, 2004). These diseases reflect underlying disease of the blood vessels and usually occur in association with cardiovascular risk factors (e.g. smoking, hypertension, obesity, elevated cholesterol, cardiovascular disease or diabetes) reflecting the need to address health prevention interventions in relation to these risk factors. Additional risk factors in younger people may include kidney failure, amphetamine and cocaine use as well as systematic lupus (Mocellin et al, 2013). In vascular dementia memory is less affected than for AD but there are problems with organisation, apathy/motivation and planning. Language and

communication problems are common as are motor problems such as difficulty walking and controlling the bladder. Behavioural problems can also occur particularly if the mini-strokes occur in the frontal areas of the brain.

Fronto-temporal dementia (FTD) has three main subtypes – FTD behavioural variant, Progressive Non Fluent Aphasia (PNFA) and Semantic Dementia (SD). The FTD behavioural variant is the most common type (Alzheimer's Australia, 2013) and the onset of FTD usually occurs between 45- 60 years of age and males may be more frequently affected (Sampson et al, 2004). A number of genetic causes have been identified in association with mutations in the tau gene (Sampson et al, 2004). Most cases of FTD are not inherited but it is estimated there are about 20-30% of cases where a strong family history of dementia associated with a higher risk (3.5*) for developing the disease (Hodges et al, 2009; Mocellin et al, 2013; Sampson et al, 2004) although most of these cases will not have any of the known genetic mutations that can cause FTD directly.

With the behavioural variant there are dysexecutive problems (e.g. apathy, planning and organising) and symptoms of disinhibition (with regard to food, money, sleep or sexual behaviour). In the language variants (PNFA and SD) there is a progressive breakdown in language and verbal communication with non-fluent speech in PNFA and fluent speech but loss of word and object knowledge in SD (Burrell, 2012; Rossor et al, 2010). Behavioural and psychological symptoms of dementia (BPSD) are a key characteristic of the behavioural variant of FTD and, as the reviews in the following section indicate, this is often associated with increased carer burden and stress. Morhardt (2011) notes that people with FTD and their families report consistent difficulties in their attempts to access services and support and as with other forms of younger onset dementia experience difficulties in obtaining a diagnosis.

FTD can overlap with a number of other related syndromes. A proportion of people with Motor Neurone disease develop symptoms similar to FTD (e.g. behavioural and language problems) and some people with FTD develop symptoms of MND (slurring of speech, problems with swallowing or weakness and wasting of the muscles of the limbs). In cases where there is an overlap of MND and FTD symptoms delusions and hallucinations have been noted (Hodges et al. 2009; Mocellin et al, 2013). Two other overlapping syndromes include corticobasal degeneration and progressive supranucleur palsy (Sampson et al, 2004).

Parkinson's disease is a degenerative disorder which includes motor abnormalities (muscle rigidity, tremor and slowing of physical movement), impairment in speech and in some cases cognition. Dementia where it occurs is a later development starting with slowing of thought and progressing to difficulties which may include problems with abstract thought, memory, behavioural regulation and hallucinations. Psychiatric symptoms are also common including depression, anxiety and obsessive behaviours (Hodges et al, 2009; Mocellin et al, 2013).

People with dementia with Cortical Lewy Bodies (DLB) show similar cognitive features to AD but have motor symptoms that are similar to Parkinson's disease (stiffness, shakiness) and are prone to falls. They may experience visual hallucinations and there is fluctuation of symptoms over the course of the day varying from confusion to lucidity. Sleep disorder is common (Hodges et al, 2009; Mocellin et al, 2013). It is more common in later onset dementia although the age range for onset is from 50-80 years.

Huntington's disease (HD) is a genetic disease caused by gene mutation which is inherited as an autosomal dominant disorder and thus children of these patients have a 50% chance of inheriting the disease (Hodges et al, 2009; Mocellin et al, 2013). The first symptoms emerge between 30-50 years of age and characteristic symptoms are jerky, random and uncontrolled body movements. There is also a general lack of co-ordination and slurring of speech. As the disease affects the frontal lobes of the brain there are problems with planning, motivation flexibility and abstract reasoning and as the disease progresses memory problems also appear. Psychiatric problems (e.g. anxiety, mania, depression, blunted affect, compulsive behaviours, irritability and aggression) are common but vary across patients. This form of dementia is different to AD in that those affected continue to recognise people and places until the very late stages of the illness. The availability of genetic counselling is an important issue for such inherited disorders.

Some people with **Multiple Sclerosis (MS)** experience some loss of their cognitive abilities if damage caused by the MS occurs in certain parts of the brain. Evers (2009) indicates that it is now accepted that 45-65% of people with Multiple Sclerosis have some evidence of cognitive decline although it is only rarely the case that these cognitive issues are sufficiently severe to warrant a diagnosis of dementia with MS. The mental abilities most likely to be affected are memory, concentration and problem solving (Alzheimer's Society UK, 2012) and these are more likely late in the course of this disease (Sampson et al, 2004). Notwithstanding the above, Harvey et al (2003) note a prevalence of 4% of younger onset dementia cases with MS and dementia in their catchment sample.

Down syndrome is caused by a third copy of chromosome 21 and this genetic abnormality is associated with intellectual impairment and some physical traits. The gene responsible for the amyloid precursor protein (APP) is also located on chromosome 21 and this is associated with the development of brain plaques that characterise Alzheimer's disease (Alzheimer's Australia, 2012b). It is known that there is a greatly increased risk for people with Down syndrome to develop Alzheimer's disease as they age and some studies suggest that up to 75% of those with Down syndrome aged 65 and over have AD which is nearly six times the percentage of people in this age group that do not have Down syndrome (Alzheimer's Association USA, 2013b). Silverman (2010) indicates that the majority of people with Down syndrome and dementia develop AD between 40-60 years of age and thus largely fall in the younger onset dementia grouping. In people with Down syndrome changes in overall function, personality and behaviour may be more common earlier signs than memory loss. These earlier signs of dementia may be a further deterioration of existing difficulties and thus harder to recognise. Common earlier signs include reduced ADL function, deterioration in short-term memory, increased apathy, a reduction in communication skills, difficulties in comprehension, disorientation and confusion, changes in sleep patterns and increased wandering (Alzheimer's Australia, 2012b). Early age at menopause is commonly reported ($\leq$ 45 years) and this has been associated with an increased risk of Dementia in Down syndrome women (Cosgrave et al, 1999; Coppus et al, 2010; Alvarez et al, 2012). Silverman (2010) indicates that high cholesterol is also a risk factor and notes a later onset of dementia was associated with the use of statins by people with Down syndrome.

HIV associated dementia (HAD) is a severe complication that can occur in people with HIV/AIDS and is associated with major cognitive, behavioural and motor problems which impair day to day functioning. As early as the early nineties (El-Mallakh et al, 1993) identified the need

for neuropsychiatric assessment of HIV/AIDS patients and identified the need for increased awareness of this condition and for the provision of more appropriate services.

This condition is also sometimes referred to as AIDS Dementia Complex. Symptoms may include problems with short-term memory, language and thinking, difficulties in concentration and decision making, unsteadiness, apathy, lethargy, mood changes and hallucinations. HAD is the most severe type of HIV associated neuro-cognitive disorder (HAND). HAND in its milder forms may affect cognition but not to the degree that this would warrant a dementia diagnosis. HAND may be associated with inadequate brain levels of antiretroviral drugs and it has been found to respond to the use of highly active antiretroviral treatment (HAART/cART; Alzheimer's Society UK, 2012; Alzheimer's Australia 2012a). Sampson et al (2004) notes that since the advent of highly active antiretroviral treatment new cases of HAD are less frequently seen. Ellis et al (2007) note that the incidence of HAD (number of new cases) is decreasing in developed countries and Heaton et al (2010) note that prevalence estimates for HAD have dropped from 10-15% of HIV/AIDS patients before combination antiretroviral treatment was introduced to estimates of 2% since the advent of these therapies – although less severe forms of HAND still have a high prevalence amongst HIV/AIDS patients (estimated at 52%; Heaton et al, 2010). However, this is an example of a condition where a new biological treatment can affect the incidence which over time will ultimately lead to a reduction in both incidence and prevalence and the proportion of the dementia population experiencing the condition. ADAHPS (2013) provide a brief description of a complex case-management system for people with HIV/Dementia in NSW which includes an outreach service.

Alcohol related dementia and Korsakoff's syndrome and the Korsakoff/Wernicke syndrome are associated with a thiamine deficiency associated with chronic excessive drinking (e.g. over 6 drinks per day) and this in turn has been associated with a shrinkage of the frontal lobes (Hodges et al, 2009). Korsakoff's syndrome symptoms include an abrupt onset of amnesia and physical problems such as loss of balance, painful or weak limbs and disordered eye movements. Other symptoms include poor initiation, planning, organisation, motivation and problem solving and the presence of confabulation (false memories). These symptoms may be partially reversible, or decline reduced, if the person stops drinking and if the thiamine deficiency is urgently addressed. However, alcohol related brain damage (ARBD) can also be associated with poor nutrition, dehydration and metabolic disorder and damage caused though secondary factors such as assaults, falls and car accidents (Rota-Bartelink, 2009). ARBD clients often experience social problems associated with chronic drinking such as relationship breakdown, unemployment, financial breakdown and homelessness. It has been estimated that 75% of older Salvation Army Service clients in Melbourne were reported to have a cognitive impairment; the majority being alcohol related brain damage (Hecker, 2002 in Rota-Bartelink, 2009). It is suspected that a number of these cases might also meet the criteria for a diagnosis of dementia. The current Australian younger onset dementia prevalence study (Withall, 2013) found that 22% of the younger onset dementia cases were identified as ARBD which raises the need for primary prevention initiatives to address this potentially preventable type of younger onset dementia.

Moderate and particularly severe **traumatic brain injury** (TBI) may also be associated with the development of dementia either directly as a result of the brain damage caused by the injury or possibly through an increased risk for developing Alzheimer's disease at a later age (Alzheimer's Association USA, 2013a). A recent systematic review by Iverson et al (2012) indicated there

were conflicting findings in the literature but concluded there was a small increased risk for AD for those experiencing severe TBIs and that meta-analyses only identified this association was true for men.

Chronic traumatic encephalopathy has been found in the autopsies of individuals with a history of repetitive brain injury incurred through sporting or military activities (N = 50; Stern et al, 2011). Contact sports (e.g. football, boxing) may be associated with this neurodegenerative condition which can ultimately lead to dementia (Stern et al, 2011) and can also lead to a form of motor neuron disease. Stern et al (2011) think these recent neuropathological findings, combined with the millions of people regularly participating in contact sports that involve repetitive brain trauma, indicates this is a public health issue that warrants far more attention. There is little known about the underlying mechanism of the disease or about the incidence and the prevalence of this condition at this time. Research is currently endeavouring to find earlier bio-markers of these conditions.

Otherwise, the general search undertaken identified little literature pertaining to dementia in association with brain injury and some of this was out of date (e.g. AIHW 2007 Disability Survey; Ehrlich 1994) and did not focus on the relationship to dementia per se. Of the Alzheimer Association sites only the Alzheimer's Association (USA) site had a page identifying traumatic brain injury as a cause of dementia and cognitive difficulty and the information provided was sparse. This would appear to be an area where there is a significant information gap.

There are numerous other much rarer diseases and brain damage syndromes associated with younger onset dementia (e.g. Creutzfeldt-Jakob disease, Wilson's disease etc.) and readers are referred to summaries provided by Alzheimer's Australia (Hodges et al, 2009 and Mocellin et al, 2013), Sampson et al (2004) and later updates and fact sheets provided at the Alzheimer's Australia and international websites.

3.1.1 Treatment

With regard to treatment approaches Livingston and Cooper (2013) provide a summary of common treatment approaches for people with dementia which also largely apply to those with younger onset dementia. While no disease modifying treatments for most forms of dementia are available as yet some drug treatments have been used to improve cognitive performance with mild to moderate effect and trials of some newer drug treatments are in progress. Drug treatments are sometimes used to manage BPSD but there have been concerns about the undesirable effects of anti-psychotic medications (increased risk of cardiovascular events and death particularly with typical antipsychotic medication; reduced cognitive function for antipsychotics and benzodiazepines) which have been used to control symptoms such as agitation. For some forms of dementia (e.g. DLB and FTD) the use of neuroleptic medication to control agitation is not recommended due to potentially dangerous side effects. Sampson et al (2004) indicated much care needs to be taken with such drug treatments and they should only be used where absolutely necessary, at a low dosage, for a short time and under close supervision. However, a retrospective review by Chemali et al (2012) reported high levels of prescribed medication use by 85 people with EOD (younger onset dementia) and polypharmacy was common at the later stages of the illness. A study by Baldwin (1994) also noted the high level of use of psychotropic medication to manage BPSD. Koopmens and Thompson (2013)

indicate there is little information concerning psychotropic drug use for the younger onset dementia group and further research is required to clarify this issue.

Ratcliffe et al (2013) note that for the field of dementia overall there have been relatively few health economic evaluations of interventions for dementia and thus the data for younger onset dementia in particular is likely to be minimal. A study of chlorinase inhibitors found that Donepezil was the most cost effective drug for the treatment of mild and moderate vascular dementia and some improvement in the cognitive status of patients was reported (Ratcliffe et al, 2013).

The factors concerning side effects and the risk of adverse events with pharmacological treatments increase the need for non-pharmacological interventions. Cognitive stimulation therapy, which can improve cognition, is widely used and recommended in the UK and has been found to be cost effective (Knapp et al, 2006; Ratcliffe et al, 2013). Integrated diagnostic approaches, training of staff, teaching carers how to manage and monitor behavioural symptoms, and the use of Cognitive Behavioural management techniques have also been found to be effective (Livingston and Cooper, 2013; Ratcliffe et al, 2013). Diversional therapies (e.g. music and art therapies, sensory stimulation) appeared to only have short-term effects (Livingston and Cooper, 2013) and a befriending intervention was found not to be cost effective (Ratcliffe et al, 2013). Most of these findings relate to dementia rather than younger onset dementia so the applicability of these findings to younger onset dementia would need to be further assessed. In the section on Programs (Section 6) some similar programs are discussed.

3.1.2 Behaviours and psychological symptoms of behaviour (BPSD)

As can be seen from this description behavioural and psychological symptoms of dementia (BPSD) are more common in some types of younger onset dementia and the prevalence of particular symptoms varies by type. Ferran et al (1996) examined BPSD symptoms of people with various diagnoses of younger onset dementia. Depression was most common in AD, vascular dementia and CLBD (@ 50% of cases). Disinhibition and aggression were more common in FTD and alcohol related dementias but it should be noted the size of these sub-samples was small. Van Vliet et al (2012) compared the prevalence of neuropsychiatric symptoms of young onset AD to those with later onset AD across a 2 year period. Overall the younger onset AD group had less BPSD across the study period than the later onset AD group (e.g. a lower rate of delusions, agitation, depression, anxiety, apathy, irritability and abnormal motor behaviour). However, the most common symptoms for younger onset group at study onset were apathy (38%) and aberrant motor behaviour (25%) and these showed an increase in prevalence over time. The symptom profiles of younger and later onset AD groups were roughly similar across the two groups although eating changes were overall more common in younger onset AD and delusions more common in later onset AD. It should be noted that other younger onset dementia conditions such as HIV AIDS dementia, Down syndrome with dementia, ARBD, TBI, and Huntington's disease were deliberately excluded from this study as the behavioural profiles were likely to be quite different for non-Alzheimer types of dementia and thus not directly comparable with the later onset AD group.

3.1.3 Diagnostic issues

However, it is clear from the above description of symptoms that there are many overlapping symptoms across these dementias which make the task of differential diagnosis quite complex

and indicates the need for specialist assessment including neuro-imaging and neuropsychiatric assessment. There is a need for a co-ordinated multi-professional input to the diagnostic process (e.g. neurologists, psychiatrists, geneticists and a case manager; Bakker 2013, ADHC et al, 2013). Thompson (2011) notes that there is difficulty diagnosing younger onset dementia due to a lack of understanding about these conditions by health professionals and due the large number of tests/ assessments required to accurately confirm a diagnosis. Bakker (2013) also notes that symptoms of younger onset dementia are often attributed to more common causes in younger people such as depression and anxiety and as some people with younger onset dementia present with predominantly behavioural changes this can also lengthen the diagnostic process. As younger onset dementia is not common it may initially be misdiagnosed as depression or as stress-related sometimes resulting in the inappropriate use of some medications for these clients and the lack of appropriate referral for more specialist assessment.

An issue associated with accuracy of diagnosis is the use of appropriate neuro-pychiatric assessment tools to assess cognitive status and other symptoms that may be experienced by people with younger onset dementia (e.g. BPSD). It was noted that many of the studies make use of the original MMSE (Folstein et al, 1995) to assess cognition. Although this is a short but validated assessment some modifications to this measure have addressed problems with its scoring (Standardized Mini- Mental State Examination; Molloy et al, 1991) and the sensitivity of the measure to dementia status (The Modified MMSE (3MS) Examination; Teng and Chui, 1997). From a review conducted in 2007 (Jeon in Sansoni et al, 2007) it was concluded that the MMMSE (3MS) had superior psychometric properties to the original MMSE and the literature review indicated it was also more sensitive to dementia status. It was recommended that for general dementia samples or where dementia is suspected that the MMMSE (3MS) or the ADAS-Cog (Rosen et al, 1984) should be preferred although culturally more appropriate instruments (e.g. RUDAS, Storey et al, 2004; KICA-Cog, Lo Guidice et al, 2006) should be used for other cultural groups. However, nearly all the studies in this literature used the original MMSE despite concerns about its sensitivity to dementia status.

Associated with the complexity of differential diagnosis many studies have reported the delay between the onset of dementia symptoms and the arrival at a dementia diagnosis (Alzheimer's Australia 2013a; Alzheimer's UK, 2005; ADHC, 2012; Bakker, 2013; Bentham and La Fontaine, 2008; Brodaty and Cumming, 2010; Brown et al, 2012; Dartington, 2007; Hodges et al, 2009; Husband and Shah, 1999; Liebson et al, 2005; Luscombe et al, 1998; Mocellin et al, 2013; Morhardt, 2011; Reed and Bluethman 2008, Roach et al, 2008; Thompson, 2011; Tyson, 2007; Sperlinger and Furst, 1994; Svanberg et al, 2012; van Vliet et al, 2012; Werner et al, 2009; Williams et al 2001 – refer Table 1 and Table 2). A recent study from the Netherlands indicated that the time to diagnosis for younger onset dementia is on average 4.4 years compared to 2.8 years for later onset dementia (van Vliet et al, 2012). Misdiagnosis or misrecognition of symptoms is not uncommon (Bakker, 2013; Bentham and La Fontaine, 2008; Brown et al, 2012; Ferran et al, 1996; Svanberg et al, 2011) and there is a need to develop standardised clinical processes or a referral pathway for younger onset dementia for health professionals (Brown et al, 2012). Numerous studies concerning client and carer experience indicated the delay in diagnosis was a major issue for clients and carers (see Table 2). Prior to diagnosis clients and carers are unable to access many of the support services available for people with younger onset dementia.

In Australia Phillips et al (2011) conducted a review of barriers to timely diagnosis for dementia. In Australia symptoms of dementia were noticed by families on average about 1.9 years prior to the first health professional consultation and there was an average of 3.1 years before a firm diagnosis was made. It was noted that people from non-English speaking backgrounds were diagnosed later after the onset of symptoms than other members of the population (LoGuidice et al, 2001). It is suspected the time to diagnosis may also be greater for people with younger onset dementia as data from the Netherlands suggests (Bakker et al, 2013a). Barriers to timely diagnosis and management included patient/carer, GP and systematic factors that interact to inhibit optimal detection. It is also noted that these barriers operate within a socio-cultural context in which dementia is not well recognised, accepted or understood (Phillips et al, 2011). Patients and carers may not recognise the early symptoms as an important health issue and this combined with dementia associated stigma may deter or delay them from raising their concerns with their GP. Diagnostic uncertainties and a lack of education about dementia may contribute to GPs difficulty in diagnosing dementia. System factors may include poor communication links between service providers. Although service providers may desire transfer of information between services and coordinated service provision, a lack of information transfer between providers and between clients, families and other providers, may result in poor service coordination.

3.1.4 Care and Support

A particular issue for people with younger onset dementia is that their life cycle stage at onset is quite different than for people with later onset dementia. As younger onset dementia occurs before the age of 65 and may often commence in the person's 40's to 60's, many clients have families with dependent children. They may still be working and facing difficulties in the work place (Maslow, 2006) and there may be financial and legal ramifications as many are required to retire at an early age due to their dementia (Bakker, 2013; Koopmens and Thompson, 2013). Such issues need to be addressed by relevant support services/ programs and currently some workplace initiatives in this area are being undertaken by Alzheimer's Australia (Hodges et al, 2009; Mocellin et al; 2013).

Young-onset dementia also forces individuals to assume dependent roles within their families and they are more likely to suffer the loss of roles within the family such as being a parent, financial provider or spouse. These factors may result in the loss of key elements of their sense of self and identity (Bakker, 2013; Harris et al, 2009; Tolhurst et al, 2012). If the affected person is the primary caregiver, this role change may result in feelings of helplessness and frustration (Bakker, 2013; Hunt, 2011). Bentham and La Fontaine (2009) and Ferran et al (1996) suggest these needs require skilled multidisciplinary staffs that are able to deliver a range of psychosocial interventions with the person with dementia and his/her family.

Younger people with dementia are more likely to be physically healthy than older adults with dementia and may require alternative approaches to providing care. Many dementia care settings are primarily designed for older adults and may not be equipped to meet the needs and interests of younger people with dementia (Alzheimer's UK, 2005; Beattie et al., 2004; Morhardt, 2012; Werner et al, 2009).

Chemali et al (2012) undertook a medical and service use review of 76 people with early/younger onset dementia attending a memory clinic in the USA. They found that only 48% had been given an available social work consultation, most were heavily medicated and lacked

access to adequate age-related community services and home based support services. Although there are limits to which this can be generalised to other countries with different service systems, audits of services received by people with younger onset dementia can be useful in determining what services are being accessed and in identifying any barriers to such access (Alzheimer's UK, 2005). The issues related to service design and development are addressed further in Section 5 below.

Some earlier studies (Harvey, 1998; Ferran et al, 1996) have reported a high level of institutional service use by people with younger onset dementia. Harvey (1998) noted in his cost of illness study that compared to older people with dementia people with younger onset dementia appear to use less community services and more costly institutional care. A study by Ferran et al (1996), in a retrospective review of 200 patients aged 45-65 years referred to a presenile dementia assessment service, found that 8% of the younger onset dementia patients were in a residential care facility at study onset but this rose to 22% by the completion of the study 14 months later. A further 9% were receiving regular respite care in hospitals or nursing homes. Approximately 32% of the patients were also admitted to a hospital ward in the year following their assessment by the service. Livingston and Cooper (2013) have noted that both older and younger people with dementia tend to have longer hospital admissions that those without dementia and are more likely to die in hospital. Low levels of community service use such as domestic assistance and assistance with ADL tasks have been reported (Bakker et al 2013b; Georges et al, 2008; Newens et al, 1995; Lim et al; 2012). While some of this may relate to lack of knowledge about available services or absence of service referrals it may reflect a reluctance by some carers to make use of these services until really needed (Bakker et al 2013b) or as suggested by Lloyd and Sterling (2011) the acceptance of such services might impinge on some aspect of the carer's identity. There is little information available concerning service utilisation (in either the community or acute sectors) or cost data for this group internationally or in Australia.

Although Harvey et al (1988) examined the costs of care for people with younger onset dementia, and found evidence that indicated that costs of care for the younger onset dementia group may potentially be higher than for later onset dementias this study did not include indirect costs of care (Werner et al, 2009) and thus the cost is probably underestimated. Werner et al (2009) also noted the study did not also factor in the 'double economic strain' for people with younger onset dementia (loss of income while not being eligible for financial assistance or access to some subsidised support services).

3.1.5 Living arrangements

With regard to time to institutionalisation 2 year longitudinal study by Bakker et al (2013a) found a significantly longer time to institutionalization/permanent residential care amongst people with younger onset dementia compared with people with later onset dementia. The time from symptom onset to institutionalisation was more than twice as long for people with younger onset dementia (@ 9 years) compared with later onset dementia (@ 4 years). With regard to neuropsychiatric symptoms only the apathy symptom emerged as a significant predictor of institutionalisation for the younger onset dementia group. An earlier follow-up study by Newens et al (1995) of 109 patients in a catchment study had similar findings for early onset AD and found the median time from symptom onset to residential care was 8.4 years and from confirmed diagnosis it was 5.5 years. Five years after diagnosis 57% of people with

younger onset dementia were still living at home. Some of the differences between these studies may relate to inclusion criteria and methods and some dementia syndromes have quite a different BPSD presentation to early onset AD. Tindall and Manthorpe (1997) also note the lengthy period of care duration for people with early/younger onset dementia. However, the limited evidence suggests there is a long period between symptom onset to institutionalisation for young onset AD patients. It is hoped the current 'Inspired' project (Withall, 2013) may cast further light on these issues for Australia.

An issue that warrants further examination is the number of people with younger onset dementia who are living alone and whether those that live alone have access to a carer. On this issue the data is sparse as many studies do not report it – although Baldwin (1994) indicated that 38% of their pre-senile dementia patient group were living alone. However, for most studies reviewed the rate appears to be much lower but it is not directly reported. Harvey (1998) indicated that for the 185 cases identified in the UK catchment study 82% had an informal carer providing assistance and 57% were living with a cohabitant spouse. A study by Sait et al (2013) using data sources from AIHW (2012), census data from 2011 and the Aged Care Assessment Program (ACAP) data estimated that approximately one third of people with dementia live alone. Although some of these people with dementia may have informal support provided by carers there are others that may have no access or limited access to a carer. Sait et al (2013) note that the literature identifies there are a range of risk factors associated with living alone such as problems with nutrition, falls, hygiene, household fires and financial and money management. Due to these risk factors they may be placed in residential care earlier that other people with dementia that have more adequate care support. Sait et al (2013) note there is only a limited acknowledgement of this group in Australian policy documents on dementia and yet this is a vulnerable group with high service needs. This group requires additional service support to navigate the service system and to avoid potential adverse outcomes such as social isolation, exploitation and self-neglect including poor nutrition. It is thought the introduction of the key worker program for younger onset dementia (Woolley, 2013) may help to address the particular needs of this group although as yet there is little data available concerning the number of people with younger onset dementia in Australia that live alone and/or who have limited informal care supports.

3.1.6 Life Expectancy

An important issue for people with younger onset dementia and their carers is the impact of dementia on life expectancy. Brodaty et al (2012), considering all dementias, noted that the average survival times varied widely by study (ranging from 3 – 10 years) due to methodological differences (scope of sample between the studies, diagnostic criteria, definition of onset). The authors note that characteristics of the individual (e.g. age, sex, co-morbidities) and the nature of dementia (type and severity at diagnosis) will influence survival rates. If the life expectancy data could be described as vague for the dementias overall it is particularly vague for younger onset dementia and many of these clients are younger and more physically fit at the time of their diagnosis with less co-morbidity. Newens et al (1995) estimated the average survival time for younger onset dementia was 9.6 years from the onset of symptoms and Bakker et al (2013a) identified similar estimates. Kay et al (2000) estimated the median early/younger onset dementia survival time as 6.08 years from diagnosis and 7.6 years from symptom onset. Mitchell (2012) cites two studies pertaining to younger onset dementia (Xie et al, 2008; Koedam et al, 2008) and these had the conflicting findings of longer life expectancy and higher

mortality risk respectively. The paucity of information in this area needs to be rectified by further and more substantive research but the limited literature suggests the period of survival from symptom onset may be between 7-9 years.

3.1.7 Stigma

The experience of stigma is commonly reported throughout the literature for all younger onset dementia diagnostic groups and for dementia more generally (Mitchell, 2012; Alzheimer's UK, 2008) although organizations such as the Alzheimer's Association continually help to raise public awareness concerning younger onset dementia (Hodges et al, 2009; Mocellin et al, 2013). There is also still a general misunderstanding by the public that dementia is only an old person's disease (Morhardt, 2011). In Japan (Miyamoto et al, 2011) report on a change to the official term used for dementia from *chiho* (meaning a disease of cognition associated with idiocy) to *ninchisho* (cognitive syndrome) in order to overcome these negative connotations. As Livingston and Cooper (2013) indicate stigma has the potential to increase social isolation as people may avoid those with the illness and it may also operate in services and institutions where people with younger onset dementia may be excluded from services they may potentially benefit from.

3.1.8 Information and education

Information provided by peak associations and government publications available on the web can be viewed as information services in their own right. Many people with younger onset dementia and their families report the need for clear and accurate information (Mitchell, 2012). In preparing this section it was noted that websites, and documents available on websites, varied greatly in the currency of information and the detail of information provided. While it is appreciated that many of the web sites are trying to present information in plain English and in a simple form it is important that there is a regular review to keep this information up to date. Some of the information on some sites is also provided without any referencing whereas other sites provide references for their summaries so that those who are interested can obtain further follow up information. The latter approach is recommended.

3.2 Prevalence Estimates and Issues

There is no completed study that provides definitive prevalence estimates for Australia. Most estimates are based on meta-analysis of studies conducted internationally –many of these studies have used somewhat different methods, many have quite small samples and there were relatively few studies for some regions including Australasia (Prince and Jackson, 2009). Although meta-analysis is an important and useful tool it is useful to remember that the 'garbage in, garbage out' rule can apply and that great care needs to be taken with the inclusion criteria for the studies although more recent meta-analyses are using increasingly more stringent methods. For the under 60 age group the prevalence estimates for Australia rely heavily on extrapolations from the catchment area prevalence study (N = 567,000 catchment population) conducted by Harvey (1998, 2003) in the late 90's in the UK. How representative or accurate these estimates can be, given the different population characteristics of the countries involved (even after adjusting for different age and sex compositions), is debateable. Another factor, evidenced by this literature review, is that awareness of Young Onset Dementia has changed considerably over the past 15-20 years, there have been considerable improvements in neuro-imaging technology and diagnostic procedures and practices and these factors may influence the identification of dementia cases. Thus it is considered that the following estimates

provided from the literature should be treated as 'estimates' to which numerous caveats apply, rather than to be referred to as established 'fact' as often occurs in publicity literature for this field. It is; however, clear that a more definitive study of the prevalence of younger onset dementia /Dementia in Australia, using a larger catchment area than the Harvey study is necessary. As discussed below an Australian prevalence study by Withall et al (2013) is currently in progress but only preliminary data is available to date.

The Harvey (1998; 2003) study identified 185 cases of younger onset dementia (onset < than 65 years) from their catchment area of 2 boroughs (urban and semi-urban) in the UK (N = 567,000) and from this it was extrapolated using population census data that for 2001 in the UK there would be 18, 319 (*CI* 15, 296-21,758) cases of younger onset dementia. Harvey, however, noted that the low number of cases of Down syndrome (@ 1%) associated with dementia was probably an artefact of sampling bias and these cases may be underestimated due to a lack of referrals received from disability services. It is unclear from this study as to whether cases of traumatic brain injury and dementia, and HIV/AIDs were actively recruited and included – but certainly no cases were reported for this sample. No significant differences were reported by gender although the prevalence rates are somewhat different (e.g. 62.6 per 100,000 at risk for males 30-64, 45.4 for females and 54 overall). However, there were only a relatively small number of cases identified and the confidence intervals were very large. Harvey notes that the main weakness of the study is that despite using a catchment area with a population over 500,000 the rarity of the condition meant that only 185 cases were identified and that to obtain more robust estimates with smaller confidence intervals a much larger population catchment would be required.

The AIHW in 2007 stated they used the Harvey study to produce estimates for the 60 and under age group but used the findings of a meta-analysis of dementia prevalence studies in Europe (Lobo et al, 2000) to make estimates for the older age groups (>65 years). It is unclear what study was used as the base for the estimates for those between 60-64 years of age but one assumes it was the Harvey study as the Lobo et al (2000) meta-analysis only provides estimates only for those over 65 years. On this basis (AIHW, 2007) it was estimated in 2003 there would be 8,100 cases of younger onset dementia in Australia. For 2011 using population projections they estimated there would be 10,000 cases (AIHW, 2007).

In 2012 (AIHW, 2012) estimates from Harvey et al (2003) were again used for the 60 and under age group but data from a more recent and stringent meta-analysis - the World Alzheimer Report 2009 (Prince & Jackson, ADI, 2009) - was used for the other age groups. AIHW (2012) estimated that there were 23,900 Australians under the age of 65 years with younger onset dementia in 2011. There is a big difference between this estimate and the earlier AIHW (2007) estimate for 2011 of 10,000 cases. It is suspected the difference arises because of the use of ADI (Prince and Jackson, 2009) estimates for those aged between 60-64 years. This is the most populated age band for younger onset dementia.

It should be noted that AIHW, in deriving these later estimates for 2011 (for those 60 and over) used an equally weighted average of ADI (Prince and Jackson, 2009) estimates for Australasia, Western Europe, and North America. The estimates for Australasia were only based on 3 of 4 assessed studies and these did not contain both age and sex rates (only age rates) and these were calculated by using the pooled estimates from the Western European and North American studies. Following this age and sex rates were estimated for the three study sets and the overall

dementia prevalence rates were found to be similar (6.91; 6.92 and 6.46 respectively). In the 60-64 years age group the rates were estimated to be 1.8, 1.6 and 1.1 respectively.

As with the Harvey study the issue is raised as to how comparable these populations are to the Australian population as the ethnic/racial mix is known to be quite different and some studies (Cooper et al, 2010; Livingston and Cooper, 2013; Manly and Mayeux, 2004;) have indicated there are ethnic/racial differences in the prevalence of dementia. If these estimates are including subtypes such as HIV/AIDS dementia, which are related to infectious factors, the prevalence of such diseases may also vary across populations. The ADI (Prince & Jackson, 2009) review also notes that many of the prevalence studies contained in the various meta-analyses for high income countries are now quite old (undertaken in the mid 90's) and there is a need for current prevalence studies as prevalence can change over time and more current data is critical for policy making and planning.

Studies by Access Economics (2005) and Deloitte Access Economics (DAE; 2011) also used estimates from Harvey et al (2003) for the under 65 age group and estimated that for 2011 there were 16,239 cases of Younger Onset Dementia (DAE, 2011). The differences in figures to those provided by AIHW (2012) are probably due to differences in calculating the rate for the 60-64 years age group for 2011 data (Harvey study vs. ADI rates) and other methodological differences. The DAE estimated that younger onset dementia represents about 6.1% of all dementias whereas the AIHW estimates this group comprises 8% of all dementias. DAE (2011) make an interesting point that due to the relatively large growth in the older population the proportion of younger onset dementia cases in all dementias is likely to reduce over time. It is projected to decline from around 6.1% in 2011 to 2.9% in 2050 but this should be seen in the context that the crude numbers of younger onset dementia cases will also be increasing.

There is also a summary and critical review provided in DAE (2011) of Australian studies that have provided previous prevalence estimates for dementia in Australia. Most of these studies do not examine dementia rates for those aged less than 65 years (e.g. the DYNOPTA study) and others have issues such as using a self-report/identification methodology (e.g. Disability, Ageing and Carer's Survey) which may underestimate the prevalence of dementia.

The current 'Inspired' study by Withall and associates (Withall, 2013) provides some preliminary estimates in press releases at www.inspired.com.au, and in Withall & Draper (2010) and Withall (2013) but these sources do not as yet provide sufficient detail of the study methods used. However, it is stated that a case finding survey and hospital records search with capture-recapture methodology was used. Withall (2013) indicates that in an initial catchment sample in eastern Sydney (N = 130,000 for 30-64 years) 136 cases of younger onset dementia were identified indicating a higher prevalence rate (67.4 per 100,000) than was evident in the Harvey et al (2003) study. In particular the proportion of ARBD cases in the younger onset dementia group was much higher at 22% of younger onset dementia cases compared with 10% in the Harvey et al (2003) study. One suspects the differences in these rates may partly reflect changes in diagnostic practices concerning younger onset dementia over the intervening years.

A number of the studies (e.g. DAE and AIHW studies) use prevalence and incidence estimates combined with age-specific population projections to estimate the future number of dementia cases until the year 2050. These studies assume that dementia prevalence and incidence will remain the same over time although the age structure of the population may change. Jorm et al

(2005) noted that if there are successful preventative interventions in the future this would reduce the incidence and prevalence rates and affect these projections. Jorm et al (2005) examined the impact on these projected estimates based on a hypothetical model where interventions could delay the onset of dementia by 5 years. If interventions (e.g. anti-inflammatory medication, anti-oxidants, anti-hypertensive and cholesterol lowering medication etc.) could delay the onset of dementia by 5 years there could be a substantial impact on these future projection figures. Livingston and Cooper (2013) noted that while disease modifying treatments for dementia are not yet available many trials are currently underway (mainly targeting beta- amyloid but also tau phosphorylation or aggregation and glucogen synthase kinase-3) which show some potential promise. The Jorm et al (2005) study is important in that it reminds us that prevalence and incidence estimates can change with effective medical interventions and some evidence to this effect has already been seen with antiretroviral treatments (HAART) for HIV acquired dementia (Ellis et al, 2007).

There is a lack of national data on the prevalence of dementia among Indigenous Australians. A study by Smith et al (2008) examined dementia prevalence amongst Indigenous people in a remote location and identified 45 cases of dementia in their sample of 363 Aboriginal and Torres Strait Islanders. As AIHW (2012) indicate this equates to a prevalence rate of 12% whereas the AIHW (2012) estimated 3.4% of all Australians over 45 had dementia. As this study was small and localised it was decided it would not be appropriate to generalise from it to provide the national AIHW estimates (AIHW, 2012). A more recent unpublished study by Li et al (2013) based on 2011 data for the Northern Territory found much higher age-adjusted prevalence estimate (6.5%) for the NT Indigenous population when compared with the non-Indigenous population (2.6%).

Data collection for the Koori Growing Old Well study (Broe, 2013) has recently been completed and this study aimed to determine the prevalence and potential risk factors for dementia in urban Aboriginal settings where the majority reside. Three hundred and thirty six Aboriginal and Torres Strait Islander people over 60 years of age were identified across 5 communities (urban and regional) in NSW. The study also included a survey of health, cognitive function, well-being, family and life history and service use which was undertaken with consenting participants. This study also did not have a particular focus on younger onset dementia but the crude dementia prevalence estimate was 13.4% and when age adjusted the rate (21%) was three times the general Australian rate. Alzheimer's dementia was the most common (44% of cases) followed by vascular dementia (17%) dementia due to brain trauma (7%) along with mixed dementia diagnoses (29%). Alcohol related dementia was uncommon in the NSW urban and semi-urban catchment but whether this would be applicable in other jurisdictions and in particular to more rural and remote communities such as those found in the Northern Territory and WA (Smith et al, 2008; Li et al, 2013) requires clarification. The study by Smith et al (2008) estimate the prevalence rate amongst rural and remote Indigenous Australians to be in the vicinity of 12% which is much higher than the general estimates for Australia. The studies by Smith et al (2008), Broe (2013) and Li et al (2013) do not focus particularly on cases of younger onset dementia but suggest that the current prevalence estimates for Australia do not take into account a likely higher prevalence of dementia in Indigenous communities and further research will need to be undertaken to confirm these estimates.

The discussion above indicates that there has been no national study of dementia prevalence using clinical diagnoses (DAE, 2011) and that due to the lack of epidemiological data Australian

estimates have used meta-analysis performed on a set of epidemiological studies largely undertaken in other countries. For the younger onset dementia group most analyses have either used the Harvey et al (2003) prevalence estimates from the UK or used them in combination with other estimates (Lobo et al, 2000; ADI, 2009). It has been noted above that many of the studies on which these estimates are based are quite old (undertaken in the 90's) and they assume that Australia has the same dementia incidence and prevalence rates as Western Europe and Northern America which is somewhat questionable. For 2011 the younger onset dementia estimates vary from 10,000 cases AIHW (2010), through 16,239 cases (DAE, 2011) to 23,900 cases (AIHW, 2012). With such a large degree of difference between these estimates their usefulness for policy making and planning must be limited. There is a need for a national study of dementia prevalence, including the younger onset dementia group, using clinical diagnoses and current methodologies (Prince and Jackson, ADI, 2009) in Australia. The current 'Inspired' study represents a promising start in this direction. However, as the study by Harvey et al (2003) suggests this would be no small undertaking as a substantially larger catchment sample than the Harvey study (567,000) would be required given the relatively rarity of younger onset dementia. However, until such a study is completed, the accuracy of current Australian estimates for dementia and younger onset dementia will remain debateable and questionable and their usefulness for planning services will be limited.

3.3 Conclusion

This introductory overview has described the different types of younger onset dementia and has noted the similarities and differences in the range of symptoms for these subtypes. Some studies have reported a greater presence of BPSD for some sub-types such as FTD but the evidence is as yet equivocal but BPSD is relatively common for most types which add to the needs and care requirements for people with younger onset dementia.

The overlapping of some symptoms across younger onset dementia types makes differential diagnosis complex and difficult. Problems experienced by people with younger onset dementia in obtaining a diagnosis, including the lengthy time to diagnosis and frequent initial misdiagnosis, is a common theme in the younger onset dementia literature. Although this issue has been reported for many years it still remains a major issue for service improvement.

As the onset of younger onset dementia commonly occurs in people aged between 40 – 65 years it occurs at an earlier period in the life cycle stage. This earlier onset raises a number of issues for people with younger onset dementia including loss or diminishment in roles such as provider, parent and spouse and the significant adjustment to those changes that is required. Associated with the common loss of employment there are also problems experienced by people with younger onset dementia and their families concerning loss of income. Financial problems are commonly reported which exacerbates an already difficult situation for this group.

As people with younger onset dementia are younger they are often physically healthy and active and may not experience the co-morbidities that are associated with later onset dementia. Another common theme in this literature is the need for access to individually tailored, person centred services and the need for existing services to provide programs/services that are more age-appropriate for people with younger onset dementia.

Some types of younger onset dementia such as Huntington's disease carry a high level of genetic transmission, Down syndrome carries also a high risk for the development of dementia and some forms of AD are more strongly associated with genetic risk factors. Obviously for groups so affected genetic counselling is of prime importance.

Some types of younger onset dementia are potentially more preventable, such as ARBD, and yet more recent prevalence studies indicate this is more common in Australia than elsewhere. This is an area where health promotion and prevention campaigns would seem warranted.

Recent findings concerning potent combination antiretroviral treatments for HIV/AIDS appear to be reducing the incidence of this form of younger onset dementia. This serves to remind us that new treatments have the potential to affect both the incidence and the prevalence of younger onset dementia so the importance of adequate funding for biomedical research should also not be ignored.

The limited literature available indicates there is quite a long period from onset of symptoms to permanent residential care placement for people with younger onset dementia (e.g. 6 -9 years)and that the level of informal care provided is high which places a significant burden on these families. Although some studies indicate a relatively high use of institutional services for this group (e.g. hospital admissions, nursing home respite etc.) authors also report that community service use is relatively low for this group. One of the issues may be the lack of appropriate referrals to relevant support services by professionals but it also may be related to a lack of awareness about how these services might assist people with younger onset dementia and their families. In view of this many authors suggest the need for a central gateway to services for people with younger onset dementia or the adoption of case-management and key worker approaches.

There are few studies that comprehensively examine service utilisation and the costs of illness for the younger onset dementia group or that include consideration of social and informal care costs. There are relatively few studies that examine the cost effectiveness of both pharmacological and non-pharmacological for dementia overall and the application of these findings for the younger onset dementia group needs to be further assessed.

Although it has been estimated that approximately one third of people with dementia live alone there is little data available concerning those that live alone in the younger onset dementia research literature and yet this is a group that is likely to have high service needs. It might well be that premature placement in residential care facilities may be an issue for this group and this needs to be further explored.

Numerous other research issues and gaps have been identified in this overview including those concerning prevalence, incidence, life expectancy and the proportions of people with younger onset dementia that are diagnosed with the various sub-types of younger onset dementia. More accurate and up to date estimates will be critical for service planning purposes.

4 Experience, Issues and Stated Needs of People with Younger Onset Dementia and their Carers and Families

A large number of studies were found that covered these aspects (see Table 2 below) but the strength of evidence relating to these studies was often rated at a relatively low level. Relatively few studies have comparison or control groups and relatively few use standardised measures as well as semi-structured interviews. A large number of studies use qualitative research methods and the sample size for many of these studies is relatively small. In this section studies that examine the experiences of clients will be examined initially, followed by studies that examine the impact on children, spouses/ partners and studies that address broader issues relevant to all carers. The final section relates to studies that focus on carers and service issues.

Table 2 Studies relating to People with Younger Onset Dementia and Their Carers and Families

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
Allen et al (2009)	UK	Having a father with YOD	Interviews with children	Emerging practice	Children of people with YOD	12 children	Overarching response was to take 1 day at a time. 5 other themes identified-damage of dementia, reconfiguration of relationships, caring, strain & coping. High levels of stress reported by children
Arai et al (2007)	Japan	Care giver difficulties EOD (YOD) vs. LOD	Assessment of families	Promising practice	Carers EOD (YOD) and LOD	14 EOD, 54 LOD carers	Carers of EOD (YOD) perceived greater difficulty due to presence of BPSD than did LOD carers despite no significant patient differences in number of BPSD. EOD (YOD) carers may require additional support services
Arends & Frick (2009)	USA	Without Warning program; lessons learned	NA - Program description only	NA	EOAD patients & family	40 family members	Describes a group meetings program for family members but does not provide any formal program evaluation. Provides tips re running groups meetings
Bakker et al (2010)	Netherlands	Needs in EOD, qualitative case-study	Prospective random case-study, 12 months	Case-study	EOD (YOD) client & carer	1 carer and client	Patient & carer dyad journey from initial symptoms to residential placement. Need for timely diagnosis & specialised EOD (YOD) care /services sensitive to evolving needs of both client & carer
Bakker (2013)	Netherlands	YOD care needs and service provision	Longitudinal observational studies	NA	YOD clients & carers		Compendium of articles by Bakker and colleagues
Bakker et al (2013b)	Netherlands	Use of formal and informal care: YOD	Longitudinal data of 215 patient carer dyads.	Promising practice	Carers AD	209 patient-caregiver dyads	Study showed that in general patients receive over 3 times the amount of informal care than formal care. Factors increasing formal care were disease severity, behavioural problems and low initiative re: ADL tasks. No comparison group. Identifies research gaps
Bakker et al (2013c)	Netherlands	Unmet needs & HRQOL in YOD	Cross-sectional, standardised measures	Promising practice	YOD clients & carers	209 patient caregiver dyads	Unmet needs of both patient and carer related to several domains of HRQOL. Patient HRQOL was associated with depression. Carer HRQOL was lower than Dutch population for most SF-36 domains -particularly those related to role functioning
Baldwin (1994)	UK	Acquired cognitive impairment in the presenium	Catchment survey, interviews & standardised scales	Promising practice	Clients & carers - cognitive impairment	43 clients, 12 carers	Patients had high behavioural dependency & there was high use of psychotropic medication by patients. Seven of twelve carers had diagnosable psychiatric symptoms. Few support services used by those residing in the community
Beattie et al (2004)	UK	A qualitative study of views of younger people about their dementia	Qualitative interviews	Emerging practice	YOD clients	14 clients	Themes-experience of dementia, diagnosis, age, risk and danger. Clients desire age-appropriate services. Need to assess patient views
Boldy et al (2005)	WA (Aust)	In-home Host	Retrospective service	Routine	Dementia carers	31 primary	Short-term in-home respite (up to 3 days) service may assist in

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		Family Respite	evaluation	practice	using respite	carers	delay institutionalisation of client. Low rate of GP referral to the service. Need for links with other respite services
Boutoleau-Bretonniere et al (2008)	France	Zarit Burden Inventory and ADL in FTD	Standardised Scales comparing YOD & LOD	Acceptable practice	YOD/FTD & LOD carers & clients	26 FTD Dyads, 20 LOD dyads	Greater burden for carers of FTD than AD clients although the level of functional disability of these groups were similar. Carer burden related to NPI behavioural score
Bray (2012)	Australia	Young carers-carer payment and allowance	Analysis FaHCSIA dataset	Routine practice	Carers older than 25 receiving allowance	>20,000	Most carers were females in outer urban/rural locations. 'Youth' Carers assisting parents and grandparents, 'Adult' carers assisting disabled children. Educational and social disadvantage of young carers reported
Brown and Roach (2010)	UK	My husband has YOD….	Case -study	Case-study	Spouses YOD	1	Anecdotal experience of carer who cared first for her mother and then her husband with YOD. Notes how helpful it was to have specialised YOD service support by the time of onset of disease for her husband
Bunn et al (2012)	UK	Adjusting to diagnosis - carer and client	Literature Review of qualitative studies	Literature review	Dementia Carers and Clients	102 studies @3,000 N	Identifies need for early provision of info about financial aids and entitlements, professional and specialist support and appropriate referrals
Calvette et al (2011)	Spain	Depression and grief, Spanish families and TBI	Assessment of families	Acceptable practice	Carers TBI	223 carers	Interventions with families should focus on improving social networks (emotional, instrumental, professional support) as well as help carers to develop adaptive coping strategies
Clemersen et al (2013)	UK	Towards living well with EOD	Interviews clients of memory clinic & YOD service.	Emerging practice	EOD (YOD) clients	8	Four qualitative themes emerged from the analysis: 'disruption of the life-cycle', 'identity', 'social orientation' and 'agency'
Dartington (2007)	UK	Two days in December	Case-study	Case-study	YOD client & carer	1 client, 1 carer	Themes included patient decline, change in couple relationship, caring role and adjusting to paid carers in the house
Delaney & Rosenvinge (1995)	UK	Presenile dementia; sufferers, carers, services	Interviews and standardised scales	Promising practice	Patients & carers AD & MID	18 AD, 9 MID & carers	Carers showed strain, psychiatric morbidity and they reported a negative impact on their employment. Identified unmet carer needs e.g. for information, advice & support and the need for greater day care provision for patients
Denny et al (2012)	USA	Caring for Children of parents with FTD	Review of literature and resources	Expert opinion	Children and spouses FTD	NA	Identifies need for additional support services and resources for children and spouses. Identifies research gaps
de Vugt et al (2006)	Netherlands	Impact of behavioural problems on spousal carers	Standardised Measures with AD & FTD	Acceptable practice	AD & FTD spouse carers	AD 47 carers, FTD 27 carers	Patients with FTD had more behavioural problems and their carers had higher mean NPI, distress and burden scores compared with AD carers. FTD carers found it hard to cope with the disinhibition symptom
Ducharme et al (2013)	Canada	Unique experience of spouses in EOD	Interviews 12 spouses -qualitative	Emerging practice	Spouses – EOD (YOD)	12 spouses	6 themes in spousal interviews -delay in diagnosis, managing BPSD, non-disclosure/denial, grief, managing responsibilities, future planning
Easton (2011)	Australia	People with YOD &	Survey	routine	YOD clients/carers	17	Reviews retrospective experience of people with YOD/carers

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		their carers -period of diagnosis		practice			concerning the diagnostic period and immediate aftermath and suggests a number of issues for service improvement
Evans & Lee (2013)	SA (Aust)	Impact of dementia on marriage	Systematic literature review	Literature review	Spouses - Dementia	23/115 studies included	Two majors themes identified from the review of 23 articles - transition (relationship, roles, intimacy) and loss (loss of partner and marriage)
Freyne et al (1999)	Ireland	Burden in carers of dementia patients	Comparison carer burden measures YOD & LOD	Emerging practice	YOD vs. LOD patients and carers	22 YOD & 22 LOD cares of community residents	Carer burden for YOD Carers higher than for LOD Carers. Comparator group had shorter duration of care which is a confounder
Furniss et al (2011)	UK	Views of Carers: Downs with Dementia	Qualitative - interviews	Emerging practice	Carers: Downs with Dementia	13 carers	Carers needed for more information and support including review meetings and had concerns about the future and the sustainability of care arrangements
Garbutt (2006)	UK	Experience of having parent with YOD	Qualitative - interviews	Emerging practice	Offspring of YOD	5 adult offspring	Themes - experiencing change in relationships, understanding the change, managing change and experiencing change in self
Gelman and Greer (2011)	USA	Young Children in EOAD families	Lit. review and case-study	Literature review	Children of people with EOAD	Case study	Child carers experience stress and potential psychological and social disadvantage. Little research available - identifies numerous basic research gaps & need for support services
Georges et al (2008)	AA Europe	AD in real life -the dementia carer's survey	Survey	Acceptable practice	Alzheimer disease carers	200 carers per country >1000	Care burden, hours of informal care and issues re impact of IADL and ADL function
Gilbert (1992)	UK	Huntington's Disease-Community Care?	Case-study	Case-study	HD carer	1 carer	Anecdotal account detailing the lack of appropriate and specialised services for Huntington's in the Nottingham area of UK -issues re slipping between the cracks of service coverage.
Gilliard (1999)	UK	Young carers (< 21 years) - dementia caring	Case-study	Case-study	Children of parent with Dementia	2 children-YOD parent	Discusses the impact on children, their need for guidance and support and ways of establishing rapport
Harris (2004)	USA	The Perspective of Younger People with Dementia: Still an Overlooked Population	In-depth face-to-face or on-line interviews and a focus group.	Emerging practice	People with YOD	23 participants with YOD	Focus groups, face-to-face interviews, and on-line interviews were conducted with members of a support group for people with YOD and their families and members of the local Alzheimer's Association. Common themes were trouble obtaining an accurate diagnosis, marginalization, changing relationships within the family structure, workforce/retirement issues, dependency, lack of meaningful occupation, issues of self-esteem, and awareness of changes in self. Practice guidelines were formulated for working with people with younger onset dementia.
Harvey (1998)	UK	Impact of YOD	Catchment survey,	Promising	YOD	YOD 185,	Examined patient characteristics and carer burden. High level of

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
			interviews & standardised scales	practice		carers 40	carer burden associated with patient BPSD and low levels of community support. Presence of psychiatric symptoms for 52% carers suggests need for carer assessment
Harvey et al (1998)	UK	CANDID - telemedicine service supporting YOD	Retrospective review of helpline calls	Routine practice	Dementia/YOD all	574 public, 547 re registered patients	Approx. half the calls were public enquiries, the other half were made concerning registered patients. Of all calls 61% were from carers, 4% from patients, 19% professionals, 16% from other. 45% concerned general information, 37% clinical advice and 18% social advice
Hain et al (2010)	USA	What matters most to carers	Interviews with carers	Emerging practice	Carers-Mild to mod. dementia	10 carers	Three key themes (seeking guidance, self-abnegation, uncertainty about the future). Notes that care giving is not a static role but varies over the course of the patient's illness - one size does not fit all and thus an individualized approach needs to be taken
Harris and Keady (2009)	UK,USA	Selfhood in YOD	Qualitative: interviews carers and clients	Emerging practice	Carers and Clients YOD	23 clients, 15 carers	Qualitative analysis identified 5 themes for carers and clients-as worker, as abandoned individual, sexual identity, family identity, individual engaged in living. Identified need for YOD services and research gaps
Hellstrom et al (2007)	Sweden	Sustaining couple-hood	Longitudinal interviews spousal carers	Acceptable practice	Dementia - spouses	20 clients 150 interviews	Follow-up of 20 carers over 5 years. Three phases - sustaining couple-hood, maintaining involvement, and moving on. Framing care relationships in terms of just stress and burden is viewed as simplistic
Husband & Shah (1999)	UK	Information & advice received by carer of people with YOD	Qualitative interviews - compared service types	Acceptable practice	YOD	40 carers	Compared information received by carers who had used Old Age Psychiatry services (12) to that received by carers using other services (28) - Old Age Psychiatry services gave better information & advice
Janicki et al (2010)	USA	Coping with dementia -families of adults with Down's	Interviews: qualitative analysis' standardised scales	Acceptable practice	Carers of adults with Down's	17 older carers	Used interviews and standardised scales. Carers provide 2* the amount of hours of care for a patient with Down's and dementia
Johannsen & Moller (2011)	Norway	Experience of Persons EOD: Quality of Life	Qualitative study 20 EOD journeys over 1 year.	Acceptable practice	EOD (YOD) clients	20/217	Randomly selected 20/217 patients. Identified 2 stages of patient journey (toward dementia diagnosis, fighting for dignity) over 1 year period, identified unmet needs, issues for services & the need for specialised EOD (YOD) services
Kaiser & Panegyres (2007)	WA (Aust)	Psychosocial impact YOD on spouses	Survey with standardised measures	Acceptable practice	Spouses of YOD	100 spouses	Carers high levels of burden, stress, $ concerns and need for support services. Implications - depression needs to be monitored for all carers and Carers of FTD people had higher rates of depression
Keady & Nolan	UK	YOD developing	Longitudinal model	Emerging	YOD carers	38 carers	Outlines a 9 stage model of dementia progress based on carer

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
(1994)		Longitudinal model for research	of stages of YOD	practice			responses. Identified the need for longitudinal research
Keady and Nolan (1999)	UK	Family caring & YOD	Qualitative - interviews	Emerging practice	YOD Carers of	58 carers	From themes derived they outline a 6 stage model of caring transitions -building on past, recognising the need, taking it on, working through it, reaching the end, a new beginning
Keenan et al (2007)	UK	Young people's experience growing up in family affected by HD	Qualitative - interviews	Emerging practice	Children of people with HD	33 offspring	Thematic analysis - 4 themes - young people as carers, the worried well, those who cope and those at risk or in need. Offspring who grew up knowing about HD from an early age appeared to cope better
Killick (1999)	UK	Experiencing the worlds of people with YOD	Case-studies carers & clients	Case-study	Clients & carers YOD	3 YOD clients, 3 carers	Overview of patient & carer experiences including diagnostic process, changes to lifestyle and adaptation to dementia
Liebson (2005)	USA	EOD diagnostic implications and family impact	Case-report	Case-study	Client & family EOD (YOD)	1 family	Case-study addressing diagnostic issues and impact on family. Raised the issue of early FTD/AD being misdiagnosed as depression. Identified the importance of a thorough history to identify potential genetic factors
Lloyd & Stirling (2011)	Tas (Aust)	Ambiguous gain, uncertain benefits of service use for dementia carers	Interviews and service feedback	Emerging practice	Dementia carers	33 carers	Qualitative analysis of interviews suggested that the receipt of support services may sometimes impinge on the carer's identity
Livingston & Cooper (2013)	UK	The need for dementia care services	Literature review	Literature review	Dementia and care services		Examines overall prevalence and burden of disease estimates for dementia to identify need for specialist services. Management issues that are topical in 2013 are addressed
Lockeridge & Simpson (2012)	UK	Experience of caring for partner with YOD	Semi-structured interviews	Emerging practice	Carers YOD	6 carers	Analysis indicated 4 themes in coping strategies of younger carers -denial, dealing with stigma, struggling to maintain control and adaption to loss. Identified the need for a longitudinal study and tailored interventions to assist carers in developing appropriate coping strategies
Luscombe et al (1988)	Australia	Younger people with dementia, diagnostic issues, effect on services	Self-report survey	Promising practice	Carers YOD	102 carers	Delays in diagnosis a common problem. Carer's report psychological problems, financial worries, employment concerns and the effect on children
Mackay & Marriott (2000)	UK	YOD: carers experience of services	Interviews, survey, standardised scales	Acceptable practice	Carers YOD	10 carers	Carers reported a negative effect on their employment, needed more information and required additional services. Eighty percent of the carers showed evidence of psychiatric symptoms
McCallion et al (2004)	USA	Increasing use formal services -	Telephone survey primary carers	Acceptable practice	Carers-dementia in general	608 carers	Examines rates and factors that affect choice for referral to local AA chapters by carers

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		dementia					
McCarron et al (2005)	Ireland	Alz. Dementia - Downs Syndrome	Caregiver survey	Promising practice	Carers Down's syndrome residential facilities	63 with AD and 61 without	Carer time increases for patients with Downs syndrome and dementia
Meadows et al (1999)	UK	Burden of care of HIV associated dementia	Caregiver interviews	Emerging practice	Carers HIV dementia	11 carers	Carers required better information and communication with health professionals
Menne et al (2002)	USA	Trying to continue to do	Qualitative: interviews with patients	Emerging practice	Early stage AD clients	6 clients	Day to day experience of early stage dementia - maintain continuity with previous way of life while coping with dementia necessitated changes
Miranda-Castillo et al (2013)	UK	The needs of people with dementia….	Carer & client interviews	Acceptable practice	Dementia carers & clients	125 carer, 125 clients	Need to examine perspectives of carers, client and professional in designing care plans -perspectives differ
Mitchell (2012)	UK-Wales	Coping with YOD….	Interviews& qualitative analysis	Emerging practice	EOAD Couples incl. patient and professionals	6 couples,6 professionals	Overview. Interviews identified needs for couples re clarity of information provided, flexible support services, participation in service planning, and increased public awareness to reduce stigma experienced. Further research required re coping styles and the identification of precursors to poor coping in couples
Mourik et al (2004)	Netherlands	FTD: behavioural symptoms and carer distress	Standardised Assessment Scales	Acceptable practice	Carers & Clients FTD	63 dyads	Carer distress linked to BPSD particularly the agitation/psychosis cluster followed by mood disorder cluster. Disinhibition only mildly related to carer distress
Newens et al (1995)	UK	Dependency & community care in presenile AD	Standardised Assessment Scales	Acceptable practice	Carers & Clients EOAD	109 dyads	Identified carer's need for ADL assistance particularly with incontinence but received little support from services
Nichols et al (2013)	Canada	Needs assessment survey-young caregivers	Focus groups & survey, descriptive analysis	Emerging practice	Young caregivers FTD	14	Focus groups six themes for web site development-impact living with FTD, care giving, symptoms, diagnosis, relationships and support. Need to assist young carers in overcoming stigma and to address their developmental needs
Nicolaou et al (2010)	WA (Aust)	Needs, burden and stress of carers of people with FTD vs. Alz. Disease	Assessment using standardised scales	Acceptable practice	Carers from FTD & AD Groups	2 (N = 30) carer groups	Needs of carers of FTD group significantly higher. Statistical control of potential confounders
Nurock (2000)	UK	Carers and YOD	Qualitative - interviews	Emerging practice	Carers & ex-carers YOD	21 carers, ex-carers 12	Having a partner to offer support and care for family lessens likelihood of residential placement. High use day care but little formal support. Social isolation - female carers more affected by this
O'Connell et al (2013)	Canada	Rural teleconference	Provision of teleconference	Routine practice	FTD/EOD (YOD) 10 spouses - rural	10	Teleconference support group for rural carers useful in sharing practical information and reducing social isolation-evaluated at

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		support for spouses - EOD	support group				follow-up workshop
Pipon-Young et al (2011)	UK	I'm not all gone….	interviews with patients	Routine practice, action research	YOD clients		Clients identified need for sources of social support, to share a sense of identity, to focus on remaining strengths, and to receive information from those that have experienced dementia that fosters hope and resilience
Reed & Bluethmann (2008)	USA	Voces of Alzheimer's disease	NA - forums	Emerging Practice	early stage AD	301 participants	Town Hall and virtual forums -57% EOAD (YOD). Themes - stigma, dissatisfying interaction with the medical community- untimely diagnosis, uncertainty re support services, retaining independence, desire for continuing involvement
Riedijk et al (2006)	Netherlands	Carer burden, HRQOL & coping in dementia carers	Assessment using standardised scales	Emerging practice	Clients & carers FTD, AD	63 FTD dyads, 90 AD dyads	Carers of EOFTD clients more burdened that carers of LOAD clients but issues with equivalence of comparator group
Roach et al (2008)	UK	Subjective experiences of younger people with dementia	Literature review of qualitative studies	Literature review	YOD (EOD) clients		Three major experience categories -1 recognizing -diagnosis & information 2) relating - impact on feelings & family 3) restructuring -adjusting to living with dementia. Issues - inadequate referrals and supports, reviewing service provision
Rosness et al (2008)	Norway	Support to family carers : FTD	Interviews primary carer, patient assessment	Promising practice	Carers 2 groups FTD & EOAD	23FTD dyads, 37 EOAD dyads	FTD patients had higher admission rates to nursing homes; FTD carers had less satisfaction with information provided and with treatment by health professionals
Sait (2012)	NSW Aust	Service and support requirements YOD	Survey clients & carers	Acceptable practice	Clients ,carers, providers-YOD	34 Carers, 20 YOD, 8 providers	Small NSW survey re service requirements Issues - diagnosis & lack of referrals; services found useful; difficulties with respite care; unmet needs. Need for referral pathway, support for working carers, case-management
Saunders (2013)	Australia	Get your voice heard	Focus groups & survey	Acceptable practice	Clients ,carers, providers	145 clients & carers, 176 providers	Focus groups with a) carers and patients and b) providers in rural SA. Reports issues with the diagnostic process, a lack of support post diagnosis and the need for support in linking to services. Rural issues concerned the limited availability & scope of services and need for additional transport & travel allowances to support people with dementia rural and remote regions
Schlosberg (2004)	UK	What users and carers think of service for younger people	Qualitative - interviews	Routine practice	Clients, carers EOD (YOD)	10 EOD, 5 carers	Evaluation of a day care service for EOD (YOD); users happy with age appropriate service and involvement/participation; carers happy with it assisting with their employment and providing a respite - both groups felt the service needed better resourcing and should be expanded
Seddon (1999)	UK	Negotiating care and employment- YOD	Qualitative - interviews	Emerging practice	YOD Carers	4 carers	Discusses changing requirements of the carer's experience, need for flexible service provision - particularly for employed carers

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
Skirton et al (2010)	USA	Huntington's Disease-families experiences of health care	carer survey & standardised scales	Acceptable practice	Carers-HD	108 UK,109 US carers	Carers had concerns about knowledge of health professionals re HD and the insufficient resources to support both carer and client - need for comprehensive facilities and resources for HD
Soltysiak et al (2008)	UK	Exploring supportive care Huntington patients & families	focus groups & 3 individual interviews	Routine practice	HD Clients, carers, family, staff-HD	33 all	Qualitative evaluation (focus groups) of needs and coping strategies of patients and whether these were addressed by the HD service. Three themes - transition/journey, challenges in both finding & providing support, & the role of the unit in providing support. Noted carer concerns about health professional knowledge re HD and communication
Sperlinger & Furst (1994)	UK	Service experiences -people with presenile dementia	Qualitative - interviews	Emerging practice	YOD Carers	15 carers/ex-carers	Carers experienced inadequate support initially and had issues with the diagnostic process - timeliness etc. Carers reported high levels of stress
Sussman et al (2009)	Canada	Influence of Community-Based Services on burden of care	Survey	Acceptable practice	Carers - dementia	85 spousal carers	In-home services did little to reduce burden whereas adult day programs were seen as effective. Spousal carers report a relatively high level of service related stress. Degree of burden not directly related to degree of service use
Svanberg et al (2010)	UK	Just helping. Children living with parent with YOD	Qualitative - interviews; standardised measures	Acceptable practice	Children of YOD clients	12 children of YOD	A 3 stage model was proposed with children moving through grief to emotional detachment and increased maturity. Few children showed depressive symptoms but over half showed high levels of carer burden
Svanberg et al (2011)	UK	Impact of YOD on the family	Literature review	Literature review	YOD and family	26 articles	Twenty-six papers reviewed revealing a number of negative impacts for individuals and carers e.g. stigma, lengthy time to diagnosis etc. and a greater negative impact on carers of people with YOD vs. LOD
Truscott (2003)	USA	Life in the slow lane	Case study	Case-study	Early AD client	1	A patient journey - early AD
Tyson (2007)	Australia	Exploring needs of young people with dementia	Qualitative interviews	Emerging practice	Clients ,carers, providers	YOD 29, carers 31	Themes-delays in diagnosis, lack of specialist services, difficulty accessing appropriate services; emotional impact; social situation & financial & legal issues
van Vliet et al (2010a)	Netherlands	Research Protocol for NeedYD study	longitudinal observational study	Promising practice	YOD	217 dyads	Outlines research protocol for innovative 2 year longitudinal study in Netherlands
van Vliet et al (2010b)	Netherlands	Impact of EOD on caregivers	Systematic literature review	Literature review	EOD (YOD) carers & family	17 articles selected	Articles reviewed indicated that EOD (YOD) carers experienced high levels of burden, stress, depression and psychosocial problems. When compared with LOD carers - results inconclusive due to methodological issues in this literature
van Vliet et al (2011)	Netherlands	Caregivers perspectives on pre-diagnostic	Qualitative semi-structured interviews	Acceptable practice	EOD (YOD) carers & family	92 carers	Seven themes - changes in family member, disrupted family life, misattribution, denial & refusal to seek help, lack of confirmation, non-responsiveness of GP, misdiagnosis. A

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		period in EOD					number of these factors may prolong diagnosis
Willis et al (2009)	UK	Clients and carers satisfaction with a memory service (CMS)	Qualitative interviews	Routine practice	Clients & carers - Dementia	16 dementia clients, 15 carers	Thematic analysis derived 7 quality indicators 1) provision of broad based care & assessment 2) Clear communication - diagnosis and care 3) continuing peer support groups 4) easy availability of staff 5) professional staff behaviour 6) services useful for people with YOD & carers 7) strategies to manage those with subjective memory impairment
Williams et al (2001)	UK	From pillar to post: A study of people with YOD	Survey -service experience and needs	Acceptable practice	YOD clients and carers	132 YOD, 61 carers	Need for specialist services & single care pathway as difficulty experienced finding appropriate services. Carers reported their well-being as poor & those who had been caring for > 3 years had poorer emotional well-being

4.1 The Voices of People with Younger Onset Dementia

Beattie et al (2004) noted in their earlier literature review concerning younger onset dementia and dementia care services that of the 74 articles they identified only 5 articles had assessed patient views and many of these had very small samples. More studies are now available and there is an increasing trend to also undertake studies which involve carer and patient dyads and these will be considered in a following section.

Clemerson et al (2013) interviewed 8 people with young onset AD and identified four key themes based on the qualitative analysis of interviews about their experience of dementia. The themes and challenges identified were a) the disruption of their life style due to their diagnosis and coming to terms with the shock of this b) issues concerning threats to their identity and the redefining of self c) social orientation – feeling isolated and then reconnecting and d) the loss of agency and feelings of powerlessness – feeling as though they were no longer in control of their own lives.

Pipon –Young et al (2012), using an action research methodology to further understand peoples' experience of dementia (N = 8) and to develop strategies to address their emerging issues. They identified three theme areas a) the experience of people with younger onset dementia b) activities that people with younger onset dementia found helpful and c) developing areas for change. With regard to the experience of dementia key themes that emerged were age-related difficulties associated with being a younger person receiving a diagnosis that is commonly given to much older people and the arrival of that diagnosis in relation to their life cycle stage. People indicated they needed to acknowledge that changes had occurred and this included a loss in social status and an ability to carry out everyday tasks. Another theme concerned 'saving face' and not telling people they had dementia so that they would be treated as normal. All were concerned about their future as the dementia progressed and were concerned about the negative connotations (stigma) and misunderstanding about dementia in those they had contact with. A need was identified in relation to their retaining their sense of self and although acknowledging their dementia they found it better not to dwell on dementia too much.

The activities that people with younger onset dementia found helpful were keeping active and involved and to try to do things as long as they could to retain independence. Sharing a social identity, by relating with other people with younger onset dementia, was also important as was maintaining their social networks (family, friends etc.) as general areas of support. The theme associated with developing areas of change was to develop greater resilience, to maintain a sense of worth and control, to stay engaged with the world and to develop a positive and practical approach to managing their dementia that focussed on their strengths rather than their impairments.

Johannsen & Moller (2011) from Norway undertook a qualitative analysis of 20 interviews with people with early onset dementia, randomly selected from a pool of 217 clients/patients. They identified 2 main stages of 'patient journey' (toward a dementia diagnosis, fighting for dignity) over a 1 year period. The process toward a dementia diagnosis included noticing changes in their behaviour (e.g. memory problems, difficulties and not coping at work) and then the process of obtaining a diagnosis. Many people experienced initial misdiagnosis (e.g. burnt out or stressed) and an associated delay in diagnosis. Getting the diagnosis came as a shock for some and a number reported feeling like a second class citizen once the stigmatic label of dementia was applied to

them. Most people interviewed stated they had a very difficult time after being diagnosed and required assistance and support at this time which in the majority of cases was not received.

The 'fighting for dignity' phase included a variety of psychological and social challenges. These challenges included feeling embarrassed because they had dementia and feeling as though they were a burden on society. Having memory difficulties and associated communication difficulties affected their self-esteem and led to feelings on both anxiety and frustration. Not going to work anymore, while at times considered a relief, also meant they lost their social network and friends and they found they did not have enough to do. One person, due to the consideration of his employer had retained his job part-time with an adaption to his tasks and others indicated they would have liked an opportunity such as this. Another issue included the loss of independence when they could no longer drive. Issues about the disclosure of their illness to others were raised, and the importance of coming to terms with the illness themselves before informing those outside the family about it. Most were managing to cope with their illness and had reconciled themselves to living with dementia 5 months post diagnosis but many reported feeling lonely.

With regard to services the lack of available support services immediately post–diagnosis represented an area of unmet need, as did the issue of relating to the potential to retain employment. However, some appreciated the services of activity day centres. The authors conclude that health services should listen to the voices of these patients and assist persons with early/younger onset dementia to maintain contact with society and to reduce their social isolation.

Reed and Bluethmann (2008) report on a number of town hall and virtual town hall meetings (e.g. web based) conducted by the Alzheimer's Association in the USA for people with dementia. There were 259 early stage participants (many of whom had onset before 65 years) at the live meetings and 42 contributors for the 'virtual' town hall. Some of the issues raised were the stigma associated with a dementia diagnosis; the shock of the diagnosis and their ways of personally coming to terms with this; dealing with the lengthy time it took to receive an accurate diagnosis combined with a desire for earlier detection; difficulties with the manner of health professionals during this diagnostic and assessment period; issues around experiencing misdiagnosis due to their young age; and feeling abandoned following diagnosis in the absence of appropriate referrals for community and support services.

Many participants were concerned about their increasing loss of independence and concerns about when they had to stop driving and the restrictions and dependence that this can impose. A common theme was staying active and participating despite the fact that their relative independence and their sense of normality were affected by the disease. There were also concerns that their carers might take them out of the decision making process, in a misguided endeavour to be helpful, when they wanted to remain involved. There was a desire to rebuild their life, finding new ways to do things and to focus on and enjoy those things they could do. A major issue of frustration was relationships because people started treating them differently, and sometimes distancing themselves, once the 'dementia' label was applied. It was also reported by many patients that they had to teach their carers how to work with them particularly as they could not cope with multi-tasking or interruptions mid – task.

Younger participants noted that the impact of early onset dementia was greater because many were still in the middle stages of their career. They had to adapt to a substantial loss of income and had also had less opportunity to plan for their financial future.

With regard to services people with younger onset dementia were very positive about support groups where they could share their experiences with others in a similar situation. However, they noted that they fell between the cracks of service systems – for example they may be too young to receive some services/ subsidies (e.g. transport etc.) and they may not qualify for service benefits and allowances provided to those over 65. Many were keen to participate in clinical trials but found they were too young to qualify for enrolment.

Overall people with younger onset dementia wanted to stay active, involved and engaged in their communities and many wished to undertake an advocacy role to help raise the level of awareness in the community about dementia.

Harris (2004) undertook focus groups, face to face and online interviews with members of a younger onset dementia support group and their families and also members of the local Alzheimer's association. Similar themes were identified and included the difficulty in receiving an accurate diagnosis, marginalisation, changing relationships within the family structure, dependency, workforce/retirement issues and the lack of meaningful occupation. There were also issues concerning self-esteem and the client's awareness of changes in self. From these consultations practice guidelines were developed for working with people with younger onset dementia.

An example of where a patient voice has initiated service action is reported in Arends and Frick (2009). The Without Warning program in the USA was inspired by an EOAD patient. He could not find programs for people with early onset AD in his area as he felt available early stage programs were not appropriate for him. He was 20 years younger than the other participants and issues such as stopping work and dealing with young children were not discussed. He raised this with the Rush Alzheimer's Disease Center (Arends and Frick, 2009) and this paper reports on the EOAD (younger onset dementia) program they have developed since 2003. This has included seminars, family meetings, events for younger children and adult children and numerous social events for the whole family. From these consultations the authors have identified a range of concerns which people with EOAD raised in these meetings and these included issues over the length of time taken to achieve an accurate diagnosis; employment and financial issues; particular effects on the individual, spouse and the children and a range of emotional and social impact factors including changing roles.

Roach et al (2008) undertook a systematic literature with a focus on the subjective experience of those with younger onset dementia. They identified only 14 studies which met their inclusion criteria (they excluded papers with mixed diagnoses, those pertaining to Down syndrome with dementia and ARBD and those not focussing on the patient' subjective experience) and identified 11 studies with first person accounts/ case-studies. They also included 3 research/service summary articles which were based on the qualitative experiences of people with younger onset dementia. They identified 3 overarching categories which included a) 'recognising' which encompassed diagnosis and information provision b) 'relating' which encompassed the impact on the family and their own feelings and c) 'restructuring' which encompassed relationship and role change, strategies for coping and moving on and adjustment.

These categories and themes are very similar to those discussed in the literature above. However, the authors noted the paucity of studies and the low level of research evidence which demonstrates the lack of high quality research that focuses primarily on the subjective experience people with younger onset dementia. Some of the studies in this field could also be described as

one shot case studies and although they identify important issues for the particular individual (e.g. Truscott, 2003) the ability to generalise from these is limited. This highlights a research gap but it is also a service issue as services need to understand and act on the voices of their client group in their service development and evaluations.

4.2 Children of People with Younger Onset Dementia

Some of the earlier research focussed on spousal carers views on the impact of younger onset dementia on their children (Luscombe et al, 1998). In this study 75% of carers affirmed their children had suffered psychological and emotional problems (e.g. stigma, shame, bewilderment, conflict with the YWPD and problems at school) as a result of dementia but the reports were not first hand and it is unclear concerning the age of the children and whether they were living at home.

A number of studies have examined the experience of children of people with younger onset dementia and the issues that arise. Allen et al (2009) interviewed 12 participants whose fathers had younger onset dementia and analysed the transcripts using grounded theory methodology. Five major themes emerged a) the damage of dementia –noticing behavioural change, coping with difficult behaviours, concerns about the father's safety, accepting the diagnosis and acquiring awareness b) reconfiguration of relationships – loss of their 'real' father, supporting their mother c) caring- adjusting to care responsibilities and taking on a parental role d) strain – both physical such as a loss of sleep and the development of psychological issues such as depression, facing 'stigma' and e) coping – acceptance strategies or emotion focussed strategies such as avoidance, smoking and drinking. The coping strategy of taking *'one day at a time'* was an overarching theme through all categories of the children's experience which helped them not to become too overwhelmed by the experience.

A similar grounded theory approach to the analysis of 12 interviews with children was undertaken by Svanberg et al (2010) but was supplemented by a screening measure for depression, a carer burden tool and a resilience scale. Four themes evolved from the interviews a) the process of discovering dementia b) developing a new relationship c) learning to live with it and d) going through it together. Few children showed symptoms of depression but over 50% exhibited high levels of carer burden and most showed moderate levels of resilience. A model of adaption was proposed where children move through grief to emotional detachment and increased maturity. The authors suggest undertaking a whole family approach by dementia and children's service may help to reduce the carer burden experienced by these children.

Svanberg et al (2011) also undertook a literature review of studies (N = 26) on the effect of younger onset dementia on the family and a few of these studies included children of a parent with younger onset dementia but most concerned adult children acting as carers for their parent. Gilliard (1999) in a case-study emphasized the additional challenges faced by younger children and the need for a more flexible approach including informing supportive people (such as teachers) about dementia to help them provide support to the child. Garbutt (2006) interviewed 5 young adult carers and identified 4 themes concerning the coping process (experiencing change in relationships, understanding the change, managing change and experiencing a change in oneself) which are not dissimilar to the themes that emerged from the Svanberg et al (2010) study.

Gelmann and Greer (2011) also undertook a literature review of studies concerning children with a parent with early onset AD. They particularly noted the early studies by Becker and associates in

the UK concerning this issue (Aldridge & Becker, 1993; Dearden and Becker, 1999). These studies noted negative effects on children such as the physical challenges of caring, the restriction on their peer contact, the impact on their schooling and the emotional and psychological effects of role reversal with a parent. Gellman and Greer's (2011) review of these studies, and a case-study, indicated that children as carer's experience high levels of stress and potential psychological and social disadvantage. They noted the limited availability in the US of resources and services to support such children. They also recommended that the impact of gender, age and socio-economic status on these children's experiences needs to be further explored. Bray (2012) examining a carers data set in Australia also noted the educational and social disadvantage of 'youth carers'; for example, those that play a caring role with their parents or grandparents.

Menne et al (2002) undertook 6 interviews with six patients in the early stage of dementia to explore their day to day experience. Only 2 of these cases would be considered to be people with younger onset dementia. The themes that arose were to maintain continuity with their previous way of life while coping with dementia necessitated changes.

Keenan et al (2007) explored the impact of growing up in a family affected by Huntington's disease and they interviewed 33 offspring of Huntington's patients (9 – 28 years) and 12 of these had acted as carers for their parent. The themes that emerged from the qualitative analysis were a) young people as carers b) the worried well c) those who cope and d) those at risk or in need. The young carer's described difficulties juggling their own needs with parental needs and those that were most in need of support were those where the unaffected parent was working long hours, was also ill or where there was only one parent. The 'worried well' theme related to the children's worry concerning their own risk status for this genetic disease and this worry affected them physically, psychologically and socially. Those children that appeared to be coping successfully had good systems of social support and strong attachments. Those children at risk were those with an unmet need for help or support including information (from either families or professionals) and 3 children had experienced some form of physical or sexual abuse requiring child protection services.

For these children where there is a high level of genetic transmission associated with the parental risk this appears to add quite an additional degree of stress. The authors also noted that those children who grew up from an early age knowing about Huntington's appeared to cope better than those that only found out in their late teens or early twenties but note the limitations of their sample in this regard.

Nichols et al (2013) in Canada undertook 2 focus groups with 14 young carers (< 18 years) of patients with FTD in order to develop a website information resource for young caregivers. The focus groups identified six themes – the emotional impact of living with FTD, care giving, symptoms, diagnosis, relationships and support. The web pages for the teens were organized into five sections and included information on the disorder and diagnosis; how to deal with health professionals; what psychologists say about young carers and the challenges they face; advice from young carers on how to cope and how to spend time with the parent with FTD; how to get help including an information page on FTD with links to further sites and downloadable resources. Although there were challenges and some negative experiences the young carers saw the experience as positive overall and they suggested some ways that health professionals could help them to overcome the stigma associated with dementia and to address their own developmental needs in the context of their caring role.

As can be seen from the above discussion there are relatively few studies concerning the impact on children and their service needs and even fewer studies that relate to those sub-types of dementia where there is a high genetic risk. Most of the studies have limitations with regard to strength of evidence considerations but they do generate a range of issues which services can address.

4.3 Spouses: Their Experience and Issues

Studies which focus on the experience of spouses with younger onset dementia largely include case-studies and studies which undertake a qualitative analysis of interviews with spouses. In this section those studies that have a particular focus on the experience of spouses are included but many of the studies discussed in the following subsection also include spousal carers in their mixed samples of carers.

Ducharme et al (2013) noted that few studies have examined the experience of spouse caregivers living with a person with early onset AD and related conditions. A qualitative analysis of twelve spousal semi-structured interviews was undertaken. Six themes emerged from this analysis: a) the long quest for diagnosis; b) difficulty in managing BPSD; c) nondisclosure and denial of diagnosis; d) grief associated with 'loss' of spouse and planned mid-life projects; e) difficulty juggling their unexpectedly early caring role with daily life responsibilities; and f) difficulty in planning for the future. The authors suggested the need for dyadic case-management approach in order to examine the support needs of the dyad collaboratively (but also including interactions within the family system as a whole) and to facilitate the spousal carers to come to terms with the transition in their spousal role.

Lockeridge and Simpson (2012) interviewed 6 spousal carers of people with younger onset dementia. Qualitative analysis (IPA – interpretative phenomenological analysis) indicated 4 common themes concerning the coping strategies of younger carers. These were denial, dealing with stigma, struggling to maintain control of events and emotions, adaption to the loss of their future plans with their partner and the 'loss' of the person as a partner with the continuing decline in their abilities. The author's state there is a need for further longitudinal research concerning these caring relationships and they also suggest the use of tailored interventions to assist carer's in developing more effective coping strategies.

Hellstrom et al (2007) examined the transitions in the spousal role by following up 20 spousal carers over 5 years (152 interviews of the couples). It should be noted this study is concerned with dementia patients in general and does not examine the experience of those with young onset dementia in particular. From their qualitative analysis of interviews they identified 3 phases a) sustaining couplehood b) maintaining involvement and c) moving on. These generally operated in an iterative rather than a linear fashion although the 'moving on' phase (developing more of a spousal 'I' focus than a 'we' focus) was more common at the advanced or end stages of the patient's illness.

The article has a much more positive focus than much of the literature about carers and explores the ways in which the majority of couples sought to maximise their quality of life and maintain their relationship. The authors suggest that framing relationships in terms of just spousal/carer stress and burden represents a 'simplistic reduction' of their experience. The authors noted that the majority of couples had a warm relationship prior to diagnosis, which they strove to maintain and thus there are limits to the degree this can be generalised to couples who may have poorer relationships such as those identified by Kaplan (2001). They note their work identifies similar

themes to the prior work undertaken by Chelsa et al. (1994), Kaplan (2001) and Keady (1999) although the first two of these studies did not include the perspectives of the person with dementia. Their findings are contrasted to those of Svanstrom and Dahlberg (2004) who, analysing unstructured interviews depicted the couple's experience as an 'unbalanced' life characterized by feelings of futility, hopelessness and loneliness. There are few studies, however, that take a relationship focus and studies incorporating this focus with people with younger onset dementia would seem useful given the emergence of younger onset dementia at an early life cycle stage for these couples and given the lengthy period of care prior to institutionalisation that Bakker et al (2013a) have reported.

Mitchell (2012) undertook a qualitative analysis (using IPA) of 6 interviews of couples where one was affected by younger onset dementia. Couples employed a range of coping strategies (e.g., ranging from self-protective strategies such as avoidance to integrative responding) experienced substantial role changes within their relationship and sometimes struggled to cope. Once again a need for further support immediately following the diagnosis was identified as an unmet need by couples. However, addressing social identity issues through 'finding a group identity' alongside other couples in similar situations was reported as being very helpful for couples in this study. As the study did not focus explicitly on predictive factors the author suggests future research could focus on identifying precursors to 'not coping' including relationship factors as well as individual patient and carer aspects.

Van Vliet et al (2010b) examined the experiences of 92 caregivers (largely spousal) from the time of the onset of first symptoms to their partner receiving a confirmed EOD (younger onset dementia) diagnosis. Seven themes were identified: - noticing first changes in the family member, disrupted family life, 'mistaken attribution' of the patient's symptoms by the carer, denial & refusal to seek help by the patient, lack of confirmation by the social context, non-responsiveness of the GP and misdiagnosis. A number of these factors may prolong diagnosis and 45% of the sample had received a diagnosis other than dementia to begin with. Common earlier diagnoses and/or misdiagnoses were stress, burnout and psychological problems and about 1/3 of the carers felt they were being 'passed from pillar to post'. The findings identified the need for more timely and more adequate help from health professionals during the pre-diagnostic period.

Evans and Lee (2013) undertook a literature review of qualitative research on the issue of the impact of dementia on marriage. Two majors themes identified from the review of 23 articles - transition (relationship, roles, intimacy) and loss (loss of partner and marriage). During their journey traditional roles are challenged and one spouse must step up and assume new roles and the other has to relinquish roles that helped define their place within the marriage and the household. Thus the presence of dementia challenges the communication, reciprocity and intimacy within the relationship. It was noted that the literature indicated that in the later stages of dementia spouses were unsure if the partner was still present and if the marriage existed (see Hellstrom et al, 2007).

Kaiser and Panagyres (2007) undertook a survey concerning the psychological impact of the younger onset dementia diagnosis with 100 spouses of patients with younger onset dementia registered with the Neuroscience Assessment and Care clinic in Western Australia. The survey included the Zarit Burden Interview (Zarit et al, 1985) and the Beck Depression Inventory (Beck and Beamesderfer, 1974). There was a mix of younger onset dementia diagnoses in the patient group but most were diagnosed as AD or FTD. Thirty percent of the sample indicated that their partner was no longer living at home and 54% of the survey respondents were wives. There was a

significant correlation between the FTD diagnosis and the depression scores of their carers which was not found for the other dementia diagnoses (largely AD). In view of this the authors recommend that carers should be screened for depression although the majority of the carers (@80%) had no or mild depression but some cases of moderate and severe depression were identified. The authors report that overall the spousal carers had high levels of burden and stress. The carers expressed concerns about their financial status and identified the need for further support services such as counselling and domestic support.

De Vugt et al (2006) compared spousal caregiver's stress related to the behavioural symptoms of AD and FTD (N = 47 AD carers, 27 FTD carers). Patients with FTD had more behavioural problems and their spousal carers correspondingly had higher mean NPI (Neuropsychiatric Inventory) symptoms score and an overall distress rating compared with AD carers. FTD carers reported higher levels of general burden and felt less competent than AD caregivers. In the FTD group apathy, aberrant motor behaviour and disinhibition were the most common symptoms and the FTD carers found it hard to cope, in particular, with the symptom of disinhibition which they found highly distressing.

Several case-studies raise some issues concerning the service needs of spouses although the ability to generalise from these studies is limited. Nurock (2000) based on a case-study of her own spousal experience suggests that having a partner to offer support and care for the family may lessen the likelihood of residential placement and suggests that improved primary care services could reduce the devastation that families can experience. She raises the issue of the social isolation that spousal carer's can experience.

Dartington (2007) is a diary of one husband's account of daily living with his wife with EOD (younger onset dementia). It covers extracts of 2 days in their lives across a six year period. It provides valuable insights into the daily challenges faced by the spouse at the early stages of the disease and then at the later stages of the disease. He notes that dementia involves an intensification of moods and recourse to ritual, confrontation, reconciliation, mutual adjustment and development on a daily basis. A particular issue relates to the reflection on the progressive and continuous decline of the person with younger onset dementia requiring adjustment by the spousal carer but also associated with a sense of loss. Particular services issues that are raised are the lengthiness and the demanding nature of the cognitive assessment process, falling between service cracks of disability and aged care systems and issues concerning with coping with caregiver support services particularly at the period immediately prior to institutionalisation.

Gilbert (1992) provides an anecdotal account (a carer's tale) detailing the lack of appropriate and specialised services for people with Huntington's disease and their carers in the Nottingham area of UK. She raises issues of people with HD slipping between the cracks of the service coverage available at that time and this is still being raised as an issue in the current literature. An important issue she raises is that people become carer's by force of circumstance (e.g. their partner has become ill) and it is a role that is largely imposed upon them and one that they would not have chosen. The role imposes a lot of burden on the carer and the carer can find it increasingly difficult to maintain a close loving relationship with the patient without an immense amount of help and advice from outside agencies. There is also the assumption by services that because a patient has a relative living at home that this person is capable of caring for a sick patient.

Brown and Roach (2010) in the UK describe the experience of carer (case-study) who cared first for her mother and then her husband with younger onset dementia. This study notes how helpful it was for the spouse to have specialised younger onset dementia service support available by the time of the later onset of disease for her husband. Support from specialist younger onset dementia services enabled the spouse to keep working, to maintain her relationship with her husband and to continue to live as a family for a lengthy period despite the progression of symptoms.

Bakker et al (2010) present a case-study which examines a patient and carer journey from initial symptoms to residential care placement. It explores the experience of a caregiver of a patient with EOD (younger onset dementia) and identifies unmet needs of the patient and caregiver and the caregiver's experience of transitions in care and health care services. Issues that arose for the EOD caregiver and patient included a lengthy time to diagnosis, a lack of fit between needs and services, the strain of dedication to care being balanced with the caregiver's own future perspective and the need for response by health care services to changing individual preferences and needs over the course of the illness. Bakker et al (2010) note in this case formal diagnosis was critical for the spousal care-giver to change her perspective on the situation, to start grieving and to seek appropriate support from health care services (e.g. day care, support groups, individual support and assistance for managing behavioural problems and respite care). The availability of support services enabled the caregiver to prolong the period that she could care for her husband at home. Thus timely diagnosis is a critical service need. In the absence of a diagnosis, or in the presence of a misdiagnosis, carer's can also misinterpret the behaviour of the patient and attribute it to causes other than dementia and believe the person affected by dementia still retains control over his or her behaviour rather than it reflecting the symptoms of the disease.

The early stage of institutionalisation, in a service designed for elderly people, was found to be particularly difficult for the patient and carer as the service did not adequately address their needs which resulted in an increase in behavioural issues for the patient. The authors argue for a case-management approach that addresses continuity of care and they identify the need for specialist services for people with EOD/ younger onset dementia.

4.3.1 Other carer studies

One gathers from the literature above that the majority of carers of people with younger onset dementia (about 80%) are partners or spouses but in the studies below the sample of carers can include adult children and siblings. In some cases the studies have included carers of people who are now deceased (ex –carers).

Keedy and Nolan (1994, 1999) draw on the results of qualitative studies and interviews with family carers (58) of people with younger onset dementia to develop a temporal model of care from symptom onset through to bereavement. In the 1999 study outline a 6 stage model of caring transitions - building on the past (what is brought to the situation by the patient and carer), recognising the need (noticing early signs –pre-diagnosis), taking it on (diagnosis), working through it (managing and coping), reaching the end (relinquishing care), and a new beginning (post institutionalisation /death). Keedy and Nolan (1999) do not see these stages as a rigid framework but as a device to aid awareness and to sensitise practitioners to issues relevant to their assessment and intervention models. Keedy and Nolan (1999) also identified the need for more longitudinal research.

Baldwin (1994) identified 43 patients with pre-senile dementia in a catchment survey and 32 patients were interviewed with their carer, or, if too impaired the primary carer was interviewed. Patients had high behavioural dependency as measured by Clifton dependency rating & had a high use of psychotropic medication (about 80%) to manage symptoms. There were 12/18 full-time carers that completed the General Health Questionnaire and seven of these carers had diagnosable psychiatric symptoms and the majority were stressed and poorly supported. It was noted that very few support services were used by those residing in the community (e.g. meals and home care services) and only 3 patients attended a day centre. This might well reflect a lack of awareness of available services at that earlier time.

A follow-up study by Newens et al (1995) describes functional impairment (ADL) among 109 patients with presenile AD in relation to their place of residence and the duration of their dementia. At five years post diagnosis 57% of the patient remained at home and of these 20% required assistance in all 6 areas of ADL (dressing, bathing, toileting, mobility transfer, feeding and incontinence). The principal reasons for those patients that entered residential care during this period were identified by carer/relatives as violence by the patient, the extensive burden of 24 hour care, wandering and incontinence. At the time of follow-up assessment they required significantly more ADL assistance than those that had remained at home although their cognitive status was similar. A stepwise regression analysis indicated that the symptoms of incontinence in particular, and the relationship to the patient (non-spousal), were the best predictors of institutionalisation. With regard to service use respite care had been offered to 63% of cases where the patient remained at home and 71% of these offers were accepted. The study identified the carer's need for assistance with ADL tasks, particularly with incontinence, but it was noted that few of these carers (12%) had received support from community services. Contact with the GP was also infrequent with the majority of patients seeing the GP less than once a year. These reports from carers indicated there was scope for a considerable improvement in the provision of support services and the routine monitoring of the people with younger onset dementia.

Killick (1999) used 3 case-studies, involving interviews with people with younger onset dementia and their carer, to provide an overview of patient and carer experiences including issues concerning the diagnostic processes, changes to their lifestyle and their adaptation to dementia.

Liebson et al (2005) examined a case-study of person with early onset AD to address diagnostic issues and the impact on the family. They raise the issue of early AD and FTD being misdiagnosed as depression and the authors stressed the importance of collecting a thorough history to identify potential genetic factors.

Tyson (2007) undertook a literature review and interviews with both people with younger onset dementia (N = 29) and their carers (N = 31) and identified the following key issues for this overall client group from their interviews:

- Difficulty and/or delays in getting an accurate diagnosis;
- Family responsibilities including still actively raising a family;
- Currently working or being only recently retired;
- Having significant financial commitments based on previous earnings;

- Needing to revise their expectations of everyday life, such as work, finances, living arrangements, social and sexual relationships, and independence and responsibility for others;
- Future plans that are affected at an earlier stage in life;
- Being more likely to have a rarer form of dementia than Alzheimer's disease or a genetically-based cause; and
- Experiencing difficulty in accessing appropriate services, particularly as younger people with dementia are often otherwise physically strong and healthy.

The themes derived from the patient and carer consultations strongly reflected the emotional impact issues that have already been raised in the sections on the experience of people with younger onset dementia, their spouses and children (e.g. the shock of diagnosis, lack of support following diagnosis, the effect on children and spouses and the need for family counselling, the 'robbing' of the future of both the person with younger onset dementia and their carer/spouse, changing roles, grief and loss, loss of identity and independence etc.).

Tyson (2007) noted the then current, inadequate and haphazard service framework did not adequately address the unique and complex needs of people with younger onset dementia and this study provided evidence for an individualised approach to improving services for this group and their families.

Harris and Keady (2009) as part of a conjoint USA and UK study the UK authors undertook 15 interviews with carers of people with younger onset dementia and the USA team undertook 23 interviews of people with younger onset dementia. It appears they pooled this data for the qualitative analysis (grounded theory) and identified five common identity themes for both the clients and the carers. The themes identified were –identity as a worker/ former worker; as an abandoned individual, sexual identity, family identity and as an individual engaged in living. One wonders whether pooling carer, ex carer and client interview data to derive common themes might mask particular identity themes that were more relevant to either clients or carers respectively. The examples provided showed quite different perspectives of the members of these groups to the theme areas that were outlined. While it is not doubted that aspects of self-identity are important to explore for both clients and carers across the duration of the illness it is thought that more carefully controlled studies will be required to explore these issues more thoroughly.

A qualitative analysis of interviews with a mixed group of family carers (N = 10) was undertaken by Hain et al (2010). An important additional issue that this study raised was that carer needs vary over the duration of the illness and the avoidance of a 'one-size-fits all' approach to service provision should be avoided. Different information and kinds of support are needed at different times and matching interventions with the stage-specific needs of carers is important.

Svanberg et al (2011) also undertook a literature review of studies (N = 26) on the effect of younger onset dementia on the family and in these studies the carers could be spouses, children, or other relatives and in one case included formal carers. Few studies (e.g. Tyson, 2007; Beattie et al, 2004; Delaney and Rosenvinge, 2005; Williams et al, 2001) interviewed patients directly with most interviewing family carers but these studies revealed a number of issues for the patient which included diagnostic concerns (including the emotional impact of diagnosis), feelings associated with stigma, the need for age related services, lifestyle changes and coping strategies. The studies

involving carers also raised the diagnostic process (accessing a diagnosis, and the lengthy time to diagnosis, misdiagnosis, being turned away by professionals and lack of communication) as key concerns.

The majority of studies (N = 17) discussed the impact on the carer and most reported negative outcomes for the carer which included high levels of psychiatric symptoms (e.g. depression and anxiety), high levels of burden, stress, poor emotional well-being, poor health and feelings of loss and grief but most studies did not examine the risk factors that may be associated with these factors. Only Nurock et al (2000) reported any positive outcomes with 11/12 ex-carers reporting higher self-esteem and increased assertiveness. Many of these studies have been reviewed separately in this report.

More recently an Alzheimer's Australia (Saunders, 2013) rural study conducted focus groups with a) carers and patients and b) providers in rural SA. Similar themes were raised such as issues with diagnosis, lack of support post diagnosis and need for support in linking to services. Particular rural issues concerned the limited availability & scope of services and need for additional allowances for transport (and associated travel time costs) to assist with support visits to clients in rural and remote regions.

Some studies suggested that the burden for carers of patient's with FTD may be greater Boutoleau-Bretonaire et al, 2008; Mourik et al, 2004, Riedijk et al, 2006) or that the burden for younger onset dementia carers may be greater than for LOD carers (Arai et al, 2007; Freyne et al, 1999) but due to methodological issues the findings from many of these studies are questionable. For example, uncontrolled factors, such as age and the duration of caring, might explain some of the differences between the later onset and younger onset dementia groups. Svanberg et al (2011) report on numerous other methodological issues which limit the conclusions that can be drawn from this literature.

Some of the studies reviewed raised additional issues that may affect carer outcomes and these included the effect of diagnosis on employment for the individual and their carer (Seddon et al, 1999; Mackay and Marriott 2000), financial and legal issues (Mackay and Marriott 2000), social isolation (Delaney and Rosenvinge, 2005) and predictors of residential placement (Newens et al, 1995) or issues concerning residential placement (e.g. distress; Sperlinger and Furst, 1994). This latter issue is also picked up in a case-study by Bakker et al (2010).

Svanberg et al (2011) also raised the issue of the lack of research concerning those individuals who may not have an informal care-giver that these individuals may be most in need and may be more likely to be placed in residential care (Newens et al, 1995; Tyson, 2007). This issue has been raised previously in this review and represents an important research gap. These authors also raise the issue as to whether further research should be differentiated by age (as this relates to service boundaries and also the issue of age appropriate services) or by diagnosis or by multivariate studies which examine both of these aspects. They also note that while some studies have included parent caregivers (Luscombe et al, 1998; Mackay and Marriott, 2000; Mourik et al, 2004) the impact on parents of looking after offspring with younger onset dementia is rarely discussed.

Bunn et al (2012) undertook a systematic review of the qualitative evidence about how patients and carer's adapt to the diagnosis of dementia. They identified 126 papers reporting 102 studies including a total of 3,095 participants. Thematic synthesis indicated there were 3 main themes a)

pathways through diagnosis including its impact on identity, roles and relationships 2) resolving intrapersonal conflicts relating to the acceptance of the diagnosis 3) adjusting to living with dementia and using strategies and support to minimise the impact of dementia. The authors identified the need for the early provision of information about financial aids and entitlements and the need for professional and specialist support and appropriate referrals to support services following diagnosis. They noted that support needs to be sensitive to the needs of different group such as those with early onset dementia or minority ethnic groups and needs to take into account the need for continuity of care.

Other studies have examined care-giver issues with respect to some of the rarer forms of younger onset dementia.

McCarron et al (2005) found a significant difference in the amount of time formal caregivers spent addressing care activities for persons with Down syndrome with (N = 63) and without (N = 61) Alzheimer's disease which lends support to the additional care requirements of people with Down syndrome and dementia.

Janicki et al (2010) undertook a study concerning the experience of people (N =17) caring for a person with Down syndrome (over 35 years) some of whom had developed dementia (N =4). However, it should be noted that as cases of advanced dementia were excluded from the study the patients with dementia were in the early stages of the disease. It was found that carers provided about twice the amount of hours of care for a patient with both Down's and dementia than for those with Down syndrome without dementia but the sample is very limited.

The carer's in the Janicki study were described as 'adaptive copers', they appeared to be settled in their long term roles and did not appear to evidence the level of health-related issues reported for carers of people with dementia more generally. It was thought that this may be related to the fact that they had cared for these individuals with an intellectual disability for a very long time (usually since childhood) and had likely adopted coping styles that worked for them. This evidence is only suggestive at best but it may be that there are differences, given the different contextual factors, between carer's for people with Down syndrome who later develop dementia as against other carer's of people with younger onset dementia and this could be further explored.

Furniss et al (2011) undertook semi-structured interviews concerning caring, needs and services received with family carers, relatives and staff that were caring for people with Down syndrome and dementia (N=13 interviews out of 16 patients identified). Most of the clients were living in a residential care facility. Three main themes emerged from an IPA analysis and these were a) knowledge and information b) coping and support and c) concerns about the future. Family carers and relatives required more information about the diagnosis, symptoms and duration of dementia and most lacked prior awareness of the link between Down syndrome and dementia whereas staff carers were more knowledgeable about these aspects. Coping and support covered the emotional impact and the burden of care experienced but also reflected positive experiences such as working with others to overcome difficulties. Caring about the future concerned whether present care arrangement could be sustained as the dementia progressed and anticipatory grief concerning the patient's progressive decline and ultimate death. The authors suggest a range of service strategies to address these issues including better provision of information and training.

Skirton et al (2010) undertook a survey of carers of people with Huntington's disease in the UK and USA to identify carer concerns. Carers had concerns about the depth of knowledge of health professionals with regard to HD and noted the insufficient services to support both the carer and client. The authors identified a need for more comprehensive facilities and resources for HD patients and their carers. Similar findings were reported by Soltysiak et al (2008).

Little literature was found that related to carer experience or issues for carers of people with early onset HIV/AIDS dementia. High levels of carer burden were reported by Meadows et al (1999) and carers identified that they required better information and communication about the condition from health professionals.

Calvette et al (2011) undertook a cross-sectional study of Spanish caregivers (N = 223) of individuals with severe, traumatic brain injury to examine associations between social support, coping responses and depression and grief. The cognitive status of the patient group is not described but 60% of the sample had major physical disabilities. A range of standardised measures concerning family needs -TBI, grief, depression and responses to stress/ coping styles were utilised. Three types of coping strategies were identified: 1) Primary control coping – problem solving and emotional regulation and expression 2) secondary control coping – positive thinking and acceptance 3) disengagement coping –avoidance and denial. The structural equation model indicated that secondary control coping was associated with less grief and depression as was the availability of emotional and instrumental support. The authors suggest that interventions with families should focus on improving social networks (emotional, instrumental, professional support) as well as helping carers to develop adaptive coping strategies. As patients with TBI may also be diagnosed with dementia it suggests that these issues could be investigated further with people with younger onset dementia.

4.4 Carer - Patient Dyad Studies

In some of the studies reviewed above data has been collected from both carers and clients/patients but the two sources of data have not been directly linked. In this section data has been collected from both patients and carers concurrently and in a linked fashion and these are referred to as dyad studies. The value of dyad studies is that data relating to the patient (e.g. severity, presence of BPSD etc.) can be directly related to carer findings and vice versa which provides for a somewhat higher level of evidence.

In the Netherlands a 2 year prospective longitudinal study of people with younger onset dementia and their carers has been undertaken (van Vliet et al, 2010a) and an increasing number of studies from this source are currently being published. A compendium of articles about some of their recent work (younger onset dementia –care needs and service provision) can also be found in Bakker (2013).

Bakker et al (2013b) examined the use of informal and formal care by people with younger onset dementia and their carers (N = 209 dyads) using a resource utilisation in dementia scale (RUD-Lite) in a cross-sectional study. In general it was found that patients received over 3 times the amount of informal care than formal care (259.6 hours vs. 79.6 hours/month) with supervision and surveillance activities (including the management of BPSD) constituting the largest part of this care (230 hours/month). Other major types of informal care were ADL and IADL support. In 54% of cases there was only the primary carer but in 46% of cases secondary carers (children/family members) assisted with informal care activities such as supervision or assistance with ADL tasks. Fewer

informal care hours were associated with more caregiver paid employment hours and the younger age of patients which may indicate that caregivers of these younger patients might experience difficulties in finding a balance between care-giving, working and being a parent. The authors identify that this 'double strain' needs to be addressed by care-giver support groups.

Formal care was provided in 79.9% of cases with an average utilisation of 79.6 hours per month. Formal care services that were utilised were day care (66%), home care (30%) or district nursing services (7%) but meals services were used rarely (5%). Disease severity was significantly associated with the number of hours of informal and formal care. Factors increasing formal care use were disease severity, the presence of behavioural problems and low initiative of the patient re their activities of daily living (e.g. bathing, toileting, dressing etc.).

The proportion of formal care hours was higher for those with BPSD and for those with greater disease severity reflecting the later stage of the disease in the latter cases. The authors suggest this may reflect a postponement of the use of formal care services until later stages and support for an earlier acceptance of formal care by care-givers and patients might have important implications for patient and care-giver well-being such as delaying institutionalisation.

A study was undertaken with 209 patient-caregiver dyads to explore the health related quality of life (HRQOL) and unmet needs of these dyads (Bakker et al, 2013c). HRQOL for patients was assessed using the Quality of Life-Alzheimer's disease scale (Logsdon et al, 2002); for the carer it was assessed using the Dutch Version of the RAND-36 scale (Hays et al, 2001) and the assessment of (un)met needs used the Camberwell Assessment of Need for the Elderly (CANE) structured interview (Reynolds et al, 2000). Patient symptoms were assessed using the Neuropsychiatric Inventory (NPI) and 90% of patients had at least one BPSD and the majority of patients were diagnosed with early onset AD (57%), FTD (20%) and vascular dementia (12%). FTD patients had a greater number of BPSD symptoms identified.

The highest proportion of patient unmet needs reported by carers (proxy) was in areas such as daytime activities, company, communication difficulties, memory, mobility and psychological distress. Patients that were able to complete the CANE (30%) reported they lacked companionship, experienced difficulties performing tasks that were dependent on eyesight or hearing and those tasks that depend on memory. There was a strong relationship between unmet needs and the development of neuropsychiatric symptoms over time. Many of these unmet needs could potentially be addressed by care services (e.g. day care, activity centres, counselling).

Carers had significantly average lower scores on many dimensions of the RAND-36 (e.g. mental component score, role limits emotional, mental health, vitality, general health, physical component score and role limits physical) compared with the Dutch population. This was particularly true for the role limitation subscales. Higher levels of patient unmet needs related to several domains of carer HRQOL (e.g. less vitality, poorer perceived general health and higher level of physical difficulties and pain associated with performing daily tasks). Care-givers with more unmet psychological needs also seemed particularly at risk for experiencing limitations in social function and feelings of depression and anxiety.

The authors raise the limitations of their study including the lack of a comparison group such as LOD patients, and note they had to use carer proxy data for some of the analyses.

Miranda-Castillo et al (2013) undertook a cross-sectional survey including 152 interviews with carer-patient dyads where the patient had been diagnosed with dementia and was living at home. The unmet needs of patient were also assessed by professionals, carers and patients (professionals did the data entry based on patient interview) using the CANE measure. The most common unmet patient needs reported by carers were daytime activities, company and psychological distress and the most common unmet needs reported by patients were psychological distress, daytime activities, company and information (about care and treatment). The ratings concerning patient unmet needs were quite similar across the three groups but care-givers and professionals rated daytime activities as the most frequent unmet need whereas patients' rated psychological distress as their commonest unmet need. The authors consider the results confirm the importance of including patient views in the assessment of patient needs and in the care planning process.

Harvey (1998) examined patient characteristics in relation to carer burden. The high level of carer burden reported was associated with the patient having BPSD and low levels of community support. The presence of psychiatric symptoms for 52% of the carers suggested the need for carer assessment.

Delaney and Rosenvinge (1995) identified and assessed 27 patients with presenile dementia less than 65 years of age in the Southampton district of the UK and interviewed and assessed 24 of their associated primary carers concerning service use and caring impact. Carer's evidenced high levels of stress and psychiatric symptoms (50%) and they reported a negative impact of the caring role on their employment (e.g. needing to retire, reduce hours etc.). Identified unmet carer needs included the requirement for more information, advice and support and the availability of greater day care provision for the patients.

Mourik et al (2004) examined carer distress in relation to behavioural symptoms for 63 FTD dyads. From an examination of patient NPI data two behavioural clusters were identified a) agitation/psychosis and b) mood – anxiety and depression. Carer distress was associated with patient BPSD - particularly the agitation/psychosis cluster followed by mood disorder cluster. The symptoms of disinhibition and aberrant motor behaviour were only mildly related to carer distress although it has been reported in other studies that coping with disinhibition can be found troublesome by carers (Riedijk et al, 2006).

The studies above indicate there are high levels of burden, a high level of psychological symptoms and unmet needs for carers of people with younger onset dementia and these factors may well have the potential to increase the likelihood of the people with younger onset dementia being admitted to residential care when the carer can no longer cope. Livingston and Cooper (2013) have note that a review by Selwood et al (2007) indicated that six or more sessions of individual behavioural management therapy for carers centred on the behaviour of the person with dementia could alleviate the carer's depressive symptoms for up to 32 months. They noted this finding has not been translated into clinical practice but this type of therapy might well be applicable to some carers of people with younger onset dementia and is worthy of further investigation.

4.5 Carers - Comparative Studies

Few studies have made use of comparison groups and the studies/literature below include some form of comparative analysis. Many of the studies reviewed in the sections above undertake no comparative analysis of the needs of patients and burden on carers for later onset and younger

onset dementia groups, but have concluded that further and specialised services are required for the younger onset dementia group in the absence of any direct comparison.

An early study by Freyne et al (1999) examined carer burden (measured by the Zarit) and the clinical characteristics of people with EOD/ younger onset dementia (N = 22) and later onset dementia (N =22) residing in the community. There were no difference between the groups in terms of severity and the presence of BPSD. There were a range of diagnoses in the early onset/younger onset dementia group (AD, FTD, vascular dementia) but the later onset group were largely diagnosed with AD. It was reported that the carer burden for the EOD carer group was significantly higher than for the LOD group. However, as van Vliet et al (2011) point out, the EOD carer group had provided a significantly longer period of care and thus these findings might relate to the duration of care rather than to any difference between these groups per se.

A study by Riedijk et al (2006) from the Netherlands examined caregiver burden, HRQOL and coping in dementia caregivers for patients with FTD (N = 63) and AD (N = 90). Unfortunately the AD comparator group were not early onset cases of AD and thus this paper really is a comparison between FTD/ younger onset dementia and later onset AD with the age of caregivers and patients being a potentially confounding factor in the interpretation of results. This is particularly true for HRQOL data as it is known that there are age differences for some dimensions of HRQOL – particularly mental health (Ware et al, 2001). It was found that carers of FTD reported more burden than AD clients and this was associated with the presence of the symptoms of disinhibition and anxiety. There were no differences found between the coping strategies of FTD and AD carers but the use of passive coping strategies such as 'distraction' was found to be associated with poorer HRQOL for both groups.

The study by Arai et al (2007) compared patient- caregiver dyads for 14 patients with early/younger onset dementia and 54 patients with later onset dementia. The patients met the diagnostic criteria for AD, FTD, or vascular dementia but it is unclear whether the proportions of these diagnosis in each of the comparator groups was similar and if not this could have been a potentially confounding factor. The sample size for the EOD group is very small and as a result the potential for a type 2 error (not finding a difference when there is one) may be correspondingly high for some comparisons. The authors, however, did control for age as a potential confounder in the key statistical analyses.

No differences were found between the diagnostic groups in terms of patient clinical features, duration of care giving, number of hours of care giving per day and number of hours of care giving relief per day. After adjusting for potentially confounding variables such as age no significant associations were found between the type of dementia and caregiver characteristics or care giver burden. The one significant difference found (after adjusting for age, severity and the presence of NPI symptoms) was that the caregivers of people with early/younger onset dementia perceived greater difficulties due to patient behavioural disturbances than did the caregivers of people with later onset dementia. On this basis the authors recommend that additional care services should be provided to the EOD group to allow them to cope better with the perceived difficulties associated with patient behavioural disturbance - although the groups did not actually differ with regard to the frequency and severity of the patient's NPI symptoms. It is unclear from the study as to why the EOD carers perceived this greater difficulty in coping with behavioural disturbance. It is suggested that further research needs to clarify this issue, for which a targeted intervention might then be developed, rather than to just suggest the blanket provision of additional services.

Boutoleau-Bretonniere et al (2008) in a cross-sectional study compared ADL caregiver burden in FTD (N =26) and early onset AD (N=28). ADL function was assessed using the Disability Assessment for Dementia Scale (DAD; Gelinas et al, 1999) and the Zarit Burden Interview (ZBI; Zarit et al 1985) was used to assess carer burden. The groups were of similar age and there was no difference in the duration of caring. There was a trend for the FTD group to have slightly higher MMSE cognitive scores ($p < .10$) but there was a highly significant difference in the NPI (Cummings et al, 1994) scores with the FTD group having many more neuropsychiatric symptoms. There was no significant difference in the ADL function scores but there was a highly significant different in the burden scores and this was associated with the presence of NPI symptoms for both groups. The study concluded that greater burden was reported by carers of FTD than carers of AD patients although the level of functional disability of these patient groups was similar.

A literature review (N = 17 articles) by van Vliet et al (2011) examined the impact of early/younger onset dementia on caregivers (largely spouses) and this was compared with the research findings concerning later onset dementia. The methodological quality of the 17 research studies included varied, there were very small sample sizes and overall they were classed as 'limited' concerning their methodological quality. Most of the studies were only based on cross-sectional data so no inferences could be drawn on the different stages of dementia.

The results showed that EOD carer's experienced high levels of stress, burden and depression. A variety of psychological problems were reported including relational problems, family conflict, employment and financial difficulties. Carer's in these studies also reported difficulties in obtaining a diagnosis, problems with the referral period and distress experienced by caregivers of people with early/younger onset dementia due to the delay.

Only two of the studies included compared caregivers of people with early/younger onset dementia and later onset dementia (Arai et al, 2007: Freyne et al, 1999) and one of these (Freyne et al, 1999) used groups that varied in care duration. As a result of the scarcity of this literature and the limitations of these studies no conclusions could be drawn. It was recommended that future research should include cohort studies that compare caregivers of people with early/younger onset dementia and later onset dementia during the course of the illness and taking into account such factors as dementia subtype, illness severity, clusters of neuropsychiatric symptoms, care setting and make use of the same outcome measures.

Rosness et al (2008) compared the provision of support to 23 FTD dyads and 37 EOAD dyads. Carers of patients with FTD were less satisfied with the provision of information about the disease and were less satisfied with counselling and follow-up advice than carers for those with EOAD. Patients with FTD were more frequently offered stays in nursing homes and it was considered this may be related to changes in personality of these patients.

A Western Australian study Nicolau et al (2010) examined the needs, burden and extent of depression and anxiety in carers of people with FTD (N =30) compared to carers of people with AD (N =30). As with the Riedijk et al (2006) study this is comparing a younger onset FTD group with a late onset AD group, however, the authors used a variety of statistical methods in their endeavour to control for age in their analyses. The differences in results between these studies are probably a reflection of a more appropriate control of this potentially confounding factor. The length of the period of caring was also similar across these groups. After controlling for age no significant

differences were found between the AD and FTD carer groups with respect to carer's levels of burden, depression or anxiety although FTD carers reported a significantly higher degree of psychological distress on the CANE.

However, the findings indicated that the needs of FTD carers were higher than for AD carers (as assessed by CANE) – FTD carers had slightly more needs overall but a much higher proportion of unmet needs and a lower proportion of met needs compared with the AD carer group. After controlling for age and gender the authors report that carer need was a significant predictor of belonging to a particular carer group. The regression coefficient for carer needs indicated that FTD carers had greater levels of care needs –but it is unclear whether this was related to overall needs, met needs or unmet needs. These needs were identified as being related to the younger onset of FTD, financial dissatisfaction, typical FTD symptoms (e.g. socially inappropriate/disinhibited, threatening, interfering and compulsive behaviours) and access to appropriate services, information and support. The results also suggested that female carers of FTD patients were more likely to report a greater severity of impact of disruptive symptoms associated with FTD.

With regard to carer distress there was no difference found between the diagnostic groups. It was found that diagnosis (FTD vs. AD), relationship to the care recipient, length of time caring, carer's physical health and perceived level of burden accounted for approximately 50% of the variance associated with carer distress. However, of these variables only carer burden was a significant predictor (31% of variance).

Given the differences found between the groups in relation to the carer need variables the authors recommended specific educational and support programs, tailoring existing domiciliary services and activities for people with FTD and their carers and programs to raise community awareness and understanding.

4.6 Carer Studies – Service Issues

Although a number of the studies already reviewed have identified a range of service needs the following studies have a particular focus on service issues and service requirements in relation to the needs of carers.

Luscombe et al (1998) undertook a cross-sectional self –report survey with 102 carers of people with younger onset dementia. Most of the carers were spouses (68%), 13% were parents and 12% were adult children. Delays in diagnosis were commonly reported (71%) and the average time to diagnosis was 3.4 years. Carer's reported frustration (81%), grief (73%) loneliness (55%) and psychological or emotional problems (57%). Of those with children all but 8% reported negative effects on their children and family conflict was common. Financial worries (loss of income, 70%; financial problems 89%) and loss of employment by patients and carers were commonly reported. For those carers that were working at the time of diagnosis many carers (59%) had to reduce their hours or stopped working after diagnosis. Although most carers had used a support service, 25% of carers had never used community support and 32% had never used respite services. Some carers expressed dissatisfaction with residential and community services as they were thought they were not age-appropriate for people with younger onset dementia.

Husband and Shah (1999) undertook a retrospective evaluation on advice and information received post diagnosis by undertaking interviews with 40 carers of people with younger onset dementia. Some of the carers (N=12) received information from old age psychiatry (OAP) services in the UK and the remainder of the sample received information from adult neurology and psychiatry

services. The frequency distribution of adequate/inadequate responses was significantly different with the OAP carer group being more likely to have received adequate information and their rating of service satisfaction was higher. There were also more frequent referrals to social services and advice on financial and occupational issues but despite this few sufferers or carers had access to OAP services. It was suspected that many of the carers and clients may have had a long involvement with other adult services prior to diagnosis and thus remained with these services or they may have viewed using old age services as stigmatizing. It may also reflect a 'falling between the cracks' service issue pertinent at that time in the UK or that staff of OAP services may have been more aware of appropriate referrals to community support services for people with younger onset dementia.

Of interest was the general finding that 13/40 carers were dissatisfied with the initial GP response mainly due to a long delay before consultant referral and late referral was also significantly associated with carer dissatisfaction.

A study by Williams et al (2001) undertook a follow-up of 132 people diagnosed with early onset dementia in the Leeds catchment area of the UK which included a review of medical records and a postal survey of carers for these patients. Most of the patients were diagnosed with EOAD and the sample included 20 people with learning disability and dementia. A review of pathways to diagnosis identified 38 different pathways for people with younger onset dementia.

Their carers reported significant delays in obtaining a diagnosis and also complained about being passed from pillar to post across services and consultants before obtaining a diagnosis and/or being referred to appropriate support services. Many of the patients had been referred to day care but only 14% had received residential respite care and there were some criticisms concerning the age-appropriateness of the services received.

Carers also noted difficulties in finding appropriate homes for permanent care. Carers reported their well-being as poor & those who had been caring for greater than 3 years had poorer emotional well-being. Higher levels of carer satisfaction were expressed in relation to services provided by the Alzheimer's Association and a specialist early onset dementia team. The authors argue for the further development of a younger onset dementia specialist service which could act as a single gateway to coordinated service provision and help to address issues such as the lengthy time to appropriate referral.

Easton of the Ella Centre (2011) in Australia also reports on the experience of people with younger onset dementia and their carers (N = 17) during the diagnostic period. A retrospective survey was used. The average time to receive a diagnosis was 1.5 years which is somewhat shorter than has been reported elsewhere. Easton (2011) highlights a number of issues for improvement which included the provision of written material about the diagnosis, more information concerning disease progression, referrals to appropriate support services and more information concerning community support services available for both the carer and the patient.

McCallion et al (2004) from a random sample of carers (N = 608) of people with Alzheimer's disease surveyed examined the factors that affected choice for referral to be contacted by an AA chapter. Approximately one third of the caregivers agreed to be referred to an AA chapter to gain assistance in finding needed health and community services. They then examined the impact of the AA chapter referral on use of formal services. Most of the carers were white, 60 years old, with some

college education and were the daughters of a person with dementia. They had provided care for more than 5 years and 68% lived with the care recipient and were assessed as having high levels of subjective and objective carer burden.

The analyses indicated that carer referral to AA was associated with a lower educational level (high school or less) and single rather than married status. Carers that thought more services might assist the person with dementia remaining at home or that thought additional services would help were also more likely to agree to a referral. The referral assistance provided by the AA chapters increased community service use but there was no change in the use of health services. This study does not focus on younger onset dementia, and the demographics of carers are likely to be different, but it represents an initiative to contact carers to see if further assistance can be provided. Such an approach might be more useful to take shortly after confirmed diagnosis when the needs of carers are greater and support needs are inadequately met.

Georges et al (2008) conducted a carers (AD carers) survey through Alzheimer's Europe member organisations across 5 European countries (@200 responders per country; total N =1,181).Behavioural problems and problems with ADL activities were reported by 89% and 96% of carers respectively and these were identified as some of the most difficult symptoms to cope with by the majority of carers. Time spent in caring increased with disease severity and 50% of carers of people with late stage dementia spent more than 10 hours per day caring. The provision of information concerning all aspects of AD was considered to be poor and key services such as home support were unavailable to the majority of carers. This study did not differentiate between patients with early onset and late onset of AD but the study by Bakker et al (2013) also indicates similarly high levels of informal care provision for people with younger onset dementia.

Sussman et al (2009) examined whether tangible and emotional support provided by formal community services affected carer burden for those caring for a person with dementia. It was found that the use of in-home services did little to reduce carer burden whereas the frequency of the use of adult day programs was significantly association with less carer burden. This study also did not differentiate between people with younger onset dementia and later onset dementia but it is evident that carers of people with younger onset dementia might well appreciate the availability of age–appropriate adult day care programs. Schlosberg (2004) undertook an evaluation of day care service for early onset dementia and found that people with younger onset dementia were happy with the age appropriate service and their involvement/participation. Their carers were happy with it assisting with their continued employment and providing a respite. Both groups felt the service needed additional resourcing and should be expanded.

A study by Willis et al (2009) concerns the service evaluation of a memory service (Croydon Memory Service) by carers (N = 15) and patients with early stage dementia (N = 16). The 6 themes identified by content analysis were the initial experience of dementia; service experience; helpful interventions; normalising the catastrophic – peer support; clear communication and gaps in service. This thematic analysis of the qualitative interviews was used to derive 7 quality indicators for service evaluation. These indicators were 1) provision of broad based care as well as assessment 2) clear communication with carers and patients about diagnosis and care to be provided 3) provision or facilitation of continuing peer support groups following psychological assessments and interventions 4) easy availability of staff to respond to client and carer questions 5) considerate and professional staff behaviour 6) service useful for people with dementia and their carers including subgroups such as younger onset dementia and 7) strategies to manage those with subjective

memory impairment but no objective deficits. This model of evaluation may not be totally applicable to all memory clinics but it suggests some useful areas for inclusion in service evaluations.

Although the level of consumer satisfaction was high one of the service gaps identified was that the service did not adequately address the needs for the people with younger onset dementia – which could be addressed either through the provision of specific services for this group or by ensuring that the activities are age appropriate for all clients of the service. There were also concerns about the limited activities offered in the day care program which indicated the need for more individual tailoring of these programs. These examples demonstrated how an evaluation based on qualitative interviews can be used to refine service approaches and service evaluations. Evaluations incorporating both satisfaction and other outcomes measures and using both qualitative and quantitative measures need to become far more a case of usual practice in this field.

Sait (2012) presented information concerning a NSW survey and interviews on the service requirements for people with younger onset dementia – which included the perspectives of people with younger onset dementia, carers and health professionals (Brown et al, 2012). Service issues identified included problems associated with diagnosis & the lack of referrals to support services; and difficulties associated with respite care (e.g. age-appropriateness). However, it is noted that earlier community based service utilisation may have the potential to delay institutionalisation (Gaugler et al, 2005; Livingston and Cooper, 2013). Unmet needs identified included the need for a dedicated referral pathway, additional support for working carers and the need for a case-management approach.

As mentioned earlier Bakker et al (2013 b) examined the use of informal and formal care by people with younger onset dementia and their carers (N = 209 dyads) using a resource utilisation in dementia scale (RUD-Lite) in a cross-sectional study. In general it was found that patients received over 3 times the amount of informal care than formal care (259.6 hours vs. 79.6 hours/month).

Livingston and Cooper (2013), referring to the general literature on dementia also note issues concerning inequalities in access to care and note there is preliminary evidence from the UK and Sweden that those from higher socio-economic classes being more likely to be prescribed a drug for dementia treatment. They also note that minority ethnic people, including those in Australia, are often referred later in their illness.

The other studies concerning carers are largely service evaluations and will be reviewed further in the section on program evaluation. Harvey et al (1998) report on the Candid program which is a telephone enquiry service for the public, people with younger onset dementia and their carers. Of all calls 61% were from carers, 4% from patients, 19% professionals and 16% from other groups (e.g. worried well). Forty –five percent of the calls concerned general information, 37% requested clinical advice and 18% social advice. O'Connell et al (2013) implemented a teleconference support group for rural carers and this was found to be useful in sharing practical information and reducing social isolation.

Boldy et al (2005) undertook an evaluation of a short –term (up to 3 days) in-home respite service (Host Family Respite) for people with dementia. They suggest the availability of short-term respite might assist in delaying the institutionalisation of client. However, the low rate of GP referral to the

service needed to be addressed and further links forged with other respite services. It is estimated that approximately 20% of the service users were people with younger onset dementia.

4.7 Conclusion

There are quite a few studies reviewed above that interview people with younger onset dementia directly about their experience of younger onset dementia. Many could be characterised as qualitative thematic analyses of interviews usually based on very small sample sizes. Each of these has a slightly different thematic analysis but the issues identified include the emotional shock of diagnosis, problems associated with obtaining a diagnosis (the lengthy time taken, earlier misdiagnoses), feeling stigmatised because of the dementia 'label', a lack of referrals to support services, falling between the cracks of service systems, a lack of access to age appropriate services and programs, and financial problems. There were a number of intrapersonal challenges to be faced including loss of independence, loss of employment, loss of empowerment, rebuilding and restructuring one's life, adjusting to dementia and coping with role changes. Loss of empowerment was associated with the feeling that involvement in decision making was being denied to people with younger onset dementia, often by well-meaning carers or service staff. There was a desire expressed by many to remain involved and to get on with their lives as best they could.

An interesting comment made in one study by a young person living with dementia was that they needed to teach their carers how to work with them as many did not understand that they could only focus on one task at a time and interjected in conversations which interrupted their train of thought! All of the above issues are testimony to how challenging being a person with younger onset dementia must be and these issues raised are important for services to address and are important with regard to the training of staff.

Some authors recommend further research on the 'experience' of people with younger onset dementia. However, 'more of the same' research is actually not required. What is required are a few well-funded studies with better research designs, larger sample sizes, a triangulation of methods of outcome assessment, and consideration of the control of extraneous variables/ confounding factors. The previous studies have provided valuable insights but the level of evidence is 'weak'. However, what should become part of routine practice is the involvement and participation of people with younger onset dementia in service design, development and evaluation.

Relatively fewer studies have interviewed or surveyed children of people with younger onset dementia with regard to their experience and in most cases the sample sizes are again very small which limits the degree to which these findings can be generalised. The literature on the effect on children having a parent with dementia makes mention of perceived stigma and associated shame/ embarrassment, bewilderment, family conflict, high care burden, the physical challenge of caring, psychological issues and problems at school. Many of these children are undertaking a demanding caring role (sometimes becoming a 'parent' to a parent) while also facing the usual development challenges of growing up. Coping strategies, family cohesion and security of attachment are raised as issues but little research has been conducted directly on these topics. Some children reported there positive effects of their caring role, such as maturation and the experience they have gained, despite the challenges. However, it is clear these children have substantial needs for support and due to the care burden placed upon them may have a potential for psychological and social disadvantaged which needs to be further explored.

In the section concerning the experience of spouses some themes that emerged were the long quest to obtain a diagnosis, adjustment to the diagnosis, managing BPSD, changing roles, grief associated with the 'loss' of spouse (as they were) and their future plans, juggling the caring role with other family and daily life responsibilities including employment, and difficulties in making plans for the future.

The issue concerning the need for earlier diagnosis is important as prior to diagnosis spouses report they may be making mistaken attributions concerning the patient's symptoms which can have a negative impact on their marital relationship.

Some authors note there are different phases of the couple's relationship which can be characterised as progressing from sustaining their 'couplehood', through maintaining their involvement and in the end stages to 'moving on'(e.g. moving from a 'we' focus to an 'I' focus) which may actually be a necessary developmental step. Although many of the studies report negative effects on the spouse such as carer burden many couples have a positive focus on their predicament and try to maximise their quality of life and to maintain their relationship. Some carers have reported developing higher self-esteem and assertiveness as a function of undertaking their caring role.

Factors that need further investigation concern the nature of the couple's relationship at symptom onset and through the illness progression, the effectiveness of the coping strategies that spouses use and the identification of precursors of poor coping strategies in spousal carers.

A number of other studies have identified issues such as role changes, disruption to family life, balancing the dedication to the caring role against the carer's own needs and reports that social isolation may be quite common amongst spousal carers. These issues also need to be addressed by support services.

Some carer studies have included mixed groups of carers in their studies (spouses, children, other relatives, formal carers, ex carers) although most of these studies include a large number of spouses/partners. However, studies that use mixed carer groups or combine patient and carer feedback on their experience run the risk of ignoring particular issues for these groups. Although some of the issues that are raised are common ones there are some different perspectives that arise from patient, carer and professional groups. An example of this is the area of unmet needs where people with younger onset dementia rate psychological distress as a more common unmet need than do carers or professionals.

Some of these studies report similar issues to those raised in the sections above (e.g. issues concerning the diagnostic process and aftermath, stigma, lack of appropriate referrals to support services, transitions in the caring role, challenges to one's identity, coping strategies, lifestyle changes etc.). A number of these studies have used more quantitative approaches, such as including the use of standardised scales. These scales have been used to assess carer burden, stress, carer and patient unmet needs, the presence of psychiatric symptoms amongst carers, and health related quality of life and well-being. Generally these studies indicate high levels of stress and burden for carers, poorer quality of life, and unmet needs including social isolation, depression and anxiety.

Some more recent studies have used patient carer dyads to explore these themes and the value of dyad studies is that data relating to the patient (e.g. severity, presence of BPSD etc.) can be directly related to carer findings and vice versa which provides for a somewhat higher level of evidence. Similarly, some studies are now using comparator groups where the younger onset dementia group is compared to a later onset dementia group and this is desirable but unfortunately many of the initial studies have poor control of confounding factors such as the duration of the caring period, age and diagnostic composition of the comparator groups. Many studies are cross-sectional so do not address the course of the illness although more recent studies from the Netherlands are addressing this research gap there is a requirement for further longitudinal research.

A few studies have focussed on the demands of the long period of caring and predictors of residential care placement. Other studies have focussed on the effects of loss or reduction in the employment of both the person with younger onset dementia and their spouse and the resultant financial and legal issues and problems that can arise.

A particular research gap that has been identified is that there no studies were found that examined the experience of people with younger onset dementia living alone or those that have no familial carer. Similarly the issue of parental carers for people with younger onset dementia does not appear to have been explored in the literature.

A few studies have focussed on issues concerning rarer forms of younger onset dementia. There is some suggestive evidence that the burden of care or carer need is greater for carers of people with FTD but the findings are equivocal. Some comparative studies indicate that carer burden may be higher but it is not directly related to the number of BPSD symptoms as these have been found to be similar across comparator groups. The issue might not be the total number of BPSD symptoms the person with FTD displays but the type of BPSD symptoms and their frequency and these factors might also interact with carer and other socio-demographic variables. The situation is complicated and the use of multivariate techniques might be required to gain a further understanding of these elements.

Some forms of younger onset dementia also have quite a different presentation as occurs with Down syndrome and dementia where the carer has experienced the caring role often since the childhood of the client. Although one study noted the provision of informal care was much greater for people with Down syndrome and dementia, another study suggested these carers were more settled in their caring roles and less prone to experience issues such as ‘burn-out’ or health related issues than for other dementia groups. This may require further exploration as the literature is sparse.

The studies that focus more on particular service issues also noted the lack of a clear diagnostic pathway and the lack of appropriate referrals to support services during the diagnostic process. This is important as more effective and earlier use of community support services may have the potential to delay institutionalisation.

One recent study highlighted the need for the provision of written information at diagnosis. It is hoped that the increasing provision of specialist younger onset dementia services and case management and key worker approaches may assist in rectifying such issues. Despite the numerous attempts by organisations such as the Alzheimer’s Association to provide comprehensive

information across a range of forums, including the internet, the need for clear information and advice is still mentioned as an unmet need for carers and patients.

5 Service Design and Development

5.1 Introduction

A large number of research articles and grey literature has been reviewed in relation to the design and development of services for people with younger onset dementia. As can be seen from Table 3, much of the academic literature is presented as discussions by experts in the field regarding issues of service design and delivery. A smaller number of articles are evaluations of younger onset dementia specific services, general dementia services, mental health or disability services.

This literature review has been conducted against a backdrop of an emerging field of evidence that seeks to clarify the specific service needs of people with younger onset dementia. The literature review conducted by Thompson (2011) examines community –based best-practice service models, both nationally and internationally for people with younger onset dementia. Thompson's review was focussed primarily on the needs of younger people with Alzheimer's disease and fronto-temporal dementia (FTD). This current review has looked more broadly at the implications for service needs of the diverse range of conditions that fall under the umbrella term of younger onset dementia. Importantly for service design and development, the needs of each individual in these diagnostic groups will vary greatly.

More recently a growing focus has been on conducting empirical studies into service needs of people with younger onset dementia. A number of major national and international studies are currently in progress. However, they are not at a stage where findings have been published. Of those that have completed, the most significant of these is the Needs in Young Onset Dementia (NeedYD) longitudinal research study conducted by Bakker (2013) and van Vliet (2010b) in the Netherlands. This study has provided significant evidence previously not available in regards to key aspects of care needs and service provision for people with younger onset dementia and their carers.

This section of the literature review begins with an overview of key findings regarding service design and development for people with younger onset dementia presented as themes from the literature. The evidence base regarding how service providers can build their capacity to deliver services to people with younger onset dementia is explored. As a basis for service design, this section of the literature review provides a set of overarching principles for service development and for delivering services to people with younger onset dementia. Critical elements of service design and delivery for each of the phases or stages of the disease trajectory of younger onset dementia have also been included. This information can form the basis of resources for organisations to develop, change and improve delivery of services to people with younger onset dementia.

A brief overview of the current services available for people with younger onset dementia in Australia is provided. Following this is an examination of the significant recent changes to the policy context for younger onset dementia service provision at both Commonwealth and State and Territory government levels. The flow-on from and the impact of these changes have not been fully realised in the current service sector due to the 'staged roll out' of some of the key reforms such as the National Disability Insurance Scheme over the coming years. Implications for younger onset dementia service providers of the policy changes are considered.

Although much of the literature concerns health and medical services, this review has a major focus on community based services. It is acknowledged however that the interface between health and community based services is fundamental to supporting the person with younger onset dementia to remain in their home as long as possible. Effective collaboration between all agencies and service providers involved in the care of the person with younger onset dementia is a key success factor in effective service delivery.

Table 3 Design and Development of Services for People with Younger Onset Dementia

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
ADAHPS (2013)	Australia/NSW	HIV complex case management	NA - project description	NA	HIV/AIDS Dementia			A brief description of a service for the management of people with HIV associated dementia or other complex needs. There is a regional outreach service available provided through a consortium of Sydney based services which is being trialled
ADHC (2012)	NSW Aust	Forum on YOD	NA - forum	Expert opinion	YOD clients & carers			Outlines key principles of care re YOD, service modifications and initiatives for capacity building for services
ADHC et al (2013)	Australia	Roundtable with Bakker	NA - forum	Expert opinion	YOD			Discussion with Bakker of NYODCP -raising awareness; integrated diagnostic services, service design and models of care; family & community support, predictors residential placement, residential support
Alt and Beatty (2007)	Australia / NSW	Appropriate HACC Service Models for people with YOD and behaviours of concern	NA - consultations	Expert opinion	YOD			Report covering a project in Sydney Metro-North HACC region to identify the key elements of HACC service models that are appropriate for people with YOD and people with dementia and behaviours of concern
Alzheimer's Australia (last updated 5 Dec 2013)	Australia	Fight Dementia - Alzheimer's Australia website	NA - website	NA	Dementia			Website for Alzheimer's Australia (AA), contains information about AA as an organisation and resources, information and service contacts for dementia generally and YOD
Alzheimer's Australia (2009)	Australia	National Consumer Summit YOD	NA - summit	Expert opinion	YOD clients & carers	CALD; Indigenous		Key priorities for YOD in 2009-agreed initiatives: increased awareness, timely diagnosis, increased service links/networks, access to services, address employment and financial needs
Alzheimer's Australia (2013)	Australia	YOD: A new horizon?	NA - overview	Expert opinion	YOD clients & carers			Key priorities for YOD in 2013 identified in context of NDIS -6 priorities: awareness, timely diagnosis, a model for NDIS, service redesign, participation & inclusion, program of research
Alzheimer's Society UK (2005)	UK	YOD guide to service provision & development	NA - guide	Expert opinion	YOD			Guide to service provision and development for people with YOD in the UK. Need for specialised YOD services. Epidemiology of YOD in UK
Armitage et al (2009)	International	Health systems integration: state of the evidence.	NA - Literature Review	Literature Review	General			Review of literature re concept of integration
Australian	Australia	Commonwealth HACC	NA - program	NA	HACC clients			The HACC Program Manual sets out the operational

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Government Department of Health and Ageing (2012)		Program Manual	guidelines					requirements of the Commonwealth HACC Program from 1 July 2012. This manual does not apply to HACC service providers in WA or VIC. It covers the aims, administration and service delivery of HACC
Australian Government Department of Health and Ageing (2013)	Australia	Consultation Paper Draft National Framework for Action on Dementia 2013 - 2017	NA - policy doc	NA	Dementia			The Framework was developed by the Commonwealth and State and Territory Governments in consultation with consumers, stakeholders and service providers. It outlines 6 priority action areas to aid government strategic planning for dementia care
Australian Government Department of Health and Ageing (2013)	Australia	Dementia	NA - website	NA	Dementia			DSS (note: still on DoHA website) information regarding Dementia as a National Health Priority Area
Australian Government Department of Health and Ageing (2013)	Australia	Report on the Operation of the Aged Care Act (1997)	NA - policy doc	NA	General			Aged Care reform process - timeline and scope of reform
Australian Government Department of Health and Ageing (2013)	Australia	Home Care Package Program Guidelines	NA- guidelines	NA	General			These Guidelines provide policy guidance to support the delivery and management of the Home Care Packages Program, including the policy context for the Living Longer Living Better aged care reforms
Australian Government Department of Social Services (2013)	Australia	National Disability Strategy	NA - policy doc	NA	Disability			The National Disability Strategy 2010-2020 sets out a ten year national policy framework for improving life for Australians with disability, their families and carers
Bakker (2013)	Netherlands	YOD care needs and service provision	Longitudinal observational studies	Acceptable practice	YOD clients & carers		Various	Compendium of articles by Bakker and colleagues
Bakker et al (2010)	Netherlands	Needs in EOD, qualitative case-study	Prospective random case-study, 12 months	Case-study	EOD (YOD) client & carer		1 carer and client	Patient & carer dyad journey from initial symptoms to residential placement. Need for timely diagnosis & specialized EOD (YOD) care/services sensitive to evolving needs of both client & carer
Bakker et al (2013a)	Netherlands	Predictors time to institutionalization YOD	Longitudinal observational	Supported practice	YOD clients		226 YOD, 120 LOD	The results of this study provided evidence for a timely diagnosis to facilitate use of services. Support

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
			study					programs aimed at enhancing the caregivers' sense of competence and ability to deal with neuropsychiatric symptoms, especially apathy, may postpone institutionalisation of people with YOD
Bakker et al (2013b)	Netherlands	Use of formal and informal care: YOD	Longitudinal data of 215 patient carer dyads.	Acceptable practice	Carers AD		209 patient-caregiver dyads	Study showed that in general patients receive over 3 times the amount of informal care than formal care. Factors increasing formal care were disease severity, behavioural problems and low initiative re: ADLs. No comparison group. Identified research gaps
Bannerjee et al (2007)	UK	Evaluation of Croyden Memory Service Model	Evaluation using a cohort study & client interviews	Acceptable practice	LOD & some YOD	CALD	45 YOD out of 247 total	The Croydon Memory Service Model appears to have high acceptability, accessibility, and effectiveness in increasing the numbers of people provided with diagnosis and care in a population. Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia
Beattie et al (2004)	UK	A qualitative study of views of younger people about their dementia	Qualitative interviews	Emerging practice	YOD clients		14 clients	Themes-experience of dementia, diagnosis, age, risk and danger. Clients desire age-appropriate services. Need to assess patient views
Bentham & La Fontaine (2008)	UK	Services for young people with dementia	Literature Review	Literature review	YOD clients	CALD		Recommends comprehensive multidisciplinary & multi-agency service that provides specialist assessment, diagnosis and interventions, & provision for meaningful activity relevant to YOD
Bradshaw (1972)	UK	The Concept of Social Need	Commentary	Expert Opinion	General			Description of 4 types of social need, normative, felt, expressed, and comparative
Brodaty & Cumming (2010)	Australia	Dementia services in Australia	NA - commentary	Literature review	YOD all	CALD		Recommendations: increase awareness& carer support, reduce stigma, improve timely diagnosis, support for special population groups, age appropriate services and correct relative underfunding for dementia research
Brodaty et al (2012)	Australia	Dementia time to death	Literature review	Literature review	Dementia			Review of life expectancy data for dementia in general
Brown et al (2012)	Australia	Service & support requirements YOD people & families	Review, interviews, on line provider survey	Literature review	YOD all		34 Carers, 20 YOD, 8 providers	Recommendations concerning early intervention, community participation & social engagement, family & relationship support, informal support, respite, employment and financial support, CALD services
Bunn et al (2012)	UK	Adjusting to diagnosis - carer and client	Literature review of	Literature review	Dementia carers & clients		102 studies - @ 3,000 N	Identifies need for early provision of info about financial aids and entitlements, professional and

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
			qualitative studies					specialist support and appropriate referrals
Burrell (2012)	NSW Aust	Types and symptoms of YOD	NA - overview	Expert opinion	YOD clients			Outlines types and symptoms of YOD and relates to therapeutic approaches
Callahan et al (2013)	USA	Historical development and state of the art approach to design and delivery of dementia care services	Discussion	Expert opinion	Dementia carers & clients			Design and delivery of dementia care services
Calsyn et al (2004)	USA	Recruitment engagement and retention of people living w HIV in services	NA - discussion	Expert opinion	HIV/AIDS Dementia	Homeless		People living with HIV/AIDS, mental health and a substance use disorder frequently do not receive adequate treatment for one or more of their illnesses. Integrated, flexible, case management, services with culturally competent staff are required
Carling et al (2012)	Australia	Experiences of supporting people -Down syndrome &AD	Case study	Case-study	YOD & Down Syndrome		3 clients and families	Families of adults with Down syndrome experienced stress and confusion as they negotiated a service system poorly equipped to meet their needs and professionals who are more focused on longstanding disability than the diagnosis of Alzheimer's disease
Chaston (2010)	NZ	Younger adults with dementia: promoting awareness	NA - discussion	Expert opinion	YOD	Rural and Remote, Maori		Discussion regarding negative experiences of people with YOD in the health system and wider community due to lack of awareness of YOD - 'reverse ageism'. Author suspects higher rate of YOD in Maori community but undetected. Strategy of YOD clients as educators proposed, also telephone advice and support and YOD newsletter to support clients in remote locations
Chaston (2011)	NZ	Between a rock and a hard place: service needs of people with YOD	Literature review	Literature review	YOD			Focussed, specialised age appropriate services are required for people with YOD. The two main themes from literature re service design - single entry point and a defined care pathway
Chemali et al (2012)	USA	Diagnosing EOD and then what?	Medical record review	Routine practice	EOD (YOD) clients		76	Review of 76 EOD (YOD) memory clinic patients - identifies lack of age-appropriate services for this group
Community West (2013)	Australia / WA	The WA HACC Wellness Approach	NA	NA	General			Information regarding the WA Wellness Approach. The WA Wellness Approach is a philosophical change in thinking behind the delivery of HACC services in Western Australia

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Council of Australian Governments (2011)	Australia	National Health Reform Agreement	NA - policy doc	NA	General			An agreement between the Commonwealth and State and Territory Governments. The objective of the Agreement is to improve health outcomes for all Australians and the sustainability of the Australian health system
De Waal et al (2013)	International	Designing and delivering dementia services	Literature review -book	Literature review	Dementia			An edited collection of recent articles concerning Dementia internationally. One chapter addresses YOD in particular (Koopmens and Thompson, 2013). See also Livingston and Cooper (2013) and Ratcliffe et al (2013)
Elliot & Reed (2011)	UK	EOD developing strategies	NA - Conference	Expert Opinion	EOD (YOD)			A conference re good practice for YOD services. Includes model of multidisciplinary health team for memory clinic and YOD specific services. Other support service models: person-centred approach, leisure activities such as swimming and art. Gaps in service - education and support for families, regional helpline and community awareness programs
Ferran et al (1996)	UK	EOD Clinical Characteristics and Service Use	Patient follow-up memory clinic	Routine practice	EOD (YOD) clients		200	An older study highlighting the need for a multi-professional diagnostic service, integrated and intensive community care, coordination of services and accessibility
Florence Centre (2011)	Netherlands	Florence Centre for specialised care in EOD	NA - brochure	NA	EOD (YOD)			Information brochure for the Florence Centre for specialised care in EOD (YOD). Provides detail regarding service philosophy and design and services provided
Grabowski (2006)	USA	Cost effectiveness of non-institutional long term care services	literature review	Literature review	General			A study of cost-effectiveness of different approaches to community based care. Care models associated with increased costs also had greater client and caregiver welfare. Capitated care models and consumer directed care were identified as having potential as efficient service delivery models
HammondCare (2013)	Australia / NSW	Services for younger people living with dementia at HammondCare Horsley	NA - website	NA	YOD			Website information regarding 'Streeton Cottage' - the special residential permanent and respite care service provided by HammondCare for people with YOD
Harris (2004)	USA / UK	Living with Early Onset Dementia: exploring the experience	Qualitative study	Emerging practice	YOD		23 YOD, 15 families	Qualitative study of experience of living with YOD and caregiver. Based on the evidence guidelines for assessment and treatment developed. Main issues

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								are: listen to younger people with dementia; flexible & person-centred services
Hean et al (2011)	UK	Integrated memory assessment & support services for people with Dementia	Service Evaluation	Expert opinion	General			Evaluation of an integrated memory assessment and support service. Service model with streamlined care pathway, single point of entry. Services offered to people irrespective of age. Positive outcomes included: increased response time for assessment, diagnosis and treatment; increase in early diagnosis; benefits of integrated service and purpose-built unit; but increased service costs
Hellstrom et al (2007)	Sweden	Ethical & methodological issues in interviewing people with dementia	Qualitative study	Expert opinion	General dementia		20 people with Dementia and spouses	Article supporting the inclusion of people with dementia in research and challenging the exclusion of people with dementia based on ethical difficulties. The benefits of participation usually far outweigh the risks, particularly when a 'safe context' has been created
Hodges et al (2009)	Australia	YOD: A practical guide	NA - overview	Expert opinion	YOD			Overview of types and causes of YOD, practical issues with respect to care of people with YOD
Hunt (2011)	US	YOD literature review and impact for clinicians	Literature review	Literature review	YOD all			Literature review re implications for clinicians and service redesign including age-appropriate services
Johansenn and Moller (2011)	Norway	Experience of Persons EOD: Quality of Life	Qualitative study 20 EOD journeys over 1 year.	Emerging practice	EOD (YOD) clients		20/217	Randomly selected 20 of 217 patients. Identified 2 stages of patient journey (toward dementia diagnosis, fighting for dignity) over 1 year period, identified unmet needs, issues for services & the need for specialised EOD (YOD) services
Jokinen et al (2013)	USA	Community Care supports: people with intellectual disability and dementia	NA - discussion	Expert opinion	Intellectual disability			A set of practice guidelines have been developed for services for people with intellectual disability and dementia covering the period from when suspicions are aroused to when care ends with eventual death
Keady and Nolan (1999)	UK	Family caring & people with YOD	Qualitative - interviews	Emerging practice	YOD carers		58 carers	Outline of a 6 stage model of caring transitions - building on past, recognising the need, taking it on, working through it, reaching the end, and a new beginning
Kenny & Wilson (2012)	UK	Successful Multidisciplinary team working: an evaluation of HD service	Qualitative evaluation	Emerging practice	Huntington's disease			A specialised multidisciplinary service was developed for people with Huntington's disease that provided users with a single point of contact and easy referral into the system. The community based service offers diagnosis, treatment and symptom control, and case management. The team relies heavily on the CNC who

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								is the case manager for all patients
Koopmans and Thomas (2013)	Netherlands	Services for people with YOD	Literature review	Literature review	YOD			Discusses issues for services, types of services and a brief description of service models in some countries. (In De Waal et al)
Kortte & Rogalski (2013)	USA	Behavioural interventions FTD	NA - discussion	Expert opinion	YOD			Examples of how behavioural interventions provided by allied health for FTD clients improves management of cognitive-behavioural symptoms and lead to enhanced life skills and quality of life for FTD clients
Lechich et al (2008)	USA	Surveys of community programs: Huntington's disease	Survey	Expert opinion	Huntington's disease			A survey of health professionals re enablers and barriers for families of people with Huntington's disease to the transition of the person with HD into residential care. Important enablers include: facility staff familiar with HD, allied health therapy available, access to recreational programs. Barriers include: resistance of person with HD to placement, lack of confidence in care facility, geographic inaccessibility
Leutz (2005)	USA	Reflections on Integrating Medical and Social Care: Five Laws Revisited	NA - discussion	Expert opinion	General			A review and expansion of the original 'Five laws for integrating medical and social care (Leutz 1999)'
Livingston and Cooper (2013)	UK	The need for dementia care services	Literature review	Literature review	Dementia general			Examines overall prevalence and burden of disease estimates for dementia to identify need for specialist services and addresses management issues that are topical in 2013
MacRae and Cox (2003)	Scotland	Meeting the Needs of People with Alcohol Related Brain Damage	literature review	literature review	ARBD			A literature review to ascertain the needs and characteristics of ARBD service users and carers; to examine how people with ARBD are identified, assessed and the services provided and to develop models of care to inform service development
McLeod (2007	USA	Maslow's Hierarchy of Needs - Simply Psychology	NA	NA	General			Overview of Maslow's theory of need / 'hierarchy of needs'
Menne et al (2002)	USA	Trying to continue to do	Qualitative: interviews with patients	Emerging practice	Early stage AD clients		6	Day to day experience of early stage dementia - maintain continuity with previous way of life while coping with dementia necessitated changes
Minkman et al (2009)	Netherlands	Integrating dementia care in the Netherlands	Qualitative study	Emerging practice	Dementia general			Client-centred care for both the dementia patient and their caregivers was the most important factor in all programs. Factors for success of case management programs: expert knowledge of case managers, a

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								strong provider network and coherent conditions for effective inter-organisational cooperation to deliver integrated care
Miranda-Costillo et al (2013)	UK	Needs of people with dementia living at home	Survey	Emerging practice	Dementia general		125 carer, 125 clients	Need to examine perspectives of carers, client and professionals in designing care plans as their perspectives differ
Mitchell (2012)	UK	Coping with YOD	Qualitative interviews	Emerging practice	YOD couples		6 couples, 6 workers	Identified needs re clarity of information provided, flexible support services, participation in service planning and increased public awareness. Further research is required re coping styles and the identification of precursors to poor coping
Mocellin et al (2013)	Australia	Understanding young onset dementia	NA - overview	Expert opinion	YOD			Information regarding YOD services such as diagnosis assessment and medical treatment of dementia. Key features of the different types of dementia are listed. This disease specific information can inform service design
Morhardt (2011)	US	Access to community based and long term services FTD	NA - Discussion	Expert opinion	FTD clients & carers			Issues for people with FTD: difficulty being diagnosed, financial issues, social security insurance access issues, poor access to community and long term services
Moriaty et al (2002)	UK	Innovative practice section	NA - discussion	NA	YOD			Discussion re good practice for service provision for YOD based on examples in Western Australia and London. Key points are: meaningful and purposeful day activities; consulting clients and carers in designing services; integration with other YOD services.
O'Connor et al (2007)	Canada	Personhood in dementia	NA - Discussion	Expert Opinion	Dementia			This study proposes a framework for investigating the performance and behaviour of persons with dementia as influenced by personal histories, social interactions and social contexts. Evidence from the study shifts attention from the disease process to the need for a more in-depth understanding of the place of personhood in dementia care
O'Connell (2013)	Canada	Rural teleconference support for spouses - YOD	Provision of rural teleconference support	Routine practice	FTD/EOD (YOD) 10 spouses - rural	10 carers participated		A monthly 90 minute meeting for spouses of people with YOD is facilitated by tele-health videoconferencing, equipment use training, monthly email telephone reminders and at 18 months an in person workshop. Found to be useful for sharing practical information and reducing social isolation-

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
								evaluated at the follow-up workshop
Putnam et al (2010)	USA	Stakeholder perspectives on dementia policies for family carers	Qualitative Study	Emerging practice	Dementia	American Indian -1	24 carers, 1 LOD	Examines problems with Consumer Directed Care (CDC) approaches to service delivery for people with dementia who are unable to direct their own care. Caregivers as 'surrogate' decision makers are required in CDC or alternate models need to be used
Reed et al (2002)	UK	Services for younger people with dementia	Service Evaluation	Expert opinion	YOD			Outcomes of the evaluation of a YOD specific health service suggested from a consumer perspective. The key to appropriate services for YOD is 'services that are sensitive to individual needs' with staff that are responsive rather than 'age specific' services per se
Rose et al (2010)	USA	Care considerations for persons with EOD	Case study	Case-study	EOD (YOD)		4 people with EOD	From four case studies 7 themes were identified regarding the main 'issues' facing a person with EOD (YOD) and their families. These are: stigma of diagnosis, access to health and community services, employment and financial issues, loneliness and isolation, safe activities for the physically able, appropriate residential placement and carer difficulties. Suggested service design / development strategies to effectively address the client and family needs and to respond to the 7 key issues were provided
Rota-Batelink & Lipmann (2007)	Australia	Supporting the long term residential care needs of older homeless people w ARBD	NA - Discussion	Expert Opinion	ARBD			This project investigates the highly specialised residential aged care needs of people with severe ARBD as provided by the Wintringham model of residential care. The model can be replicated to better support people with these complex care needs
Sait et al (2013)	Australia	Living alone with dementia	Review, interviews, on line provider survey	Emerging practice	Dementia		6 patients, 101 case managers	People living alone require additional service support to navigate the service system and to avoid potential adverse outcomes. Many services are designed around the client having a carer and will not accept people who live alone without an identified primary carer. People living alone may require more support to delay time to institutionalisation
Sansoni et al (2012)	Australia	A model and proposed items for the new assessment system for aged care	NA- Report	Expert Opinion	General			An assessment framework and needs assessment tool based on the principle that needs assessment is an ongoing process

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
Santagello (2012)	Australia	NSW service mapping YOD & info Service - move to service	Action Oriented Research	Emerging practice	YOD			NSW service maps
Saunders (2013)	Australia	Get your voice heard - rural	Qualitative interviews & survey	Emerging practice	YOD		145 clients & carers; 176 providers	Focus groups with carers and patients and providers in rural SA. Similar themes re issues with diagnosis, lack of support post diagnosis and need for support in linking to services. Rural issues concerned the limited availability & scope of services and need for additional allowances for rural and remote regions
Scott & Donnelly (2005)	UK	Early identification of cognitive impairment	Evaluation	Emerging practice	Dementia general			This article describes a research evaluation of a new screening, assessment and referral service for people with early-stage dementia and their carers who reside in Northern Ireland. The findings from this evaluation help to address the lack of available information about ways in which to organize and deliver early-stage dementia care
Swaffer (2012)	Australia	Prescribed Dis-engagement: what is it	Opinion	Expert opinion	General			Discusses prescribed dis-engagement – the expectation that a person with YOD has to give up their jobs and activities, and just wait to die
Thompson et al (2006)	UK	Interdisciplinary clinic for EOD	NA - Discussion	Expert opinion	EOD (YOD)			Discussion regarding evaluation of the trial of an interdisciplinary diagnostic and treatment clinic for people with EOD (YOD). Success of the trial led to the clinic trial being extended and the role expanded to include education and consultancy
Thompson (2011)	NSW Aust	Service & support requirements- people with YOD & families	Literature review - community based best practice models	Literature review	YOD all			Literature review of community based best practice and good practice services across Australia
Tindal & Manthorpe (1997)	UK	EOD: A case of ill-timing	NA- review	Literature review	EOD (YOD) all			Examines literature on experience & impact of YOD. Argues for specialist service provision of YOD and the development of new research agendas
Tolhurst et al (2012)	UK	YOD impact of emergent age based factors on personhood	NA - theoretical discussion	NA - discussion	YOD clients			Examines age based factors that may affect the experience of YOD personhood
van Baleen et al (2011)	Netherlands	How to evaluate quality of care from the	Literature review	Literature review	Dementia			People with mild to moderate dementia are able to talk about their experiences with care with clarity and

Author & Year	Country/ State	Topic	Study design	Strength of Evidence	Diagnosis & Focus	Special needs groups	Study Nos.	Summary
		perspective of people with dementia						insight. A minimum level of cognition is required. When assessing care quality it is necessary to take into account the patients' perspective
van Vliet et al (2010a)	Netherlands	Research Protocol for NeedYD study	Longitudinal observational study	Acceptable practice	YOD		217 dyads	Outlines the research protocol for 2 year longitudinal study in Netherlands
van Vliet et al (2012)	Netherlands	Prevalence of neuropsychiatric symptoms YOD	Longitudinal observational study	Acceptable practice	YOD		98 YOAD, 128 LOAD and carers	The prevalence of neuropsychiatric symptoms (NPI) comparing YO-AD and LO-AD patients over a 2 year period. Prevalence of NPI symptoms was lower in the young onset AD group throughout the period. Apathy is the most common symptom for YO-AD
Victorian Department of Health (2013)	Australia / Vic	HACC Active Service Model Project	NA	NA	General			The Victorian HACC Active Service Model is a quality improvement initiative that focuses on promoting capacity building and restorative care in community care service delivery
Warren,(2013)	Australia	Hope Newsletter	NA	NA	YOD			Introducing the YOD key worker position
Whitefield (2006)	Canada	Health service planning with individuals with dementia	Literature review & qualitative study	Emerging practice	Dementia general			This research study addresses organisational issues related to effective inclusion of people with dementia in planning and decision making about health service and programs
Williams (2000)	UK	Specialist services helping GPs to manage dementia	NA - Survey	Expert opinion	Dementia general			This article presents the results of surveys of GPs re what help they want from specialist dementia services. Needs of GPs include: provision of adequate long-term dementia care, support for families and health care workers, rapid access to care, clear diagnosis, special needs of YOD, clear guidelines
Withall (2013)	Australia	The challenges of service provision in YOD	NA - editorial	Editorial	YOD			Briefly refers to current and ongoing Australian prevalence study ("Inspired") in eastern suburbs of Sydney and discuses psychosocial aspects and the issues raised for service provision
Woolley, (2013)	Australia	Hope Newsletter	NA	NA	YOD			An October 2013 update on the YOD Key Worker Program
Wylie et al (2013)	USA	Management of FTD in multidisciplinary settings	NA - discussion	Expert opinion	FTD clients & carers			Article re misdiagnosis of FTD as a mental health disorder. Provides clarification re how to differentiate and diagnose FTD. Also provides information for clinicians regarding management of FTD. A multi-disciplinary team approach is recommended

5.2 Findings from the Literature - Themes of Service Design

A review of the literature regarding younger onset dementia services and good practice models reveals that, as has been identified recently in regards to dementia services in general, the evidence for good practice is not based on empirical studies rather it is mostly the expert opinion of health professionals working with people with younger onset dementia or more recently from consumers. Key themes from the literature regarding service design and development can, however, be identified (Koopmans and Thompson, 2013).

At the system level, the overwhelming evidence from the literature identifies service integration as being critical, facilitated by multidisciplinary teams, streamlined pathways, service links and case management. These components should work together to support good practice and enhance client outcomes.

At the service level, people with younger onset dementia need to be directly consulted in the design and delivery of services designed to support them. Underpinning an individualised approach is the need for flexibility, to accommodate individual and family circumstances as they change over time.

The importance of these key features of service delivery is highlighted by consumers in the National Consumer Summit for Younger Onset Dementia, (Alzheimer's Australia, 2009). Brown et al (2012) also identified these service features as key requirements for services for younger people with younger onset dementia.

5.2.1 Service integration

Ferran et al (1996) were early advocates for younger onset dementia services characterised by a multi-professional diagnostic service, integrated and intensive community care, coordination of services and accessibility.

5.2.1.1Integration of services

A recurring theme in the literature regarding support for people with complex needs is the fragmented and diverse nature of the care and support system. Dementia care services have recently been described as resembling 'islands with limited bridges between them' (Callahan et al, 2013).

Bentham and La Fontaine (2008) highlight the importance of comprehensive services that provide assessment, diagnosis and treatment interventions as well as specific activity based services. The key feature of an effective younger onset dementia service identified by The Alzheimer's Society UK (2005) is one that 'addresses all needs in some way although it is unlikely that all these areas can be met by a single service provider. There needs to be a link between medical and service parts of the pathway' (Alzheimer's Society UK, 2005). Service integration leading to a planned program strategy designed to meet the needs of people with younger onset dementia is a key to good practice in a variety of settings ranging from rural and remote communities in Western Australia to central London (Moriarty, 2002). Bakker (2013) identified integrated diagnostic services as a critical element of service design and delivery for people with younger onset dementia. Features of an effective diagnostic service include ensuring causes of dementia and neuropsychiatric symptoms can be determined. This is backed up by a team of experts who can provide holistic comprehensive needs assessment,

psychosocial support and initiate the required support services. Calsyn et al (2004) acknowledged service integration as an essential, but often lacking, feature of services required to effectively support younger people with HIV/AIDS who also have a co-occurring diagnosis such as dementia.

5.2.1.2Multidisciplinary teams

Access to comprehensive and multidisciplinary diagnosis, assessment and treatment of symptoms is essential to enable younger people with dementia to maintain the key functions required for maintaining life skills for as long as possible (Alzheimer's Society UK, 2005; Mocellin et al, 2013; Wylie et al, 2013). Specific allied health interventions such as speech therapy to support communication skills; psychology to teach compensatory memory skills; occupational therapy to support and maintain skills related to activities of daily living; and other interventions such as modification to the person's environment to prompt memory and manage neuropsychological behaviours can all enhance a person's ability to maintain aspects of life such as employment, relationships and independence with activities of daily living (Kortte and Rogalski, 2013). Psychosocial support provided as crisis and ongoing counselling by psychologists or social workers and practical support with financial and legal matters provided also aid in supporting the person with younger onset dementia and their family in a challenging time of life. Other supporters of a multidisciplinary approach include Rose (2010), Elliot and Reed (2001), Kenny and Wilson (2012). Inter-disciplinary teams, where professional roles are blended and health professionals may take on roles from other disciplines, are also seen as effective models for providing support and care to people with younger onset dementia (Morhardt, 2001; Thompson et al, 2006).

5.2.1.3Streamlined pathways

The disjointed nature of the health and care sectors, with a mix of private, public and non-government organisations involved, makes it difficult for any one service provider to fully appreciate the matrix of services available to support the differential needs of their clients. Referral pathways have been developed for a number of complex care conditions, including dementia.

> A co-ordinated referral pathway should underpin any care system supporting younger people….benefits of a co-ordinated referral pathway include a clear route to assessment and diagnosis that supports easy access (Alzheimer's Society UK, 2005).

Hean et al (2011) also advocated the benefits of streamlined care pathways, with one point of entry, whereby timely referral, treatment and support are delivered to any patient irrespective of age.

5.2.1.4Service links

A corollary to the development of pathways is the importance of linking services. As Wylie et al highlight, the care of the person with dementia 'requires partnerships with the patient and the family/carer, and will usually include other healthcare providers and community agencies' (Wylie et al, 2013). It is essential that all parts of the care system – the health service, social services, and the private and voluntary sectors – work together to support younger people with dementia. Agencies should work in partnership and develop shared objectives to meet the needs of younger people with dementia (Alzheimer's Society UK, 2005). Alt and Beatty (2007) recommend from their review of existing HACC services in Northern Sydney that funding is

required to promote cross-agency, complementary problem solving, care coordination and client support irrespective of the agency's funding source. The development of local interagency protocols for supporting younger people with dementia was seen as a key feature in a successful service system.

5.2.1.5Case management

The NeedYD study conducted by Bakker (2013) and associates (van Vliet, 2012), provides valuable empirical evidence for the case management of people with younger onset dementia. Bakker recommended that 'a younger onset dementia case manager should be introduced to the person with younger onset dementia and their family at the point of diagnosis. This role would continue through the entire dementia journey to provide continuity of care and timely recognition of issues that may adversely affect the caregiving situation such as relationship problems, financial difficulties or difficulties in managing neuropsychiatric symptoms'. Bakker also notes that 'the early introduction of case management in the caregiving trajectory might even result in a reduction of service use in later stages of the caregiving trajectory and a subsequent reduction in care expenditures in younger onset dementia'. Case management as an important aspect of younger onset dementia service delivery is also supported by Minkman et al (2009) and Callahan et al (2013).

A core aspect of the newly established network of Younger Onset Dementia Key Workers positions in Australia is that of case co-ordination or case management. The approach to case management underpinning the Key Worker Role is that of consumer directed care as opposed to a more traditional model where the case manager is the 'expert' who controls the direction of the care. 'The role of the Key Worker is to support the person with younger onset dementia and their families to navigate and link to existing services, agencies and activities that meet their individual goal and needs, promoting wellness, independence, community engagement and improving their quality of life' (Warren, 2013, Woolley, 2013). The importance of the role of key workers in assisting people to navigate the fragmented and complex health and community care systems within Australia has also been identified by Brodaty & Cumming (2010).

5.2.2 Participation and inclusion of consumers; person centred service models

Much of the literature promotes the importance of consumer involvement with the design, delivery approach and evaluation of services for people with younger onset dementia (Alzheimer's Australia, 2009; Alzheimer's Society UK, 2005; Beattie et al, 2002; Brown et al, 2012; Bunn et al, 2002; Chaston, 2010; Miranda-Costillo et al, 2013; Harris, 2004; HammondCare, 2013, Hellstrom et al, 2007; Johansenn and Moller, 2011; Mitchell, 2012; van Baleen et al, 2011; and Whitefield; 2006).

Perhaps the most fundamental principle of service design and delivery in the literature is that services for people with younger onset dementia need to be individually tailored and 'person centred' (Beattie et al, 2002; Brown et al, 2012; Minkman et al, 2009; O'Connor et al, 2007). Features of person centred care include service plans that are developed with the person with younger onset dementia and their family and are based on their individual circumstances such as age, cultural background, gender as well as interests as preferences (Thompson, 2011).

Bakker (ADHC et al, 2013) notes that services need to design a service mix that supports comprehensive care and is flexible to meet individual needs of the person with dementia and their family, and that can be modified over time.

To effectively provide this type of care and support requires a different approach to that traditionally delivered by aged and health care services. It requires organisational commitment, structures and mechanisms to be put in place for consumer involvement, as well having staff with the appropriate skills and resources to support consumers in this capacity. Brodaty and Cumming (2010) note positively the increasing focus in dementia care training and research on a person centred approach. They endorse a person centred approach involving effective communication based on respect and dignity as one that would improve quality of life for people with dementia and their carers.

In the context of the current focus on 'person centred care', in both disability and aged care sectors in Australia, the importance of a balanced approach to service delivery is also critical. A recent text '*Designing and Delivering Dementia Services'* (De Waal et al, 2013) addresses current rhetoric concerning the 'person-centred approach' as a key principle of dementia service delivery and the inherent tensions that exist between the person-centred approach and the flexibility required to underpin it's delivery.

> 'Any service which has to say 'no, we can't meet that need' is already not person-centred the second and opposite truism is that there is no point in the approach 'we can do whatever it is you need us to do' if it can't be lived up to. A balance must be struck between a service being manageable and affordable (which likely predicts a degree of inflexibility) and being able to respond to someone's personhood, given someone's predicament. In other words without the latter, the service won't work for someone; without the former, the service won't work for anyone' (De Waal et al, 2013).

The ability to listen to and work collaboratively with people with younger onset dementia and their families and provide individually tailored services is essential to an effective younger onset dementia service. These vital features of younger onset dementia service delivery must be embedded into the service in the planning and design stage.

5.2.3 Specialised Younger Onset Dementia services

A strong argument exists in the literature regarding the need for specialist younger onset dementia diagnostic, treatment and support services (Beattie et al, 2004; Scott and Donnelly, 2005; Tindall and Manthorpe, 1997). Justification for establishing specialist services is largely based on difficulties experienced by people with younger onset dementia in obtaining a diagnosis and accessing appropriate supports in a timely manner in primary care (Chaston, 2011). This may be due to in part to the uncommon nature of younger onset dementia as well as a higher prevalence of the rarer dementias in younger people (Alzheimer's Society UK, 2005). Callahan et al (2013) report that researchers consistently document suboptimal quality of [dementia] care and poor outcomes and several studies have shown that primary care physicians often either fail to make a diagnosis of dementia or misdiagnose. For younger people the literature indicates even more problems with diagnosis of younger onset dementia in primary care.

Brodaty & Cumming (2010) also describe the barriers to early diagnosis that exist in the Australian general practice context, including the:

> 'therapeutic nihilism surrounding dementia', perceived lack of time, skill and remuneration, and difficulties with communication and disclosure of the dementia diagnosis. Providing dementia training to the increasing number of practice nurses in general practice may offer part of the solution'.

Williams (2000) confirms from a survey of GPs that they do want support from specialist services in the diagnosis and ongoing management of people with younger onset dementia, and in supporting their families.

Perhaps the most compelling argument from the literature in favour of specialised dementia services for diagnosis and symptom control is the following:

> 'In the last 15 years symptomatic treatments for dementia have become available. Alongside these, growing evidence bases of non-pharmacological interventions for dementia and treatment of neuropsychological symptoms have developed…. The benefits of early diagnosis and thus access to treatment are now clear and this has led to developments in setting up of dementia specific services in the developed world' (Livingston and Cooper, 2013).

Bakker's NeedYD study provides empirical evidence regarding the benefits for people with younger onset dementia and their carers of a timely diagnosis to facilitate the initiation of appropriate care and support, especially given the long periods these younger individuals are cared for at home. Specialised support programs aimed at enhancing the caregivers' sense of competence and ability to deal with neuropsychiatric symptoms, especially apathy, may reduce the risk for institutionalisation in younger onset dementia (Bakker, 2013).

An evaluation of the Croydon Memory Service Model found that this model of a specialist dementia diagnostic and care service 'appears to have high acceptability, accessibility, and effectiveness in increasing the numbers of people provided with diagnosis and care in a population'. Those receiving such services appear to improve in terms of quality of life and behavioural and psychological symptoms of dementia'. (Banerjee et al, 2007).

Responsibility for care and support for people with younger onset dementia is often spread across various sectors – those for older people, adult mental health, adults with disabilities – with the age of the client and/or pre-existing condition rather than specialist knowledge the determining factor. Carers and professionals are confused about where to seek support and younger people are unlikely to encounter those with specialist knowledge of their needs…a differential diagnosis is very important (Alzheimer's Society UK, 2005).

Establishing major specialist inpatient and outpatient services for younger onset dementia may only be economically viable in major cities in Australia, due to the low prevalence rates of younger onset dementia and the dispersed population base in Australia compared to UK and Netherlands where specialist services have been established. In the absence of younger onset dementia specific diagnostic or support services, specialist dementia services can provide effective diagnostic services and support to people with younger onset dementia and their

carers if staff receive appropriate education regarding younger onset dementia and the special needs of people with younger onset dementia and their families. Smaller regionally based services, outpatient, outreach, 'hub and spoke' and telemedicine service models are considered appropriate for providing access to specialist services in regional, rural and remote areas (ADAHPS, 2013; O'Connell, 2013). In very remote, disadvantaged communities service models that address social determinants of health using a community capacity building approach are effective in addressing the basic service needs present in these communities.

5.2.4 Age appropriate services

The need for 'age appropriate' services for people with younger onset dementia is also identified in the literature (Beattie et al, 2004; Brown et al, 2012; Chemali et al, 2012; Hunt, 2011; Tolhurst et al, 2012; Alzheimer's Australia, 2009) as a major issue. In many instances the lack of age appropriate services is due to both a lack of awareness of younger onset dementia in aged care services and support services designed for frail aged people with dementia not being appropriate for people with younger onset dementia. Reed et al (2002) analysed consumer responses regarding service needs. Findings from this study provide an alternative approach to just considering age as the primary indicator of service appropriateness for younger onset dementia. Consumers indicated that services that are sensitive to individual needs with staff that are responsive are more important than services that are 'age appropriate' per se. This highlights the need to ensure that services responses to people with younger onset dementia are individually tailored and provided by suitable trained staff. This, unfortunately, is not the basis of many aged care dementia programs and services and may in fact be the primary reason for these services being inappropriate for younger people with dementia.

5.2.5 Younger Onset Dementia service needs and service utilisation

Issues concerning service needs and service utilisation have been discussed in Section 1. However, the literature available indicates there is quite a long period from onset of symptoms to permanent residential care placement for people with younger onset dementia (e.g. often between 6 and 9 years) and that the level of informal care provided is high which places a significant burden on these families/carers. Although some studies indicate a relatively high use of institutional services for the younger onset dementia group (e.g. hospital admissions, nursing home respite etc.) authors also report that generally community service use is relatively low for this group. It is suspected this is due to a number of factors including a lack of information provision about available community support services and thus a resulting lack of awareness concerning the usefulness of such services for both the carer and the client. However, the lower use of services can also reflect carer and client characteristics and ambivalence or concerns about the use of some services particularly when these are not always age appropriate.

Bakker (2013a) found from the NeedYD study that apathy in younger onset dementia clients significantly predicted time of institutionalization. Furthermore, the caregiver's competence in caring for the person with dementia significantly predicted institutionalization. For younger onset dementia services these findings indicate that the provision of carer and family support and education is an essential component to younger onset dementia services. Thompson (2011) also reported the importance of a family centred approach to younger onset dementia services. Alzheimer's Society UK (2005) identified input by carers as a key feature of service design and development. The Younger Onset Dementia National Summit (Alzheimer's Australia, 2009) highlighted the need for younger onset dementia services to be innovative, flexible and responsive to the needs of carers, partners and children of people with younger onset

dementia (Alzheimer's Australia, 2009). Sait et al (2012) in a survey of younger onset dementia service requirements identified support for working carers as important.

A range of other factors can influence service utilisation. Life expectancy following a diagnosis of younger onset dementia may vary across the various types of young onset dementia. This can impact on rates of service use by people with younger onset dementia. (Brodaty et al, 2012).

For people with dementia who live alone, services may be required to take a more active and comprehensive role in supporting the person to remain in their home than for a person who is well supported by a live in carer. (Sait et al, 2013).

The cost effectiveness of non-institutional long care services in the USA was reviewed in a study by Grabowski (2006). Findings indicated that, in general, the evidence concerning current models was relatively weak. The study did find that care models associated with higher costs also had greater client and caregiver welfare. Capitated care models were identified as having potential to be cost efficient service delivery models.

Another important aspect of younger onset dementia service delivery identified in the literature that needs to be taken into consideration by both policy makers and service providers is that, due to the life stage of younger people, many people with younger onset dementia and their families experience financial hardship and are unable to pay for care services. A flexible fees policy is required to ensure people with younger onset dementia and their carers are not excluded from receipt of essential support services due to financial hardship.

In view of the findings above authors have suggested the need for a central gateway to services for people with younger onset dementia or the adoption of case-management and key worker approaches. However, there were relatively few studies that comprehensively examined service utilisation and the costs of illness for the younger onset dementia group or that included consideration of social and informal care costs. Further research in this area is required.

5.2.6 Services for specific Younger Onset Dementia diagnostic groups

The wide range of diseases that can result in younger onset dementia, specified in the first section of this review, requires that younger onset dementia services are flexible enough to meet the needs of each individual. A service response for a person with early onset Alzheimer's disease may look very different to services for people with Huntington's disease, HIV/AIDS dementias, Down syndrome or ARBD. Younger onset dementia service providers need to form effective interagency working relationships with other disease specific services that provide support to the person with younger onset dementia. Withall (2013) states that people with dementia attributable to alcohol or other substance abuse are often particularly isolated clients, who are usually estranged from family members. Due to their isolation and often associated homelessness, they may require a more basic level of service such as housing and additional care services (MacRae and Cox, 2003; Rota-Batelink & Lipmann, 2007).

Casylin et al (2004) found that people with HIV/AIDS and other health conditions including cognitive problems, frequently do not receive adequate treatment for one or more of their illnesses due to fragmentation and 'silos' between diagnosis specific services. They

recommended services need to be integrated, flexible and utilise a case management approach to ensure clients receive appropriate support.

NSW Health has developed a specialist HIV/AIDS service 'ADAHPS' for people who have HIV and complex needs such as HIV associated dementia and/or HIV and mental illness. ADAHPS is a specialist state-wide service. It consists of a multidisciplinary team of health workers and uses a case management approach. The ADAHPS service delivery model has a single entry point to a 'hub and spoke' service consisting of medical specialists and rural outreach workers and a residential care facility. ADAHPS is an integrated holistic model with key partner agencies such as housing, justice, hospitals, public trustee and GPs (NSW Health). The ADAHPS service model, if evaluated and confirmed as effective, could be mirrored by State and Territory health services as an appropriate service model for younger onset dementia.

Carling et al (2012) in a study of people with Downs Syndrome and Alzheimer's disease identified a complication in the diagnosis of younger onset dementia where there is already a primary diagnosis which may cause similar behaviours. In this situation the presence of younger onset dementia may not be considered. This situation, known as 'overshadowing', was found to be most evident when families interacted with services that lack knowledge or understanding of intellectual disability and the potential for Alzheimer's disease, particularly for people with Down syndrome.

In areas of higher population density, disease specific diagnostic and support services can be established. Kenny and Wilson (2012) found that a specialised multidisciplinary service developed for people with Huntington's disease that provided users with a single point of contact and easy referral into the system was effective in supporting people with Huntington's disease.

To assist families and organizations in their planning for extended care that accompanies the diagnosis of dementia, the National Task Group on Intellectual Disabilities and Dementia Practices (NTG) in the United States adopted a set of practice guidelines covering the period from when suspicions are aroused to when care ends with eventual death (Jokinen et al, 2013). National Guidelines such as these could be developed for all of the diseases that can result in younger onset dementia. These would assist service providers to consider if an individual may have younger onset dementia and to seek appropriate assistance from a specialist younger onset dementia service.

5.2.7 Young Onset Dementia and special needs groups

In addition to the broad range of diagnostic groups that constitute younger onset dementia, people with younger onset dementia may also belong to a special needs groups such as Aboriginal and Torres Strait Islanders, people from culturally and linguistically diverse backgrounds (CALD); people who identify as lesbian, gay, bisexual, transgender and intersex; people who are homeless or at risk of homelessness; people living alone; people in rural and remote communities etc. In Section 7 particular issues for special needs groups are discussed in more detail.

The fundamental principle for design and delivery of services for people with younger onset dementia who also have special needs, is designing flexible 'person centred' services that can

be individually tailored to meet the additional special needs of the person (Brodaty and Cumming, 2010; Brown et al, 2012).

In regards to special needs group, some key points have been drawn from the literature. Alt and Beattie (2007) highlighted the need for special consideration in service delivery of the family and cultural expectations of people with younger onset dementia from CALD backgrounds. For people living alone, additional formal and informal supports are required (Sait et al, 2013). Other service design considerations include building effective linkages with formal and informal cultural and community groups to increase awareness of younger onset dementia and ensure access to younger onset dementia services (Banerjee et al; 2007) and that staff receive cultural competency training (Brown et al, 2012). Special consideration is required regarding isolation and expenses related to access to services by people from rural and remote communities (Saunders, 2013). People with younger onset dementia who are homeless will require access to appropriate accommodation options (Rota-Batelink and Lipmann, 2007).

The literature also highlights that further research into special needs groups and younger onset dementia is required.

A recommendation to the Australian Government from the 2009 Younger Onset Dementia National Consumer Summit regarding people with younger onset dementia and special needs was that funding be provided to each Alzheimer's Australia State and Territory Office to employ a dedicated worker to build partnerships with special needs group organisations on issue relating to younger onset dementia (Alzheimer's Australia, 2009).

5.2.8 Theories and approaches underpinning the development of services for people with younger onset dementia

Apart from the literature related specifically to services for people with younger onset dementia there are some theoretical constructs in the general psychological literature that are relevant to the development of services for people with younger onset dementia. It is important that services for people with younger onset dementia are designed, developed and implemented on a sound theoretical basis. Service providers when designing services for people with younger onset dementia and their carers need to consider how the structure of their service enables them to achieve the best outcomes for their clients. Taking time to strategically plan services based on accepted theories and approaches is an important factor for successful service delivery.

The theories on which a service is based will impact on how the service is provided and its impact on consumers. Examples of four social theories and how they relate to younger onset dementia service design and development are provided.

5.2.8.1Maslow's Hierarchy of Need

In light of the focus of service delivery for people with younger onset dementia into the future being based on individually tailored support being provide to consumers to enable them to maximise their independence, Maslow's motivational theory of need provides a context for applying approaches such as consumer directed care, reablement and wellness approaches to service delivery.

McLeod (2007) in discussion of Maslow's Hierarchy of Need, stated that people are motivated to achieve certain needs and that there is a hierarchy of needs. Basic needs such as

physiological needs, safety, social needs, love and esteem need to be addressed before higher level needs such as cognitive, aesthetic and self-actualization needs can be addressed. One must satisfy lower level basic needs before progressing on to meet higher level growth needs. Once these needs have been reasonably satisfied, one may be able to reach the highest level called self-actualization.

Each individual with younger onset dementia will be at different stages or 'levels within the hierarchy of need' in their life throughout their journey with dementia. Therefore, service providers need to be able to respond flexibly to individual clients and target support and services appropriately for each client to address needs, preferences and goals. For example, a client in the later stages of dementia with special needs such as chronic homelessness and who has no family or who lives in a remote location in sub-standard housing, will require a more basic level of service provision than another client in the early stage of dementia that has adequate housing and a supportive family. Due to the many stressors often present in the life of a person with younger onset dementia at any time the situation of the person may change significantly and the services provided will need to be changed to ensure they are still meeting the current needs of the person with younger onset dementia and their carer. People with younger onset dementia who live alone, without a primary support person nearby, will need additional support services to meet these basic needs than someone who lives with a supportive partner.

5.2.8.2 Bradshaw's theory of needs identification

One of the most important foundations of effective service provision is 'needs assessment'. If a person's needs have not been assessed thoroughly and utilising a person centred approach, it is highly likely that and support and service offered will not appropriately meet the needs of the younger person with dementia:

> 'A thorough understanding of (un)met needs of these patients and their caregivers by health and community care professionals should be considered a prerequisite for establishing appropriate help and support. A better understanding of the needs and wants of these families will allow health care professionals aim at empowering these patients and caregivers in retaining control over the caregiver situation and designing services that can complement informal care' Bakker et al (2013b).

Needs assessment is not a one off event; rather it is best seen as an ongoing process (Sansoni et al, 2012). The process of identification of a person's needs is a complex and multi-faceted. Bradshaw (1972) proposed four types of social need. These are:

- Normative need – this is referring to what the 'expert' or professional defines as need. If a client is identified as falling short of an identified standard then they are identified as being in need. As such, normative needs are often not needs that a client would necessarily identify themselves without the assistance of a trained assessor and or health professional. An example of normative need for a person with younger onset dementia would be an assessment that identifies the need for a range of allied health therapies to support the person to remain in the workplace or improve independence in undertaking activities of daily living.
- Felt need – here need is equated with want. When assessing the need for a service, the client is asked if they feel they need the service. Felt need is by itself an inadequate

measure of 'real need'. It is limited by the perceptions of the individual – whether they know there are services available, as well as reluctance in many situations to confess to a loss of independence. In relation to people with younger onset dementia, for many who are still in the early stages of the disease, they may not identify with the concept of 'service provision' and so may state that they do not have a need for services. If asked if they would like some help to get back to doing some of the things they used to enjoy but haven't been able to do lately such as a hobby or physical activity they may happily agree to such a service.

- Expressed need – or demand is felt need turned into action. Under this definition, total need is defined as those people who demand a service. Services will usually only be demanded by people who feel a need, however, it is also common for felt need to not be expressed by demand. Expressed need in commonly used in health services when waiting lists are taken as a measure of unmet need. Waiting lists are generally accepted to be a poor definition of 'real need' – especially for pre-symptomatic or undiagnosed cases.
- Comparative need – this refers to a measure of need found by studying the characteristics of those in receipt of a service. If people with similar characteristics are not in receipt of a service, then they are in need.

Although developed a number of years ago, Bradshaw's 'taxonomy of social need' is very relevant as a theory of needs assessment that underpins service development for people with younger onset dementia. Accurately determining the 'real' care needs of younger people with dementia i.e. 'needs assessment' is therefore a complex, exploratory interpersonal process that should be undertaken by suitably trained and skilled assessors in order to be effective.

5.2.8.3 The Behavioural Model

The behavioural model (Andersen in Bakker, 2013) can be applied to people with younger onset dementia and their carers in each unique situation to determine key factors in the use of services. The behavioural model suggests that people's use of community and residential care services is a direct result of their past tendency to use services including if past experiences were positive or negative, as well as their care needs. A person's social context, cognitive abilities, age, gender and their beliefs regarding health and health care services all contribute to their willingness to accept services. Knowledge regarding services and ease of access to services is also a contributing factor. If a person is limited in access due to financial difficulties, geographic isolation or as service not being culturally appropriate then they are less likely to use services.

5.2.8.4 Theory of Integration - Leutz

Much of the literature regarding younger onset dementia service provision advocates for service integration as an effective model of service provision for people with younger onset dementia (Alt and Beatty, 2007; Alzheimer's Society UK, 2005; Bakker, 2013; Brown et al, 2012). However, integration can mean different things to different people. There are many references in the literature to terms such as integration, continuity, coordination, collaboration, partnerships and 'improving links', but little consensus on what these terms mean. One review of the literature found 70 terms and phrases linked to the concept of integration and 175 definitions and concepts (Armitage, 2009). The most useful conceptualisation of integration we have found is the work of Leutz who proposed three types of integration – linkage,

coordination and full integration – and five laws of integration. One of the advantages of the five 'laws' is their simplicity, which is useful for understanding a complex subject:

- You can integrate all of the services for some of the people, some of the services for all of the people, but you can't integrate all of the services for all of the people.
- Integration costs before it pays.
- Your integration is my fragmentation.
- You can't integrate a square peg and a round hole.
- The one who integrates calls the tune (Leutz, 2005).

Leutz later reframed the 5th law as 'put the right person/organisation in charge of integration', in recognition of the fact that different people can develop different solutions to the same problem of service fragmentation. Leutz effectively added a 6th law in 2005 ('all integration is local') because whatever is done has to be adapted to the local context (Leutz, 2005).

When developing integrated services, service providers who consider Leutz's laws of integration will be able to ensure that in their aim to 'integrate' their service they have not in fact fragmented it or excluded some people with younger onset dementia from accessing appropriate support.

5.3 Features of effective Younger Onset Dementia services

From the literature review a number of key issues have been identified that are critical for the development of effective service provision for people with younger onset dementia and these are summarised below.

5.3.1 Inclusion of people with Younger Onset Dementia in service planning

Inclusion of people with dementia in planning and decision making about health service and programs has been identified as a key theme in the literature (Alzheimer's Society UK; 2005; Alzheimer's Australia, 2009; Whitefield; 2006).

5.3.2 Respect and consideration

The Florence Centre in the Netherlands has been established as a specialist younger onset dementia service. A full range of services is provided including: day activities programs, information services, diagnostics, treatment and support; and respite and residential care. The objective of the Florence Centre is caring for people in a respectful manner (Florence Centre, 2011). Respect and consideration are important aspects of effective individualised care services.

5.3.3 Appropriately skilled and suitable staff

Younger onset dementia services need to ensure that staff receive appropriate training concerning younger onset dementia to enable them to provide the required service and supports. Staff employed to work with people with younger onset dementia also require a different skill mix to meet the unique needs of younger people with dementia (Alzheimer's Society UK, 2009).

Alt and Beatty (2007) recommended that all health and community service professionals encompassing neurologists, nurse practitioners and allied health professionals participate in dementia awareness training. Thompson (2011) recommended that staff are not only suitably trained and skilled but that they are supported and supervised in undertaking what can be complex and challenging work. Alzheimer's Society UK (2005) also highlighted the demanding nature of working with people with younger onset dementia. Staff need to have well developed coping strategies relating to loss and bereavement and feel comfortable speaking to people the same age as themselves about having dementia. They also need to be able to support young families and children.

5.3.4 Dementia friendly environments

Services need to create environments that support social connection, a sense of self and that maximise independence for the person with younger onset dementia in their home, community and places of service delivery. Services need to recognise the importance of physical, organisational, and cultural environments to enable staff to be person-centred in the way that they interact with people and their families (Thompson, 2011).

5.3.5 Timely services

The services and support offered needs to be timely and responsive to the progression and complexities of dementia; from early identification, early intervention, referral and family support. The flexibility to increasing services to support people to continue to live in their own home and avoid premature entry into residential care is also required (Thompson, 2011).

5.3.6 Effective risk management

Working with younger people [with dementia] requires that care professionals push the boundaries in taking risks. Younger people may want to take part in activities where there is a higher level of risk involved. Over time, however, the client's perception of risk is likely to decline. Staff need to negotiate the transition to lower risk activities positively. The service also needs to create and maintain a healthy and safe environment for staff members and all care services must meet the requirements of the Commonwealth, State and Territory work, health and safety legislation. The staff ratio in services for younger people with dementia needs to be high, such as one staff member to two [clients], not including volunteers. There is no recommended ratio. The requirement will depend on the individuals involved and the type of activities undertaken (Alzheimer's Society UK, 2005).

5.3.7 Other factors

Alzheimer's Society UK (2005) has also identified some additional factors relevant to designing younger onset dementia services. These are:

- Capacity building - involve people capable of effecting change in the process of service development;
- Organisational change – identify people within the organisation as key contacts and develop effective referral pathways;
- Suspending and withdrawal of services / exit policy - as client's needs become greater, service providers may feel pressured to continue to work with them because the only

alternative appears to be residential care. For this reason services need to establish a clear policy on when a person's needs may require a different type of service.

5.4 Summary Principles for Design and Development of Services for People With Younger Onset Dementia

As evidenced in the discussion regarding themes of younger onset dementia service design and delivery, and as outlined in the section above, there is general consensus in the literature regarding what can be described as 'guiding principles' for developing services for people with younger onset dementia.

Following is a list of guiding principles for younger onset dementia service design and delivery identified from the literature. The list has been grouped in three main categories of principles of service design:

Individualised model of service:

- Listening to people with younger onset dementia and their carers
- Individualised service planning / a person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognition of the diversity among the many younger onset dementia diagnostic groups and the special needs of individuals.

Staff attributes:

- Appropriately skilled and suitable staff
- An holistic approach
- An enabling and consumer centred approach
- Case management skills
- Effective communication
- Flexibility.

Organisational attributes:

- Access to integrated specialist diagnostic and ongoing symptom management services
- Capacity for organisational change
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Ability to cater for needs of people in rural and remote communities
- Individualised service planning / person centred approach

- Respect and consideration for clients and carers
- Effective risk management strategies
- Appropriate exit policies relating to the suspension and withdrawal of services.

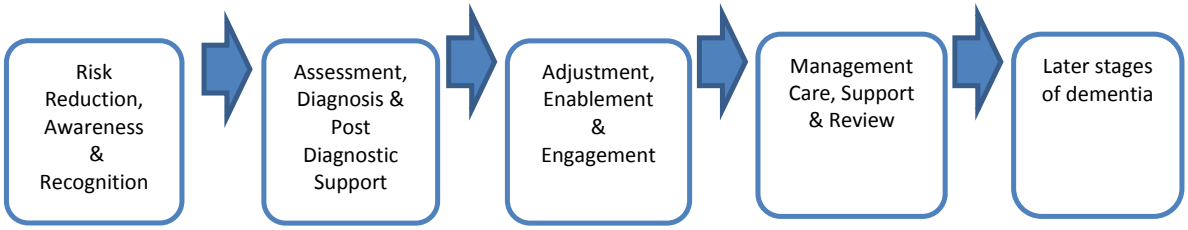
5.5 Stages of Younger Onset Dementia and Service Design and Development

This section has been structured around the phases / stages of the disease trajectory of younger onset dementia. At each stage of the younger onset dementia journey, services need to align with the Guiding Principles outlined in the previous section. In addition to the Guiding Principles, critical elements for service design and delivery are provided below.

The concept of stages of the younger onset dementia disease trajectory is reflected in the literature as a useful concept for developing service responses for people with younger onset dementia (Bakker et al, 2010; Bakker, 2013; Brown et al, 2012; Keedy and Nolan, 1999).

The *Draft National Framework for Action on Dementia 2013 – 2017* (DoHA, 2013), uses four stages of dementia that relate to service delivery and design. These are: Risk reduction, awareness and recognition; Assessment, diagnosis and post diagnostic support; Management, care support and review; and End of life. During the consumer consultation phase of this project, an additional stage of dementia experienced by a younger person was identified. We have labelled this stage 'Adjustment, enablement and engagement'. It sits after 'diagnosis' and before a person with younger onset dementia begins to access 'care and support services' in the manner usually expected of an older person. Key elements of this stage are the adjustments in life made in response to the diagnosis of dementia. These are in areas of life such as: addressing relationship breakdown issues in their primary, family and social relationships; developing new skills and strategies for remaining at work; and establishing financial and legal plans for the future. If people with younger onset dementia are appropriately supported and assisted during this critical stage they may be able to maintain their independence for as long as possible as well as preserving a sense of a 'normality' and 'control' in their changing life.

Figure 1 Five stages of Younger Onset Dementia support



5.5.1 Stage 1: Risk reduction, awareness and recognition

Despite recent efforts to raise awareness of younger onset dementia in the health, aged care and disability service sector and in the general community, there remains a widespread lack of cognisance by many people of the existence of younger onset dementia. The 'stigma' attached to younger onset dementia in many instances resembles that of many mental health conditions in the past. This increases stress and feeling of isolation for both the person with younger onset dementia and their carer.

Critical elements of effective service delivery include:

- Nationally consistent, accurate information regarding risk reduction, awareness and recognition of younger onset dementia should be available in a range of modalities – phone, website and Facebook. This information needs to be translated into community languages and be respectful of cultural diversity
- Resources regarding risk reduction, awareness and recognition of younger onset dementia need to be specifically tailored to each of the younger onset dementia diagnostic groups which could be developed by Alzheimer's Australia in consultation with peak organisations for the various diagnostic groups. Branding of these resources may need to be modified and disease specific as some younger people with dementia who do not have Alzheimer's disease may not want to access information produced by Alzheimer's Australia until they feel more comfortable with the organisation and what they can offer. An example may be an information brochure regarding dementia and Huntington's disease. The dementia specific content may be developed by Alzheimer's Australia and the brochure would also have disease specific content regarding Huntington's disease developed by the Huntington's Association but the information would be branded as a Huntington's disease information brochure, with acknowledgement of the contribution of Alzheimer's Australia.

5.5.2 Stage 2: Assessment, diagnosis and post diagnostic support

Delays in diagnosis delay the ability of the person with younger onset dementia and their family to receive the required support and services in order to minimise the impact of younger onset dementia on their lives. Due to a lack of awareness of younger onset dementia in general practice, the low level of prevalence of the disease, and the stigma that surrounds dementia, GPs may be reluctant to diagnose younger onset dementia or to refer to a specialist for diagnosis and support.

Critical elements of effective service delivery include:

- Specialist, integrated diagnostic clinics offering ongoing support and symptom control
- Education of GPs and referral pathways from primary care to specialist services
- A suite of clinical diagnostic tools, including culturally appropriate tools for culturally diverse communities, be developed to streamline and standardise the assessment of younger onset dementia. Training for health workers regarding use of the tools and possibly financial incentives for GPs may be needed to encourage the uptake of such tools into practice (Alzheimer's Australia, 2009)
- A network of younger onset dementia key workers to support people who may suspect they have younger onset dementia and their families in navigating the health system to obtain a diagnosis and receive the required treatment and ongoing support (Thompson, 2011).
- Resources to support genetic testing and counselling (Alzheimer's Australia, 2009).

5.5.3 Stage 3: Adjustment, enablement and engagement

Given the stage of life that many are at when they receive a diagnosis, i.e., with family responsibilities, employment, mortgages etc., receiving a diagnosis of dementia can be a devastating experience and the prospect of living with dementia can pose many immediate and future challenges. The experience of many people immediately following a diagnosis of

dementia has been described as 'prescribed dis-engagement'; that is, they are advised to quit their jobs, organise their finances and get their affairs in order in the expectation that there is no hope or future. This in turn:

> 'sets up a chain reaction of defeat and fear, which negatively impacts a person's ability to be positive, resilient and proactive' (Swaffer, 2012).

There is likely to be quite a period of time to pass once diagnosis has been made and, for some, *'their whole life becomes about dementia and many seem to forget to keep living the other parts of their lives'* (Swaffer, 2012). This perspective is reinforced by the prevailing policy paradigm that is outlined in the Draft National Framework for Action on Dementia 2013 – 2017 (Australian Department of Social Services, 2013), which has focused on the person moving from a point of independence at pre-diagnosis, to one of dependence on community and medical care post-diagnosis. What appears to be missing in the research, policy and service delivery sectors is a focus on how to enable people with younger onset dementia to continue to have meaningful engagement in family, social and community life for as long as possible.

Critical elements for service design and delivery in helping people with younger onset dementia adjust include:

- In the early stage of dementia, support is required to enable the younger person with dementia to maintain 'normal' life responsibilities as much as possible. This stage of dementia is seen as one that is 'pre-service use'. The specific interventions required will vary for each individual, however common needs at this stage are: individual, relationship and family counselling; education and support for workplaces to enable the person to continue working as long as possible; continuation (perhaps with some adaption for safety) of driving; leisure, sporting and community based activities; planning for changes in financial and legal matters (such as putting in place Enduring Power of Attorney and Enduring Guardianship orders); providing information to the person with dementia regarding technology based memory aids and social media support networks.
- Enablement approaches to providing support based on the person with younger onset dementia setting and achieving goals that build on strengths. Active and early support for carers to enable them to continue in employment and maintain other key life tasks such as raising children and participation in social and hobbies / interests throughout the caring journey.

5.5.4 Stage 4: Management, care support and review

The ongoing management, care and support services need to be individually tailored, age appropriate and flexible to meet the changing needs of the person with dementia and their carer / family.

Critical elements for service design and delivery include:

- When required, support for the person with younger onset dementia to transition out of employment and assisting them to access superannuation or Centrelink payments.
- Programs with a focus on providing meaningful and normalising social and physical activity for the person with younger onset dementia.

- Activity and support programs for the person with younger onset dementia with flexible hours that can cater for the needs of the carer and other family members such as children.
- Individualised services that offer a multidisciplinary team of health professionals such as medical specialist and a range of allied health professionals. The focus of services should be to enable the person with younger onset dementia to maintain their normal functions of life for as long as possible. This will include the effective management of neuropsychological symptoms such as apathy or aggression. Where it is not possible to establish an integrated specialist service, such as in rural and remote areas effective interagency service networks are require between local health workers and larger city based specialist services. This may involve the use of telemedicine and outreach clinics.
- Support networks for people with younger onset dementia their carers and family members. These may be face to face or via social media.
- Health and care staff that provide services to people with younger onset dementia need to be adequately trained and supported.

5.5.5 Stage 5: Later stages of dementia (end of life)

In the later stages of younger onset dementia when care needs have increased beyond what can be provided for in their home, many people with YOD will require permanent residential care. This needs to be provided in a flexible, dementia friendly environment.

Critical elements for service design and delivery include:

- Long term residential respite and permanent care options that cater for the special needs of people with younger onset dementia and is not just placing people with younger onset dementia alongside older people in aged care facilities.
- Appropriate palliative and end of life care.

5.6 Existing Approaches/Policies of Service Delivery

Younger onset dementia services have developed spasmodically in Australia, mostly within the context of aged care service provision. Currently the few services in Australia available for younger people with dementia, who are still living in the community, are primarily funded through the Home and Community Care (HACC) Program. These services include social / day activity groups, memory cafes and a range of carer support services. Alzheimer's Australia has played a critical role in driving the development of younger onset dementia services in Australia. Reflecting on the current situation in Australia in regards to younger onset dementia service delivery, Koopmens and Thompson (2013) state:

> 'While dementia generally has achieved significant public awareness through the work of advocacy groups over the last two decades, recognition of younger onset dementia in Australia is only just emerging….Younger Onset Dementia services are, in general, ad hoc. Compared internationally, Australia has a small population spread over vast areas, with most living in coastal regions. Finding enough people living with younger onset dementia in a geographically similar area to offer financially justifiable specialist services is difficult'.

Alt and Beatty (2007) identified two younger onset dementia specialist service models in their review of existing HACC services in Northern Sydney. These are a social support model for younger onset dementia and a club or excursion oriented model. For those people with younger onset dementia who also experience 'behaviours of concern', a quick response capacity to deal with behaviours of concern was available. At the time of the report, these service models only existed in Northern Sydney. Further information regarding programs for people with younger onset dementia is provided in Section 6 of this report.

In recent years, both within aged care and disability service provision, there has been a 'shift in focus' of service provision from a 'dependency approach' where a standard set of services were provided to the service recipient to an 'enablement approach' with a strong focus on assessment of the individual needs, wants or goals of the person or their potential to improve their physical function, health and wellbeing over time.

More recently approaches to HACC service provision that have been widely adopted in Victoria and Western Australia, have focussed on 'wellness' and 'restorative care'.

> The Wellness Approach is a philosophical change in the thinking behind and delivery of Home and Community Care (HACC) services in Western Australia (WA). In March 2006, the WA HACC Program adopted a Wellness Approach as its policy position for the future delivery of HACC services across the state. The Wellness Approach is an initiative which explicitly focuses on building client capacity' (Community West, 2013).

Due to the individualised, goal focussed and capacity building aspects of the wellness approach, services delivered within the 'wellness' paradigm, reflect the principles required for good practice in service delivery for people with younger onset dementia:

> 'The Victorian HACC Active Service Model is a quality improvement initiative that focuses on promoting capacity building and restorative care in community care service delivery. The Victorian HACC Active Service Model is based on the premise that all clients have the potential to make gains in their wellbeing and that Home and Community Care services can improve their capacity to make gains. The approach is to strengthen good practice and build capability among service providers' (Victorian Department of Health, 2013).

Similar in nature to the 'wellness approach', however broader in scope, the active service model also reflects key principle for service delivery for people with younger onset dementia.

In some aspects, not dissimilar to the concepts of 'wellness' and the 'active service model', the concept of 'reablement' has been adopted by some HACC and community care service providers and is becoming more prominent in discussions regarding approaches to service delivery.

> 'Reablement is defined as the use of timely assessment and targeted interventions to assist people to maximise their independence, choice and quality of life and minimise support required – to enable people to actively participate and remain engaged in their communities' (DoHA, 2013).

Consumer Directed Care (CDC) is a service approach that is strongly supported by some consumer groups in Australia as the preferred approach to delivery of community care services.

> 'CDC is a way of delivering services that allows consumers and their carers to have greater control over their own lives by allowing them to make choices about the types of care and services they access and the delivery of those services, including who will deliver the services and when' (DoHA, 2013).

As part of the *Living Longer Living Better* aged care reform, over the next few years there will be a phased move towards all Home Care Packages and the new Home Support Program (former HACC services) being provided on a Consumer Directed Care basis.

Both reablement approaches and Consumer Directed Care have the fundamental premise that services delivered following these approaches are individually tailored to meet the needs and goals of the consumer, and have the potential to significantly benefit those younger onset dementia clients who receive Commonwealth aged care services. Some concerns from the literature, however, about the implementation of models such as CDC needs to be heeded by policy makers and service providers.

In the USA, CDC has been adopted as the approach for home and community care programs. Putnam et al (2010), in a study of family caregiver perspectives on policies that support family needs related to providing care to relatives with dementia, found that:

> 'people with dementia are often excluded from consumer-directed home and community based service programs because they cannot direct their own care. Surrogates are permitted in some states, thereby allowing program participation….Family caregivers reported difficulty in acquiring services, high levels of psychological and physical stress, greater need for caregiving supports, and a desire for public policy change to support caregiving families….[and] suggested that surrogate decision making within consumer-directed care should, at a minimum, be an available option.'

Further to difficulty with access to CDC based services expressed by family caregivers is the need to consider the implementation of a CDC approach in the context of a person with younger onset dementia who lives alone and is no longer able to direct their own care but can be effectively supported in their home environment by community care services. The report *'Living Alone with Dementia*', (Sait et al, 2013) highlights the problem of Government policy being too heavily influenced by organisations that represents the interests of carers of people with dementia as:

> 'policy implementation which perpetuates reliance on carers and overlooks the needs of people without co-resident carers. As a result, people living alone with dementia are a cohort that tends to slip through the cracks in policy and service provision.' (Sait et al, 2013).

Not only would surrogate decision makers need to be considered for people with younger onset dementia in this instance; these surrogate decision makers would need to be able to be

considered as 'non-resident' carers. This issue has been a limitation in the past for access to Commonwealth funded aged care packages, such as the Extended Aged Care at Home (EACH) packages. As the Commonwealth transitions all home care packages to a CDC model in the coming years, for those people with younger onset dementia who may still require access to such services due to a lack of alternate State funded disability services, strategies for addressing the problem of surrogate decision making need to be developed and included in program guidelines for these younger onset dementia clients.

5.7 Overview of Current Australian Service Delivery for People with Younger Onset Dementia

5.7.1 HACC services

As mentioned previously in this section, the majority of community based services that have been developed for people with younger onset dementia have been funded under the Home and Community Care (HACC) program. Recent changes to the administration of this program will impact on these younger onset dementia services.

Prior to 1 July 2012, the HACC Program was a joint Australian, state and territory government Initiative under the *Home and Community Care Act 1985*. This Program funded services for older people, younger people with disabilities, and their carers and evolved significantly from its inception in 1985. Substantial growth in funding from governments has increased the range and volume of services provided to eligible clients and activities that support the development of the broader HACC system (DoHA, 2012). However, in most parts of Australia there are very few or no younger onset dementia specific HACC services.

The younger person with dementia generally 'falls through the cracks' between Commonwealth Government funded aged care services and State and Territory Government funded disability services; finding for the most part that they are not eligible for or suited to either service stream. Generally, the State and Territory Government funded disability services have not accepted referrals for people with younger onset dementia as dementia is perceived as a condition that develops in older age and therefore younger onset dementia clients are seen as more appropriate for aged care dementia services than for State disability services. Where younger people with dementia are able to access aged care funded services, these services are generally not suitable to the needs of younger clients, and so younger people with dementia have in the most part either endured inappropriate services or had no service options at all. The exception may be for some clients from culturally and linguistically diverse backgrounds or Indigenous clients where aged care culturally specific services may provide a more appropriate service due to the strong emphasis on culture and language in these services within a context of a culture that places a strong emphasis on a connected extended family.

Thompson (2011) found that many HACC funded centre-based day programs for people with dementia are not appropriate for people with younger onset dementia due to a focus on sedentary activities and old fashioned music. For a younger male with younger onset dementia, who has led an active lifestyle, attending a day program with older frail women is not appropriate.

5.7.2 Alzheimer's Australia

Alzheimer's Australia (and its State and Territory Associations), is the peak non-government organisation representing the needs of individuals with younger onset dementia and their

carers and have been involved in advocacy, various research projects, undertaken literature reviews and developed targeted information resources, service models and programs for this client group.

Alzheimer's Australia funds and/or operates a range of younger onset dementia specific services including: information and educational material regarding younger onset dementia; a quarterly younger onset dementia specific national newsletter 'HOPE'; resource lists of younger onset dementia specific services. In 2009 and again in 2013, Alzheimer's Australia convened a Younger Onset Dementia National Consumer Summit. The state and territory Alzheimer's Australia's all now provide some younger onset dementia specific services such as:

- support groups for people with younger onset dementia and / or their carers
- Younger Onset Dementia cafés
- educational programs for people caring for someone with younger onset dementia
- regular social and activity groups (including activities that stimulate the brain) for people with younger onset dementia
- young carer's groups and weekend retreats for people with younger onset dementia and their carers.

Alzheimer's Australia also runs a *'Living with Memory Loss*' educational and information course which has been modified to address the particular needs of people who have recently been diagnosed with younger onset dementia and their support person/s.

Perhaps the most significant development in service provision for younger people with dementia has been the recent establishment of the National Younger Onset Dementia Key Worker Program in July 2013. This Commonwealth initiative has funded Alzheimer's Australia to provide a national network of Younger Onset Dementia Key Workers to operate out of its State and Territory member organisations. With a focus on individually tailored support, coordination of services and capacity building, the Key Worker Program has the potential to address unmet needs and service gaps for people with younger onset dementia in Australia.

5.8 Recent Australian Policy Reforms

In August 2012, the Australian Health Minister's Advisory Committee recognised Dementia as a chronic disease and made Dementia a National Health Priority Area. The significance for people with younger onset dementia of the recognition of dementia as a national health priority is that it has now also been formally acknowledged that the disease does affect younger people so is not solely a disease of old age (DoHA, 2013). The broad policy context has now been set for both Commonwealth and State and Territory Governments to address systemic problems within the health and community service systems in regards to community awareness and 'normalising' dementia in the younger age cohort as well as improving processes for diagnosis, symptom management and service provision.

5.8.1 National Health Reform

Under the National Health Reform Agreement, as of 1 July 2012, the Australian Government assumed full operational responsibility for all aged care services for non-Indigenous people aged 65 years and over and for Aboriginal and Torres Strait Islander people aged 50 years and over covering basic home care through to residential care in most states and territories. This included a transfer to the Australian Government of current resourcing for aged care services

from the Home and Community Care (HACC) program, in all states and territories except Victoria and Western Australia (DoHA, 2012).

For people under the age of 65 or Aboriginal and Torres Strait Islander people aged less than 50 years, the implication of this policy reform is that the Commonwealth will no longer directly fund services for people with younger onset dementia. The Commonwealth will, however, provide support to those people with younger onset dementia who are eligible to receive services and support under the new National Disability Insurance Scheme.

The current period for the HACC program, is a 'transition' phase when the Commonwealth has taken over funding all HACC services for people over 65 or Aboriginal and Torres Strait Islander people aged 50 years, however the program has not substantially changed 'on the ground'. As of 1 July 2015, the HACC program, along with some other community care programs, becomes the Commonwealth Home Support Program and will operate under new Commonwealth guidelines for the Home Support Program.

5.8.1.1State and Territory responsibilities

The responsibility for the provision of funding services for people with younger onset dementia now lies with the State and Territory governments. If a younger person with dementia does require Commonwealth funded aged care services, such as residential or packaged care due to an absence of any other alternate care option, the person with younger onset dementia should not be excluded from accessing these services due to their age, rather, State and Territory governments will have to pay the Commonwealth for these services.

It will be important that the impact of these changes over the next 12 months is carefully monitored by both State and Territory governments, by the Commonwealth government and by Alzheimer's Australia to ensure people with younger onset dementia continue to have access to the scarce but valuable younger onset dementia specific services previously available to them under the HACC program.

5.8.2 Disability service reform

The National Disability Strategy 2010-2020 was endorsed by the Council of Australian Governments on 13 February 2011. For the first time, Australia now has a coordinated plan across all levels of government to improve the lives of people with disability, their families and carers. The National Disability Strategy outlines a 10-year national policy framework to improve the lives of people with disability, promote participation and create a more inclusive society. It guides public policy across all levels of government and drives change in all mainstream and specialist programs and services—as well as community infrastructure—to better meet the needs of people with disability, their families and carers.

The Strategy is based on the belief that all Australians—including the 20 per cent with disability—should have fair and equal access to the full range of mainstream programs and services available, whether it is employment, healthcare, education, transport, or public facilities and infrastructure (DSS, 2013).

5.8.2.1National Disability Insurance Scheme

As part of the National Disability Strategy the Productivity Commission undertook a public inquiry into a long-term disability care and support scheme for people with disability. The Council of Australian Governments subsequently agreed to the need for major reform of

disability services through a National Disability Insurance Scheme (NDIS). A staged trial and roll out of the NDIS commenced in 1 July 2013.

While NDIS represents a significant step forward for many people with disability, the National Disability Strategy remains the key to achieving improvements in access to mainstream services and support for all people with disability. These mainstream reforms are an essential element in the successful introduction of NDIS, both for participants in the scheme and for the many people with disability who may not be participants.

The introduction of NDIS is positive for those people with younger onset dementia who are eligible to receive assistance and are able to access the program locally. However, one of the key concerns regarding having an age criterion for access to services is ensuring a continuity of care as the person reaches 65years and transitions into the Commonwealth Funded aged care sector. This will need to be monitored as NDIS is rolled out nationally over the coming years.

Currently younger onset dementia service providers are predominantly HACC or Commonwealth aged care service providers with extensive expertise in dementia care. Due to these services being developed primarily in response to needs of older people with dementia, limitations in the capacity of many of these services to provide individualised services to people with younger onset dementia exist. A shift for younger onset dementia services to the State and Territory funded disability service sector, most of whom should be experienced in providing individualised services to younger people, but who are generally not accustomed to providing dementia care or the specific disease related service requirements of people with younger onset dementia, could potentially have significant adverse effects on people with younger onset dementia and their families. There is potential for situations of 'overshadowing' of dementia, and a resultant lack of diagnosis and appropriate support and symptom management, to occur for people with younger onset dementia in the disability services sector. The most effective younger onset dementia service provider is one who has both the dementia expertise and the ability to offer age appropriate, individualised services. Opportunities therefore exist, as a result of the changing policy context of service delivery for younger onset dementia in Australia, for new younger onset dementia services to emerge, and for effective networks and collaborations between the disability sector, health and aged care sectors to maximise efforts in providing appropriate, effective and efficient localised service responses for people with younger onset dementia.

5.9 Conclusion

An analysis of the key themes of the literature for the design and development of services for people with younger onset dementia has provided an evidence base for younger onset dementia service design and development. Key themes emerging from the literature relate to service integration; these include multidisciplinary teams, streamlined pathways, service links and case management. Participation and inclusion of consumers in service design and development appears in the more recent literature as a key feature of younger onset dementia service development. Individually tailored, person centred service models that enable flexible, responsive service delivery are fundamental features of younger onset dementia services. It is only through an individualised approach that the service needs of such a diverse group of people can be adequately met. The issue of specialised and age appropriate services is discussed in the context of what models can realistically be established to cater for the dispersed population within Australia. Factors impacting on service utilisation and features of

effective services have been presented. Consideration of the diverse diagnostic group that constitutes younger onset dementia is discussed in the context of effective models of service delivery. The additional requirements of people with younger onset dementia who also have a special needs such as Aboriginal and Torres Strait Islander people; people from Culturally and Linguistically diverse backgrounds; people who identify as Lesbian, Gay Bisexual, Transgender or Intersex; people from rural and remote communities; and people who are homeless. The essential service design feature to meet the needs of these diverse groups is again that services need to be individually tailored and delivered in a culturally sensitive and flexible manner.

The concept of process and stages of the younger onset dementia trajectory has been introduced. Due to the unique experience of younger onset dementia and the stage of life at which it occurs, we have introduced a specific stage of the disease 'trajectory' to guide policy and practice supporting this group. This stage 'Adjustment, enablement and engagement' requires a response that is different to the traditional 'service response' developed for older people with dementia. People with younger onset dementia need support and specialised treatment to maintain critical aspects of their life such as employment, relationships, family and social supports, and hobbies, interests and physical activity.

Deriving from the thematic analysis of the literature is a set of Summary Principles for Design and Delivery of younger onset dementia services. These guiding principles have been grouped into three main categories: individualised approach; staff attributes and organisational attributes.

In recognition of the changing needs of people with younger onset dementia and their carers in response to the stages of the disease trajectory of younger onset dementia, critical elements for service design and delivery are provided for each stage of the disease. These elements of service design sit under the overarching guiding principles for younger onset dementia service design and development as a reminder to service providers that services for each individual with younger onset dementia will need to change over time.

A review of current younger onset dementia service delivery in Australia includes a brief examination of the history of the HACC program in relation to younger onset dementia service delivery and the role of Alzheimer's Australia in providing advocacy services, specialist advice and support services to a wide range of stakeholders and consumers regarding younger onset dementia. Both HACC services and Alzheimer's Australia have made a significant contribution to the evidence base regarding the design and delivery of younger onset dementia services in Australia. Approaches to HACC program service delivery such as the Western Australian 'wellness approach' and the Victorian 'Active Service Model' are discussed in relation to the provision of younger onset dementia services. Emerging approaches to service delivery such as reablement and Consumer Directed Care are critically reviewed in the context of younger onset dementia service design and delivery.

A discussion regarding recent Australian policy reforms including the recognition of Dementia as a national health priority; National Health Reform and Disability Reform explores the possible impacts on people with younger onset dementia and their carers and families of changes to government funding responsibility for service provision for people less than 65 years or 50 years for Aboriginal or Torres Strait Islander people. A review of current Disability Service Reform including the National Disability Strategy 2010-2020 and the new National Disability

Insurance Scheme (now known as DisabilityCare Australia) examines possible implications and new opportunities for younger onset dementia service delivery.

6 Programs For People with Younger Onset Dementia and Their Families

6.1 Program Evaluations

There is a limited range of literature on programs for people with younger onset dementia. These programs are relatively recent and have often been developed in response to local expressed need by service providers. Programs tend to cover a small number of participants as the overall number of people with younger onset dementia is quite small. People with younger onset dement also vary widely in their levels of cognition and function, depending on the progression of the dementia, so trying to match programs with people can be very difficult. The causes of dementia vary widely and these differing causes may affect the utility of the program, e.g. what works for a person with a fronto-temporal dementia may not work for a person with a person with Acquired Brain Injury.

It is also difficult to measure the effectiveness of these programs. People with dementia are, in general, losing cognitive and functional skills. To determine whether an intervention has made a difference, it needs to be compared with what would have happened if that intervention had not been made, and, due partly to the small samples of programs identified in the literature, this is difficult. Some people may be able to increase their level of functioning and well-being for a time, but there will be an inevitable decline, resulting in death. For some people, maintaining their current level of functioning and well-being for a time is a good outcome, whilst, for others, reducing their rate of decline may be a good outcome. More flexible approaches to judging effectiveness of programs are needed. These approaches may include interviews and focus groups with people with younger onset dementia and their carers, and program staff and clinicians who are involved with the person.

Fifty-one documents were reviewed. Some reviewed papers were not specifically targeted at people with younger onset dementia but were considered as having some relevance for people with younger onset dementia. Seven papers were excluded as they were judged to be not relevant for this review. Only one was regarded as “Well supported practice” and two as “Supported practice”. Many of the studies had small sample sizes, which mean that it is difficult to be confident about their transferability to other groups of people besides those in the study.

6.2 Programs for People with Younger Onset Dementia

Our search identified forty one documents that were included in this section. Sixteen were studies of programs aimed at people with younger onset dementia or that specifically included people with younger onset dementia in their sample. Another fourteen were studies of programs that focussed on the general population of people with dementia but appeared to be relevant to people with younger onset dementia. There were three articles that studied related conditions including acquired brain injury and Huntington's disease. There were eight literature reviews included, of which two were focussed on people with younger onset dementia.

The level of evidence for the majority of interventions identified was rated as either emerging or acceptable practice. There were very few rated as supported or well supported practice. This was mainly because most of the studies of programs and interventions that were found used a less rigorous study design, often included only small number of participants or did not report enough information to make an informed decision about the strength of evidence.

Studies identified were mostly from the northern hemisphere with twelve studies conducted in the United Kingdom, nine from the USA, five from Canada, four from Australia, two from Sweden and one from Finland.

Eight literature reviews were identified with four reviews conducted by research teams from the USA, two from the United Kingdom, one from Canada and one by a New Zealand research team. Four of the literature reviews were systematic literature reviews, using strict search, inclusion and exclusion criteria to identify high level evidence relating to the chosen topic. Four of these were reviews of the evidence with a less rigorous approach with the aim of providing an overview of available evidence for a chosen topic.

There was a diverse range of programs for people with younger onset dementia identified in the search. These were also supplemented by an examination of some programs aimed at the general population of people with dementia where they appeared to be relevant to the needs of people with younger onset dementia. Programs most often reported on in the literature related to support groups and the use of technology to assist and support people living with dementia. There were a number of studies that related to participation in physical activity, leisure activities, horticulture, volunteering, supported workplaces and arts-based therapy. Studies examining the impact of key workers and case management, relationships and friendships, cognitive stimulation and day care programs, particularly for people with fronto-temporal dementia, were also identified.

Table 4 Programs for People with Younger Onset Dementia

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
Agnihotri (2009)	Canada	Using arts for social integration – acquired brain injury.	Pre/post/follow-up design.	Emerging practice	Adolescents with Acquired Brain Injury	5 + 1 control	The program improved social cognition and community integration with continued benefits demonstrated post program. The study numbers and the control group were small making transferability limited. May be worth further study in the YOD population
Batsch & Miller (2009)	USA	An assessment of needs for serving individuals early stage dementia.	Focus groups	Acceptable practice	People with early stage dementia & their family members	20 diagnosed participants and 19 family members	Programs pertaining to education, emotional support, financial/legal counselling, and advocacy were of most importance to people diagnosed with early stage dementia and their families/caregivers
Bird et al (2005)	Australia	Early Stage Dementia Support and Respite Project: Living with Memory Loss (LWML) program.	A repeated measure, wait-list control study	Acceptable practice	People with early stage dementia and their carers	84 clients and 87 carers at 3 month follow-up. 52 and 58 respectively at 15 months.	An evaluation of a DoHA funded time limited support groups for people living with memory loss and their carers in each state and territory. Baseline, 3 month and 15 month measures were collected. Significant impacts were noted for carers and people with memory loss. Depressive symptoms of people with memory loss reduced for those who showed symptoms at the start of the group. Carers showed improvements in general mental health. Carers also showed significant reductions in stress related to difficult behaviours and symptoms.
Burgener et al (2009)	USA	Effectiveness of Community-Based, Non-pharmacological Interventions for Early-Stage Dementia:	Literature review	Literature review	People with early stage dementia	150+ research reports	Identified interventions for mild cognitive impairment (MCI) and treatments for early-stage dementia (ESD). Recommendations for MCI included physical exercise, cognitive therapies (e.g. memory rehabilitation), comprehensive recreational activities and dietary modifications. Recommendations for ESD included sleep hygiene programs, driving evaluations, individualised instruction for e.g. cell-phones, e-mail, computer use and electronic reminders and monitoring support (costs involved).
Casey (2004)	United Kingdom	Early Onset Dementia: getting out and about.	Qualitative assessment of group activities and semi-structured questionnaire	Emerging practice	People with YOD	6 YOD women	Clients participated in a weekly meeting that involved outdoor activities. Positive outcomes were noted in relation to self-esteem and maintenance of independence
Cook (2011)	United Kingdom	Medway Horticultural Project for Younger People with Dementia	Project description	N/A	People with YOD	Not stated	Describes, but does not evaluate, a program to provide physical activity through gardening. The aim of the program was to provide a space where people with YOD

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
							could experience feelings of wellbeing. Participant stories were presented as short vignettes which focussed on the support provided as participants experienced cognitive decline.
Davies-Quarrell et al(2010)	United Kingdom	The ACE approach: promoting well-being and peer support for younger people with dementia.	Members of the ACE club conducted a self-evaluation of the service.	Emerging practice	Young onset Alzheimer's disease	There appear to be 11 members in the ACE club	The ACE Club/service uses a relationship focussed approach. The program was highly valued and has had positive effects on the lives of members, e.g. increased participation in activities that lead to improvements in physical fitness or reduced anxiety or an increased sense of security The evaluation was conducted by the ACE club members.
Goldberg (2011)	USA	A support group for young onset Alzheimer's and other dementias	Program description only. No outcome measurement described.	Expert opinion	People with younger onset Alzheimer's disease or related dementias	Initially recruited 7 people. After 3 months this had reduced to 5.	A closed, time-limited, self-help/ peer support group was established. Facilitators ran a series of information sessions for participants. No outcomes were reported
Harris (2004)	USA	The Perspective of Younger People with Dementia: Still an Overlooked Population.	In-depth face-to-face or on-line interviews and a focus group.	Emerging practice	People with YOD	23 participants with YOD	Qualitative study conducted with members of a support group for people with YOD and their families. Practice guidelines were formulated for working with people with younger onset dementia. Common themes from interviews and focus groups related to diagnosis and need for flexible, person centre services, marginalization and significant life changes.
Harvey et al (1998)	UK	CANDID: a national telemedicine service supporting the care of younger patients with dementia.	A retrospective review of all calls received by a telephone helpline over a 2-year period.	Routine practice	Focus was on younger people diagnosed with dementia and older people with atypical dementia.	1121 calls made to the service.	CANDID helpline provides direct access, by telephone and e-mail, to specially trained nurse/counsellors. 1121 calls were made to the service. 241 registered callers (patients (4%) and carers (61%)) made 547 calls. Remaining 574 calls were from the general public and health professionals. Calls were categorised into three main themes including general information (45%), clinical advice (37%) and advice on social issues (18%). Half of all calls from registered callers were for clinical advice with 67 calls generating a letter sent to the treating GP about referrals and advice given.
Hayter (2008)	Australia/ NSW	Flexible and Responsive Evaluation of The Younger Onset Dementia Social Support and Respite Program	Interviews with carers and staff	Emerging practice	YOD clients & carers	6 people with YOD and their carers	A support program for people with YOD and their carers – provides activities and peer support to people with YOD, and a support group for carers. Interviews/consultations found that the program met the needs of people with YOD and their carers; was cost effective and provided a peer group and valued role for people with YOD.

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
Hewitt et al (2013)	United Kingdom	Does a structured gardening programme improve well-being in young-onset dementia?	A mixed methods (qualitative and quantitative) study of therapeutic gardening.	Acceptable practice	YOD clients, carers/family	12 participants aged 43-65 years	This project set out to identify the benefits of a structured gardening program of for people with YOD. The project gave participants a renewed sense of purpose and increased well-being despite cognitive functioning continuing to decline during the evaluation period.
Jenkins (2013)	United Kingdom	Piloting the use of drama to explore experiences of early onset dementia and priorities for developing specialist support services.	Participatory action research framework	Emerging practice	YOD clients	Service users with YOD of the Alzheimer Scotland Lothian Early Onset Support Service	Researchers will work with service users to develop professionally acted vignettes of younger onset dementia for presentation to other service users and service staff. Workshops will also be undertaken with service users to gain their experiences of the play and their experiences of YOD. Outcomes yet to be reported.
Kinney et al (2011)	USA	Evaluation of a program for individuals with early-onset dementia. Volunteer work at zoo	Face-to-face, semi-structured interviews with YOD participants and a focus group with spouses	Emerging practice	YOD clients & carers	6 men and their wives	The "Get out of the House" involved a weekly 2 hour supervised volunteer work session at a zoo. Participants indicated that the program gave them the opportunity to experience 'normalcy' in the face of their disease. Participants strongly identified with the program and desired to share their experiences. The program allowed participants to be socially interactive, be productive and help others.
Knapp et al (2006)	United Kingdom	Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis	Randomised controlled trial	Well supported practice	People with dementia	91 people (intervention group) and 70 people (control group)	Cognitive stimulation therapy for people with dementia is more effective than treatment as usual, i.e. it provides benefits for cognition and quality of life for people with dementia, and may also be more cost-effective than usual treatment.
Kortte & Rogalski (2013)	USA	Behavioural interventions for enhancing life participation in behavioural variant frontotemporal dementia and primary progressive aphasia	Literature review: Systematic Literature Review	Literature review	People with younger onset fronto-temporal dementia and their carers	37 papers were included in the review	The authors argued that behavioural interventions should be a standard part of the care offered to individuals with bvFTD and PPA. Neuro-rehabilitation interventions and community- based activities have the potential to benefit people with FTD and PPA
Laudate et al (2012)	USA	Bingo! Externally supported performance intervention for deficient visual search in normal aging, Parkinson's disease,	Study involved age matched individuals with Alzheimer's and control subjects and Parkinson's disease and control subjects.	Supported practice	People with Alzheimer's disease and Parkinson's disease.	5 participant groups: young adult control group (19), older adult group (13), Alzheimer's	Participants undertook a series of bingo games on a computer touch screen. The authors found that improving contrast and reducing the complexity of the game helped improve cognitive function. The authors also argued that bingo provides a social aspect which also helps cognition. The study showed improvements for younger adults and

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		and Alzheimer's disease	There was also a younger adult control group.			group (14), normal control group (20), Parkinson's group (18)	may therefore be helpful for people with YOD.
Letts et al (2011)	Canada	Using occupations to improve quality of life, health and wellness and client caregiver satisfaction for people with dementia	Literature review: Systematic literature review	Literature review	People with Alzheimer's and other dementias	26 articles were selected.	The authors found there was a limited amount of high-quality evidence for the effectiveness of ADL interventions. IADL interventions for people in the community show promise, tailored activity based leisure interventions had positive impacts and social participation interventions for people with early to middle stage dementia had short-term positive effects
Leuty et al(2013)	Canada	Engaging Older Adults with Dementia in Creative Occupations Using Artificially Intelligent Assistive Technology (ePAD)	A mixed-methods study. Data were collected via written comments and questionnaires.	Acceptable practice	Participants with late onset mild-to-moderate dementia and art therapist dyads	6 dyads (client and art therapist) were included	Usability measures suggest that all participants found ePAD engaging but did not find prompts effective
Linden et al (2010)	Sweden	Perceived difficulties using everyday technology after acquired brain injury: Influence on activity and participation	A cross section of patients with ABI between 1998 and 2004 participated in semi-structured interviews	Acceptable practice	People with a previous brain injury (2–10 years post injury)	36 participants (27men and 9 women) with an ABI.	While the study found most of the participants had difficulty using everyday technology a majority still used most objects and services independently. However, participants also perceived that their difficulties affected their everyday activities and their ability to participate at home and in the community
Lloyd-Yeates (2013)	United Kingdom	Working one to one with iPads	Project description	N/A	People living with dementia	N/A	Description of the use of technology, such as mobile apps, to deliver person centred activities and opportunities for reminiscence.
Logsdon et al (2007)	USA	Evidence-Based Interventions to Improve Quality of Life for Individuals with Dementia	Literature review: Systematic literature review	Literature review	People living with dementia	69 papers were included in the review	Describes RCT interventions to improve quality of life for people with dementia but there is no focus on younger onset dementia
Martin et al (2013)	United Kingdom	Conceptualisation of self-management intervention for people with early stage dementia	Literature review: Review of evidence	Literature review	People with dementia	80 papers were included in the review	Argued that self-management is possible for people with dementia but that further research is needed with a strengths focus and an emphasis on quality of life
Metcalfe (2013)	United Kingdom	Making Sense of Relationships	2 Case studies	Emerging practice	People with fronto-temporal dementia	2	Use of speech and language therapy to reduce cognitive decline. Using a relationship centred care model to

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
							address communication challenges may help carers and people with FTD better address their needs.
Moore & Renehan (2011)	Australia/ Victoria	Evaluation of the Linking Lives Project: Final Report	Pre and post measures, participant focus group plus participant and key worker interviews.	Acceptable practice	Younger people living with dementia and their carers	5 people with dementia, 9 carers	The Linking Lives Project aimed to deliver an individualised response to the needs of each client and carer through the employment of "key workers". There was strong positive response to the project from clients and carers but the changes in outcome measures, including psychological distress and quality of life, were mixed with no clear trend in positive or negative outcomes for either of these measures.
Philips and Conn (2009)	USA	The Relevance of Creative Expression Interventions to Person-Centered Care	Editorial	Expert opinion	NA	NA	Creative expression programs are innovative non-pharmacological approaches in dementia care. Research must link important elements of these programs to outcomes
Phinney & Moody (2011)	Canada	Leisure Connections: Benefits and challenges of a Social Recreation Group for People With Early Dementia	Interviews with participants, family and staff and participant observation.	Acceptable practice	People with early stage dementia	10 interviews (15-30 mins in length) and 40 hours of observation.	Support group involving guided leisure activities. The authors argued that Leisure Connections was an example of how innovative programs can fill an important gap in services for people with dementia
Pitkala et al (2013)	Finland	Effects of the Finnish Alzheimer Disease Exercise Trial (FINALEX): A randomised controlled trial	Randomised controlled trial	Well-supported practice	People with Alzheimer's (LOD) and their carers	210 patient/carer dyads.	Looked at effect of exercise on cognition. This study showed positive results in delaying cognitive decline for people with Alzheimer's disease, reductions in health care costs and a reduced number of falls
Ratey & Loehr (2011)	USA	The positive impact of physical activity on cognition during adulthood: a review	Literature review: Review of evidence	Other	People with cognitive decline	108 papers were included in the review.	Authors found that physical activity in midlife had a protective effect against cognitive decline later in life and argued that movement improves cognitive performance and delays age-related cognitive decline
Robertson et al (2013)	Australia, SA	Side by Side: A workplace engagement program for people with younger onset dementia	Pilot evaluation involving feedback from participants and carers	Emerging practice	YOD clients	Seven people with YOD matched with a trained worker	This was a demonstration program of the feasibility of a supported workplace engagement program for younger people with dementia
Rosenberg & Nygard (2013)	Sweden	Learning and using technology in intertwined processes: A study of people with	Interviews were conducted while the participants used their own	Acceptable practice	People with Alzheimer's and mild cognitive disorder	20 participants with mild cognitive impairment	The findings underscore that it is important to support the continued use of everyday technology as long as it is valued and relevant to the person with mild cognitive impairment or Alzheimer's disease

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		mild cognitive impairment or Alzheimer's disease.	technology in their homes.			(n=10) or Alzheimer's disease (n=10).	
Ryder-Jones et al (2012)	United Kingdom	Wii can make a difference	Well- being profiling	Emerging practice	YOD clients	7 YOD clients	Positive benefits were found when Wii technology was used to engage people with in dementia in games that increased well- being, social interaction and physical activity
Schlosberg (2004)	United Kingdom	What users and carers think of services for younger people	Qualitative - interviews	Routine practice	Clients, carers -YOD	10 EOD, 5 carers	Evaluation of a day care service for YOD; users were happy with the age appropriate service and their involvement/participation; carers were happy with it assisting with their employment and providing a respite. Both groups felt the service needed better resourcing and should be expanded
Shnall et al (2013)	Canada	Development of supportive services for Fronto-temporal dementia (FTD): Day Care (Intervention 1)	Observation of behavioural changes was used to evaluate an FTD day care program.	Emerging practice	People with frontotemporal dementia	4 people	Evaluated a day care program designed specifically for those with FTD. While participants with the most severe behavioural disturbances showed the most improvement (improved facial expression, activity participation and reduced inappropriate behaviour), mildly affected individuals also benefitted from day programme activities.
Silverstein et al (2010)	USA	Adult Day Health Care for Participants With Alzheimer's Disease	Mixed methods: an electronic survey delivered to all staff and structured interviews with a sample of staff	Acceptable practice	People with Alzheimer's disease	93 out of 155 providers responded to the survey. 8 staff were interviewed	People with YOD have different day care needs and often want to be involved in helping others. More specific services for YOD are required
Sixsmith (2006)	United Kingdom	New Technologies to Support Independent Living and Quality of Life for People With Dementia	Literature review: Review of evidence	Literature review	People with dementia	29 papers were included in the review.	Reviewed programs harnessing technology to help people with dementia. While this work is still at a very early stage, devices and systems to support community participation (e.g. community design), social interaction (e.g. multi-media reminiscence), help with daily activities (e.g. smart house design), and the enjoyment of music (e.g. assisted listening systems) are being designed to meet the particular needs of people with dementia.
Spring et al (2013)	United Kingdom	Is gardening a stimulating activity for people with advanced Huntington's disease?	Mixed method design and cross-sectional triangulated sampling (residents, visitors, and staff).	Emerging practice	People with Huntington's disease	Seven out of 10 HD residents participated in the study	This paper outlines an apparently successful horticultural therapy program for people experiencing cognitive decline due to Huntington's disease. Evaluation results indicate that the program was valued by clients, staff and visitors and provided social and therapeutic benefits for the clients such as increased physical activity, sense of

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
							enjoyment and achievement, improved mood, interaction and quality of life. Anecdotal reports also noted that some clients also experienced improved wellbeing and reduced anxiety.
Stansell (2001)	Canada	A volunteer program for people with dementia	Program description and personal observations regarding a pilot program.	Emerging practice	People with dementia	Not stated	Program to help people with early stage dementia participate in volunteer work. The program does not provide details on whether people with YOD were included. The program changed perceptions and raised the profile of volunteers with dementia in the community Clear guidelines were also established including inclusion criteria, safety issues and transition from the program. Funding was noted as an issue for continuation of the group.
Troy and Zisis (2012)	Australia, NSW	Case management and Community Options Programs	Feedback on Physical Activity Program and YOD retreats	Emerging practice	Clients with YOD and Carers	9 people with YOD and their carers	Program involved a physical activity group and one off 'retreats'. Positive client feedback was received. Easy and cheap program to implement but no formal evaluation
Ward et al (2012)	UK	Supporting the friendships of people with dementia	Case study and support group evaluation via observation, focus groups and staff interviews.	Emerging practice	People living with dementia	Single person case study and support group case study, no numbers given	The authors used a single case study and a group case study to demonstrate the importance of friendships for people with dementia
Webster and Duncan (2005)	USA	E-mail Connections: A Communication Network for Families and Persons With Early-onset Alzheimer's	Program description only.	Emerging practice	People with young onset Alzheimer's, their carers and family	Database included 134 families and 42 professionals	Email database for care partners (spouse significant others), persons with dementia and adult children of persons with YOD. Positive feedback was received from care partners. Some spouses commented on how they were able to link with people in a similar situation and feel less alone. Others noted reading responses to the person with YOD who appeared to appreciate this.
Willis et al (2009)	UK	People with dementia and their family carers' satisfaction with a memory service	Semi-structured qualitative interviews	Acceptable practice	People with Alzheimer's disease, included some people with YOD	16 people with dementia and 15 family carers	Client and carer themes were investigated and reported conjointly. Overall client satisfaction with the memory service was 'good' or 'very good'. A peer support network was developed for clients and carers. Information provided by service was well received but it was also noted that services designed for older people are not appropriate for younger people. Service quality indicators were developed.

6.2.1 Support groups

Support groups appeared to be popular for people with younger onset dementia; however, outcomes were either poorly evaluated and reported or not reported at all. Focus groups conducted with people with younger onset dementia (Harris 2004) indicated that people with younger onset dementia need more socialising and social support opportunities. Batsch and Miller (2009) conducted an assessment of needs for people living with dementia found that programs deemed as of most importance to people affected by dementia were those that provided education, emotional support, financial and legal counselling and advocacy. These aspects can be provided through support groups.

An evaluation of a younger onset dementia support group and respite group based in inner western Sydney (Hayter, 2008) showed the value of the program in meeting the needs of people with younger onset dementia. The group provided age appropriate, community based activities that are specifically tailored to meet the needs of people with younger onset dementia. The group also allowed members to support each other. Interviews with carers and consumers found that it met the needs of people with younger onset dementia and their carers, that it was cost effective and that it provided a peer group and valued role for people with younger onset dementia. Further evaluation using a more rigorous study design may be required to determine the program's effectiveness. One main issue for the program was a lack of recurrent funding.

Evaluation of the Living with Memory Loss Program (Bird et al, 2005) provided some encouraging results in relation to support groups for people with dementia. Living with Memory Loss (LWML) is an Australian Government funded program provided in all States and Territories in Australia. Bird et al (2005) used a repeated measures, wait-list control study design to collect baseline, 3 month follow-up and 15 month follow-up outcome measures for participants with memory loss and their carer. There were fifteen people with memory loss under the age of 65 in the sample at the beginning of the study. Although there was some attrition and methodological issues, results showed positive effects. The authors found that for people with memory loss that had an elevated level of distress due to depression at baseline there was a significant decline in depression at 3 and 15 months follow up. There was also a reduction in stress for carers at three months follow-up. The authors argued that the findings suggest the content of the LWML programs is well chosen and delivered and that the groups deserve to continue.

Casey (2004) reported on a qualitative assessment of a support group for people with early onset dementia in the UK that involved outdoor activities such as picnics, walking and shopping. The authors reported positive outcomes in relation to self-esteem and maintenance of independence. As it was a small study of female participants only, with a less than rigorous study design, further study would be required to determine program effectiveness for a broader range of participants.

Davies-Quarrell (2010) described a support group for people with early onset dementia called the ACE club. The ACE club was focussed on developing the relationships of the person with younger onset dementia through activities, education and support. This was a participant directed program, with clients setting the agenda and staff playing a support role. Although the program was not formally evaluated, participants indicated that the club was highly valued by

the group members. Metcalfe (2013) also showed that using a relationships-centred care model helped in improving communication for people with fronto-temporal dementia.

Goldberg (2011) described a support group for people with young onset dementia. It was a time limited group that focussed on providing information sessions for participants. No outcomes were reported and so the effectiveness of this approach cannot be determined. Programs aimed at the general population of people living with dementia may also inform programs for people with younger onset dementia. Ward et al (2012) showed the importance of supporting the friendships of people with dementia. Their study highlighted the value of friendships for people with dementia next to the importance of family caring relationships. The authors propose the notion of 'facilitated friendships' and also argued that the role of the facilitator for such a group may need to be redefined, taking a more 'behind the scenes' role than a leadership role and supporting/enabling the group to function.

Phinney and Moody (2011) used qualitative methods to observe the benefits of a guided leisure activities support group. The group included 11 people aged between 63 and 84 and included activities such as flexibility exercises, ball games, word games, reminiscence activities, dancing, role playing, and crafts. Data were gathered via interviews and observation to answer questions about important aspects of the program, participant's experiences and change over time. Regarding the important aspects of the program and participants experiences, interview results indicated that participants got along well together, had fun, had a shared understanding, participants felt at ease in the group and felt wanted. Regarding change over time participants felt they "came alive" after joining the group. Another aspect of the group was that it acted as a "stepping stone" to other programs/services as their dementia worsened, thus filling an important gap in services for people with dementia who initially did not need or were not ready to accept day programs or facility based care.

Gaugler et al (2011) also found positive benefits from support groups that aim to strengthen relationships between the person with dementia and their carer. In a study of The Memory Club, a support group for people with memory loss, the authors found that people with dementia expressed lower levels of satisfaction with the Memory Club support group compared to their carers. The authors felt that some review of the Memory Club modules may be required to ensure both carers and people with dementia get the same level of satisfaction out of the program.

While support groups appear to be needed and valued by participants the evidence for effectiveness of these groups for people with young onset dementia is still emerging. There is some promising practice relating to support groups for the general population of people with dementia, including the Living with Memory Loss program. In general support groups should provide education, emotional support, including the development of relationships, financial and legal counselling and advocacy. Opportunities for social interaction and programs tailored to the needs of people with younger onset dementia are also important.

6.2.2 Day Care

One study was found regarding day care programs specifically for people with young onset dementia. A few studies were found for the general population of people with dementia;

however, younger people were noted as a special group as were people with fronto-temporal dementia.

Schlosberg et al (2004) evaluated a day care service for people with early onset dementia, wanting to know what people thought of the service. Users were happy with the age appropriate service and involvement/participation. Carers were happy with it assisting with them with maintain their employment and providing a respite. Both groups felt the service needed better resourcing and should be expanded.

Silverstein et al (2010) in a study of a day health care program for people with Alzheimer's, notes that for clientele under the age of 65 there was a need for this group to be doing 'contributing' type activities. This helped to maintain the self-esteem of the clients. Staff of the program noted that younger people often take on a helping role and often relate more to the staff than the older clients. Staff said that it was important to give younger clients jobs to do, as though they were 'volunteers' not clients. The authors concluded that there was a need for more stage specific services, including services for younger onset dementia.

Evaluations of day care programs for people with younger onset dementia and for older people with dementia or atypical dementia such as fronto-temporal dementia indicate they may need age appropriate programs specifically designed for their needs.

6.2.3 Technology

Sixsmith (2006) reviewed literature relating to new technologies to support people living with dementia and how they might improve their quality of life. Sixsmith found that there was promising research relating to devices and systems aimed at supporting community participation, social interaction, help with activities, the enjoyment of music and how these technologies can be used to meet the needs of people with dementia. In addition a Swedish study involving interviews with people who had Alzheimer's disease or mild cognitive disorder concerning their use of technology at home found that it was important to support the use of everyday technology (e.g. using a mobile phone, a microwave or television set and DVD player in combination) as long as it was valued and relevant to the person (Rosenberg & Nygard, 2013).

Linden et al (2010) interviewed people who had undergone rehabilitation for an acquired brain injury between 1998 and 2004, and examined their difficulties in using everyday technology, such as telephones and computers. A majority (78%) of the persons reported difficulties using every day technology. The most common difficulties were related to the use of telecommunication devices (desk and mobile telephones) and computers. Despite these difficulties, a majority still used most objects and services independently. Twenty-six participants (72%) perceived that their difficulties using everyday technology influenced their everyday activities and their ability to participate at home and in the community.

Relevant technology has been used to facilitate support for people living with younger onset dementia for a number of years. Communication technology has the potential to link people with dementia to service and to other people in similar circumstances. Harvey et al (1998) reported on a telephone help and support line for people with younger onset dementia (CANDID) that provided direct access by phone or email to a trained nurse or counsellor. The

authors used an analysis of routine data and found that of all calls 61% were from carers, 4% from patients, 19% professionals and 16% other callers. In addition 45% concerned general information, 37% clinical advice and 18% social advice. The authors argued that a telemedicine service, linked with primary care for people with younger onset dementia, was readily taken up by patients, carers and the general public and that the service was sustainable.

Webster and Duncan (2005) described how an E-mail Connections project was set up to allow people with younger onset Alzheimer's (and other younger onset dementia), their carer partners and family members (primarily adult children) to link with other individuals in a similar situation. While feedback from participants was positive, benefits and issues were not formally evaluated. This program uses technology that may be accessible for younger age groups who are familiar with emails and communicating in this manner.

Technology devices have also been used to engage people with dementia in various activities. Leuty et al (2013) used an art therapy based intervention for older adults but used an artificially intelligent assistive device (ePAD) to engage participants with dementia. Leuty et al collected data through written comments and questionnaires on the usability of the ePAD. Although the study showed that participants found the ePADs engaging, participants did not find the prompts effective. The authors proposed changes in the configuration of the ePAD to increase its useability but identified that further research was needed to determine the types of prompts that would be effective. Lloyd-Yeates (2013) also showed it was possible to work one-on-one using iPads with older people living with dementia.

The use of computer games has also shown promise in engaging people with dementia. A study by Laudate et al (2012) described the successful use of computer touch screens to deliver a Bingo game that resulted in improved cognitive function for people with Alzheimer's disease. Rhyder-Jones et al (2012) reported on the use of Wii game technology to engage people in games that resulted in increased well-being, social interaction and physical activity. Improvements in well-being profiles (making contact with others, pleasure/enjoyment, alertness/responsiveness and relaxed body posture) as well as reductions in ill-being indicators (physical tension, restlessness and anxiety) were reported. The authors also reported improvements in social interaction within the group and interaction with intergenerational family members.

Technology has the potential to assist people to link into services and link with other people with dementia. However the use of everyday technology can also present problems for people with cognitive difficulties. Assisting people with the use of technology as needed is worthwhile for people with dementia. The development of devices to engage and help people with various aspects of their dementia has shown promise, although the level of evidence was mostly low. Research relating specifically to people with younger onset dementia did not figure strongly in the studies identified in spite of the possibilities that may be offered to this group through technology.

6.2.4 Physical activity

Several studies indicated the importance of physical activity for people with young onset dementia.

A review of the evidence for non-pharmacological interventions for early stage dementia (Burgener et al, 2009) found that there was good evidence that participation in physical exercise helped to protect cognitive health for those with mild cognitive impairment and early stage dementia. Ratey and Loehr (2011) reviewed the literature relating to the impact of physical activity on cognition in adulthood. An important finding of the review was that regular physical activity in midlife has a protective effect against cognitive decline in later adulthood. They argued that movement improves cognitive performance and delays age-related cognitive decline through multiple neural mechanisms that support improved brain function.

A systematic literature review of the evidence for occupational interventions for people with dementia found there was a limited amount of high quality evidence supporting the effectiveness of interventions aimed at helping people with activities of daily living (ADLs) such as washing, dressing, eating or personal hygiene (Letts et al, 2011). Most of the available evidence related to self-feeding and while some strategies showed promise the authors recommended further study using a more rigorous study design. The authors did find that interventions aimed at improving participation in instrumental activities of daily living (IADLs) showed promise, including a therapeutic cooking program, modified telephones and environmental assessment of the home and compensatory strategies aimed at improving quality of life. The most promising leisure interventions were those that incorporated both leisure and social interaction. The effectiveness of social participation interventions often relied on the person's stage of dementia. They concluded that tailored activity based leisure interventions had positive impacts and social participation interventions for people with early to middle stage dementia had short-term positive effects (Letts et al, 2011).

Troy and Zisis (2012) reported on a client centred case management program for people with younger onset dementia and their carers in Western Sydney. Clients identified physical well-being, muscle strength and maintaining good health as a high priority. Physical activity was identified as a way of addressing this need. A group-based physical activity program that included a tailored program for each client was developed. While there was no formal evaluation of the program there was positive client feedback. It was noted that the program was easy and inexpensive to run.

A well designed trial of an exercise program for people with late onset Alzheimer's and their carers found that engaging in an exercise program was able to delay the cognitive decline of participants (Pitkala et al, 2013). Study participants were randomised to one of three groups, group exercise (GE), a home-based exercise program (HE) or usual care (CG). The authors were able to show that the physical and cognitive functional decline of people with Alzheimer's disease could be slowed through an intensive, tailored, home-based exercise program without causing harm or risks or increasing the cost to the health service. The authors gave several reasons why the HE program may have been so successful. Firstly, it was tailored to the person's needs. Secondly, the exercise was of an intensity and duration to be effective. Thirdly, the physiotherapists delivering the intervention were trained to treat patients with dementia. Finally, adherence to the exercise program was very high among home-based participants.

Interestingly the authors (Pitkala et al, 2013) found that the group exercise program was not as effective as the home-based tailored program in reducing physical and cognitive decline but there was a decrease in the use and costs of other health and social services. The authors suggested that participation rate was not as high for the GE group as for the HE group, although

carers preferred the GE program. The authors suggested that reduced health care costs resulting from the GE program may be more due to the respite it provides for carers. In addition both exercise programs also reduced the number of falls participants experienced but not the number of fractures or hospitalisations for falls. Unfortunately the trial was not focussed on people under the age of 65, however, given the better physical condition of people with younger onset dementia this program merits further investigation.

The study by Phinney and Moody (2011) observed the benefits of a guided leisure activities support group that included activities such as flexibility exercises, ball games and dancing. The activities appeared to be an important part of a successful program that filled a gap in services for people with early stage dementia.

Physical activity may have a positive effect on cognition, particularly in relation to delaying cognitive decline. Physical activity also has the potential to reduce health care costs relating to the care of people with dementia and their carers. Where physical activity and/or physically active leisure pursuits have been included in programs for people with younger onset dementia they have been well received. Physical activity also works well when provided as part of a support group. Physical activity and physical pursuits appear to be most effective when tailored to the needs and abilities of the participants.

6.2.5 Horticultural therapy

There were several papers that looked at horticultural therapy for people with dementia or related conditions. Cook (2011) noted that physical activity was very important for younger people with dementia as they tend to be physically well. Gardening provides more than just physical activity. There was no high level evidence relating to horticultural therapy however, with conclusions drawn from qualitative studies only.

Cook (2011) described the Medway Horticultural project for people with dementia. There were 10 participants involved in the project, who met once a week to participate in a gardening program. Other activities, such as craft and outings, were added later to broaden the program but gardening remained the main focus of the program. The project allowed participants to be physically active, be supported as their abilities declined, use skills that they would not use at home (e.g. planting bulbs, identifying plants and passing seasons and weeding), gain enjoyment and sensory stimulation (visual and tactile), to develop sense of achievement through creating something others can enjoy, and to develop a sense of belonging and security. In addition, limiting the numbers in the group helped participants avoid a crowded or noisy environment that may cause anxiety or distress. Much of the group's activities also focussed on the sensory aspects as these were important for people with limited communication abilities. High staffing levels were also integral to the success of the program.

Another study examined the benefits of a structured gardening program for people with younger onset dementia (Hewitt et al, 2013). The program provided 2 hours a week of gardening for participants. The study ran for 1 year using a mixed methods design. Carers were given standardised pre and post measures relating to activities of daily living and cognitive function to fill out on behalf of the person with younger onset dementia. They were also interviewed to gain their perspective on the benefits of the program for the person with younger onset dementia. Carers reported that the project gave the participants with younger

onset dementia a renewed sense of purpose and increased well-being, despite their cognitive function continuing to decline during the study. In particular, the study suggested that well-being can be maintained even in the presence of cognitive-decline. The authors also noted that the use of a carefully constructed control group in further studies may allow comparison between the benefits gardening activities and activities in general. They also noted that interviews with people with younger onset dementia may better capture their experience. In summary the authors argued that a structured gardening program may be an effective way of meeting the needs of younger more active people with dementia.

A gardening program at a residential facility in the UK for people experiencing cognitive decline due to Huntington's disease was described by Spring et al (2013). To evaluate the program staff and visitors completed a questionnaire and interviews and the residents completed a pictorial questionnaire. The authors found that the garden activity was associated with a perceived sense of happiness by participants. Staff and visitors felt it was important for residents to go outside and the garden had helped to facilitate this. The garden also facilitated social interaction. Staff also noted improved mood, interaction and quality of life in those who gardened. Results were positive regarding the value placed on the program by clients, staff and visitors and the therapeutic benefits (e.g. well-being) experienced by the clients (Spring et al, 2013).

Horticultural based therapy programs for people with younger onset dementia show promise but further studies with more rigorous research designs on the effectiveness of this type of program for people with younger onset dementia are warranted.

6.2.6 Volunteering/supported workplaces

The idea of younger people with dementia being involved in volunteering or supported workplaces is a more recent development. Kinney et al (2011) stated that younger onset dementia is disruptive to the life trajectory, affecting various aspects of normal life, including employment and career development. Silverstein et al (2010) in a study of a day health care program for people with Alzheimer's, notes that for clientele under the age of 65 there was a need for this group to be doing activities that helped others such as helping staff or helping older people with dementia. Staff noted that it was important to give younger clients jobs to do, as though they were 'volunteers' not clients. The authors stated that people with younger onset dementia appeared to gain satisfaction from, and maintain self-esteem through, undertaking responsibilities within the program.

Kinney et al (2011) reported on an interesting program involving volunteer work at a local zoo for people with younger onset dementia. The "Get out of the House" program involved a weekly 2 hour supervised volunteer work session at a zoo. The authors conducted semi-structured interviews with participants. The authors found that the participants strongly identified with the program, they developed a closeness/bond with other participants and selected animals, they gained socialisation benefits from the program, participants had a shared understanding that the program allowed them the opportunity to help others and gain insight into their own and others experiences with the program.

An Australian study by Robertson et al (2013) showed that it was possible to successfully engage younger people with dementia in a supported workplace program. In a demonstration

program of a supported workplace engagement program for people with younger onset dementia, participants worked in a large hardware store environment and were matched with a work buddy who was a trained worker. All of the younger onset dementia workers were able to adapt to the workplace and carers and family members reported a positive impact on self-esteem and life satisfaction. The program exceeded all expectations and demonstrated that it was possible to offer meaningful activities for people with mild dementia if appropriate support is provided.

Stansell (2001) also reported on a program helping people with dementia participate in volunteer work. It was not clear how effective the program was as the author provided personal observations only. These included the need to establish clear inclusion criteria for the group, consider safety issues (especially getting lost) and a sensitive transition process as the person's condition deteriorates. It was also noted that while there was some caution regarding volunteers with dementia early in the program once public awareness of the group was raised there was an increasing level of requests for the group to participate in volunteer work. An issue for the program was that it required further funding for the program to continue.

Research relating to volunteering and employment for people with younger onset dementia is sparse but shows promise. There appears to be the potential for benefits for participants relating to helping others such as improved self-esteem and life satisfaction. Further research on programs supporting the involvement of younger people with dementia in volunteering or supported wok environments is warranted.

6.2.7 Arts and creative therapy

Phillips and Conn (2009) argued for the use of creative expression interventions such as storytelling, visual arts, dance and movement, music and song writing, and dramatic arts in dementia care. They argued that these interventions represented innovative non-pharmacological approaches to dementia care but that the effective aspects of these programs need to be identified and linked to relevant outcomes for people living with dementia.

Only two studies were identified that related to arts and creative therapy, both of which only constitute a low or emerging level of evidence.

Leuty et al (2013) used an art therapy based intervention for older adults but used an artificially intelligent assistive device (ePAD) to engage participants with dementia. This study was primarily concerned with assessing the usability of the software/IT and did not evaluate the effectiveness of the art therapy program itself.

Agnihotri (2009) conducted a study of theatre/drama therapy for adolescents with Acquired Brain Injury. The study attempted to observe whether arts-based therapy could improve social cognition and community integration. Results were encouraging, however, the study numbers were small and further study would be needed to determine the value of this approach for people with younger onset dementia.

Currently some research is being undertaken by the Alzheimer Scotland Dementia Research Centre at the University of Edinburgh (Jenkins, ASDRC 2013) which is using a drama program to

explore client experiences of early onset dementia and to assess client priorities for health and social care policy and practice but no findings have been published to date.

There was little research on programs using arts or creative expression therapy for people with younger onset dementia found for this review. While this appears to be an innovative way of engaging people with younger onset dementia no conclusions can yet be drawn.

6.2.8 Cognitive stimulation

This review has identified some evidence for the effectiveness of cognitive therapies and/or cognitive stimulation for dementia. Cognitive therapies (such as memory rehabilitation) were recommended as a treatment for mild cognitive impairment in a recent of the evidence for non-pharmacological interventions for early stage dementia (Burgener et al, 2009).

As mentioned earlier a controlled study by Laudate et al (2012) found that the game Bingo, when conducted as a series of games on a computer touch screen, was a valid way of maintaining client cognitive function. That the study showed improvements in younger control subjects as well as people with Alzheimer's disease, may suggest there are benefits for people with younger onset dementia. The authors found that the Alzheimer's disease group benefitted most from strengthening the visual stimulus component of the game. When the touch screen contrast was increased and the complexity reduced the cognitive function of people with Alzheimer's disease improved more when compared to both older and younger controlled groups and when compared to people with Parkinson's disease. The authors argued this was probably because of the visual deficits often experienced by people with Alzheimer's disease. Other benefits of Bingo included the social aspects, which also improved cognition.

A randomised controlled trial conducted by Knapp et al (2006) looked at the cost effectiveness of cognitive stimulation for people with dementia. Cognitive stimulation therapy groups were held twice a week for 7 weeks with groups lasting for 45 minutes each. The authors found that cognitive stimulation therapy had benefits for cognition and quality of life in dementia and yet the costs relating to health care resources use were the same between intervention and control groups. The authors argued that under reasonable assumptions, there is a high probability that CST is more cost-effective than 'treatment as usual', due to the benefits to health and quality of life for participants.

Although very few studies of cognitive therapies for dementia were identified, the evidence appears to be of a higher level. The focus of research was on the general population rather than people with young onset dementia specifically. Further research on cognitive therapies for people with younger onset dementia may be warranted.

6.2.9 Fronto-temporal dementia (FTD)

It has been noted that people with fronto-temporal dementia are often diagnosed at a younger age (Korte & Rogalski, 2013). A review of the evidence for programs for younger people diagnosed with fronto-temporal dementia (Korte & Rogalski, 2013) found that neuro-rehabilitation interventions and community- based activities have the potential to benefit both the individual with behavioural variant FTD (bvFTD) or primary progressive aphasia (PPA) and the caregiver. Community-based activities included support and activity groups. The authors noted that it may be difficult for people with bvFTD to find an FTD specific group, however,

groups for people with young onset Alzheimer's may be a good match as they may be facing similar life circumstances. The authors argued that behavioural interventions should be a standard part of the care offered to individuals with fronto-temporal dementias.

Shnall et al (2013) reported on an initiative to develop support services for people affected by fronto-temporal dementia (FTD), including people diagnosed with FTD and their cares and family members. Part of the strategy was a day care intervention designed specifically for people with fronto-temporal dementia (FTD) that included activities such as exercise, arts and crafts, music and meal-times. The study found that while participants with severe behavioural disturbances showed the most improvement over the course of the study, even the mildly affected individuals seemed to benefit from their day programme activities. Results were preliminary but encouraging.

Metcalfe (2013) also showed that using a relationships-centred care model helped in improving communication for people with fronto-temporal dementia.
While people with FTD have specific needs that are different from people with Alzheimer's disease, they may be suited to programs designed for people with younger onset dementia.

6.2.10 Assistance Programs

Two Australian assistance type programs were identified in our search that aimed to improve the quality of life of younger people with dementia.

The Linking Lives project in Victoria (Moore & Renehan, 2011) involved employing 2 part time key workers (3 days per week) to provide an individualised response to younger people living with dementia and their carers. An evaluation of the program found that the program generally met the goals of people living with dementia, including finding out more about services, finding out more about dementia, meeting other people with younger onset dementia and their families and increasing socialisation. On the other hand the program only met some of the goals identified by carers, such as the goal of meeting other people with dementia and their carers and family members, but not the goal of finding out more about dementia. They also found that changes in outcome measures (burden, quality of life and psychological distress) were mixed but that there was a strong positive response to the project from clients and carers.

As discussed above, Troy and Zisis (2012) reported on a case management and community options program for people with younger onset dementia and their carers in Western Sydney. The program involved a physical activity group for people with younger onset dementia and one off 'retreats'. While there was positive client feedback there was no formal evaluation of the program. Further research relating to the case management aspect of the program should be undertaken.

Willis et al (2009) evaluated a memory service in the UK that incorporated a multidisciplinary team of which any team member could act as a key worker for clients and their carers. The key worker role included case management for as long as it was needed. The evaluation included interviews with people with Alzheimer's disease and their family/carers about their satisfaction with a memory service. When asked about the staff, clients and carers stated that the staff behaved in an acceptable manner, were appreciated and clients and carers felt comfortable with staff. There were no specific outcomes collected in relation to the key workers but

recommendations were given that staff should be considerate and professional, available to answer questions and address issues when they arise and provide clear communication about diagnosis and care provided (Willis et al, 2009).

A study by Harris (2004), in which 23 younger people with dementia were interviewed, found that social workers dealing with such clients need training in the special needs and challenges of people living with younger onset dementia.

Logsdon et al (2007) conducted a review of programs aimed at improving the quality of life of people with dementia. They took a rigorous approach, including only those studies that were randomised controlled trials. They found evidence for interventions that provided training and support to family caregivers which used a standard program that could be individualized to meet the specific and unique needs of participants and provide a means to identify and solve implementation problems. Further research with a focus on programs for people with younger onset dementia would be of interest.

A review of evidence by Martin et al (2013) also found that self-management is possible for people with dementia but that further research is needed with a strengths focus and an emphasis on quality of life.

6.2.11 Conclusion

The search identified a broad range of programs for people with young onset dementia or programs that may be relevant for people with young onset dementia. Overall the level of evidence was low with most studies only rated as emerging practice or acceptable practice. There were few higher level evidence studies that used a controlled trial or a randomised controlled trial study design.

The strongest evidence that was identified supported the inclusion of physical activity in programs with evidence that it can help to delay cognitive decline. Cognitive stimulation techniques also appeared to have positive therapeutic outcomes in improving cognitive function. Physical activity was also shown to be an effective way to reduce health care costs related to dementia and it was also noted that cognitive stimulation techniques were also likely to prove cost effective.

Interventions such as support groups showed promise. Although there were some examples of well evaluated programs with positive results much of the evidence base was poor due to the use of a less rigorous study designs. The Living with Memory Loss Program was an example of how a more rigorous study design can be effective in providing tangible results. Evidence suggests that support groups show promise if these groups are tailored towards the needs of those with young onset dementia. Support groups for people with fronto-temporal dementia are also valuable but it may be difficult to find enough people in one location to establish a group. Further research into the effectiveness of support groups designed specifically for people with young onset dementia is required.

Other programs that showed promise include horticulture-based therapy, volunteering and supported workplace participation and arts and creative therapy. Day care programs have some

merit where they are tailored for the needs of their clients, specifically for people with fronto-temporal dementia.

Technology shows promise in assisting people with dementia link in with services and with other people with young onset dementia. Given that people with young onset dementia are often diverse in location, technology such as email may be able to assist this group to link with other people in similar circumstances. Various devices have also been used to help people with dementia engage with activities and to help cognitive function. It is important to note that technology such as computers and phones may present added complexity for people with impaired cognitive function.

Assistance programs, such as the Australian key worker program also show promise and warrant further research into their effectiveness.

6.3 Programs for Carers and Family Members of People Living with Younger Onset Dementia

There were fifteen papers that evaluated programs for the carers of people with younger onset dementia and their families. Of these, two papers reported on literature reviews and thirteen papers reported on studies or interventions, one of which was a randomised controlled trial. There were five papers authored by research teams in the USA, four from Australian research/evaluation teams, three from Canadian researchers and three from the United Kingdom.

The programs and studies identified did not all exclusively focus on either carers or families. For this review we have included studies and programs that were aimed at carers as well as studies and programs aimed at the person with dementia and their carer or family member. There were seven studies or programs that were aimed solely at carers/family members and seven that were aimed at the person with dementia as well as the carer.

A smaller range of topics were identified in relation to carers but there were also a number of similarities with topics identified for people with younger onset dementia above. In particular there were a number of papers that examined ways to support carers in their caring role. Some studies and programs discussed group support for carers while other examined more individual support strategies such as key workers or training and individual follow up. Only one papers looked at carers and the use of gardens. There were several papers that reported on the use of technology to support carers and family members, mostly to help link carers and family members with other carers or family members or services. The two literature reviews evaluated programs used to reduce psychological symptoms and behavioural interventions to assist carers.

Table 5 Programs for Carers and family members of People with Younger Onset Dementia

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
Batsch & Miller (2009)	USA	An assessment of needs for serving individuals diagnosed with early stage Alzheimer's disease.	Focus groups	Acceptable practice	Early stage AD	20 clients and 19 family members	Carers wanted more information about the disease, financial and legal issues, sources of help, what to expect in the future and understanding from others who knew what they were going through
Bird et al (2005)	Australia	Early Stage Dementia Support and Respite Project: Living with Memory Loss (LWML) program.	A repeated measure, wait-list control study	Acceptable practice	People with early stage dementia and their carers	84 clients and 87 carers at 3 month follow-up (FU). 52 and 58 respectively at 15 month FU.	DoHA ran time limited support groups for people living with memory loss and their carers in each State and Territory. Baseline, 3 month and 15 month measures collected. Significant impacts were noted for carers and people with memory loss, including high satisfaction for both groups, a significant improvement in depressive symptoms for people with memory loss and a reduction in carers stress.
Brodaty et al (2003)	Australia	Meta-Analysis of Psychosocial Interventions for Caregivers of People with Dementia	Systematic literature review	Literature review	Care givers (CG) of people with dementia or Alzheimer's disease	30 studies (34 interventions)	Some CG interventions can reduce CG psychological morbidity and help people with dementia stay at home longer, e.g. carer training, structured counselling and support by professionals
Carr et al (2013)	Australia	Caring for carers: Evaluation of a support program for carers of people with dementia	Evaluation used an action research methodology. Stakeholders were interviewed at three time points.	Acceptable practice	Carers of people with moderate to severe dementia	25 carers	The Caring for Carers program provided training and follow-up support. The program was tailored to each carer's needs. The program was effective in reducing carer stress/burden and improving their sense of wellbeing. Carers also felt more adept at coping with their caring responsibilities.
Chapman et al (2005)	USA	Encouraging the development and use of gardens by caregivers of people with dementia	Formative evaluation using observation, post session evaluation sheets and 3 month follow-up visits to facilities.	Emerging practice	Carers of people with Alzheimer's and other types of dementia	NA	The program aimed to teach carers how to use the garden with the person they care for and for themselves as a form of respite. Observation of garden use found that the garden was used by a range of people, including carers. Residents and carers participated in scheduled garden activities. Formal carers/residential activity staff were also taught how to use the garden for activities with people with dementia. Participant's gardening knowledge increased.
Charlesworth et al (2008)	United Kingdom	Does befriending by trained lay workers improve psychological	A randomised controlled trial. Interviews were conducted with	Well supported practice	Carers of people with dementia	A total of 236 carers were randomised	Access to a befriender facilitator is not an effective or a cost-effective intervention. Some weak beneficial effects were identified for clients with depression that may

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
		well-being and quality of life for carers of people with dementia, and at what cost?	participants at 6, 15 and 24 months.			into the trial (116 intervention; 120 control)	warrant further study
Gaugler et al (2011)	USA	The Memory Club: Providing Support to Persons with Early-Stage Dementia and their Care Partners	A multi-site, pre-/post-test evaluation. Participants were screened (assessed), and completed a survey before the first session (T1) and then completed a second survey during the last session (T2).	Acceptable	People with memory loss (PWML) and their care partners	63 people with memory loss and 61 care partners	A multi-site pre/post evaluation of the support group found that the most important benefits were in offering information and education to carers. They also found that the Club helped prepare carers for the future and that including the person with dementia in that process may have helped to facilitate this
Harvey et al (1998)	United Kingdom	CANDID-Counselling and Diagnosis in Dementia: a national telemedicine service supporting the care of younger patients with dementia.	A retrospective review of all calls received by a telephone helpline over a 2-year period.	Routine practice	People with dementia and their carers	1121 calls made to the service.	CANDID provides direct access, by telephone and e-mail, to specially trained nurse/counsellors. 241 registered callers made 547 calls. The remaining 574 calls were from the general public and health professionals. The service, linked with primary care for people with YOD, was readily taken up by patients, carers and the general public but less so by health professionals. Of all calls 61% were from carers
Hayter (2008)	Australia / NSW	Flexible and Responsive Evaluation of The Younger Onset Dementia Social Support and Respite Program	Interviews with carers and staff	Emerging practice	Younger people living with dementia and their carers	6 people with YOD and carers	A support program for people with YOD and carers – provided activities and peer support to people with YOD, and a support group for carers. The support group met carer needs through forming connections with other carers but the evaluation also indicated a need for a case manager to assist carers
Korte & Rogalski (2013)	USA	Behavioural interventions for enhancing life participation in behavioural variant fronto-temporal dementia and primary progressive aphasia	Review of evidence	Literature review	People with younger onset fronto-temporal dementia and their carers	37 papers were included in the review	The authors argued that behavioural interventions should be a standard part of the care offered to individuals with bvFTD and PPA. Neuro-rehabilitation interventions and community- based activities have the potential to benefit both the individual with FTD and the caregiver
Moore & Renehan (2011)	Australia / Vic	Evaluation of the Linking Lives Project: Final Report	Pre and post measures of responses to validated tools, participant focus group plus participant and key worker	Acceptable practice	Younger people living with dementia and their carers	5 people with dementia, 9 carers	The Linking Lives Project aimed to deliver and test an individualised response to the needs of each client and carer through the employment of 2 part- time (3 days per week) “key workers”. The changes in outcome measures were mixed, and there was strong positive response to the

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
			interviews.				Project from clients and carers
Nicholls et al (2013)	Canada	Needs assessment survey for young caregivers of people with fronto-temporal dementia.	Two focus groups were held with young carers of people with FTD	Emerging practice	Young carers of people with fronto-temporal dementia	14 young caregivers aged 11-18 years	Focus groups gathered information on experiences and challenges of being a young carer of a parent with dementia. A website for young carers was developed using the evidence gathered
O'Connell et al (2013)	Canada	Development and evaluation of videoconference support group for rural spouses of individuals diagnosed with YOD	Qualitative methods were used including attendance data, workshop attendance and discussion analysis.	Emerging practice	Carers of people with dementia	10 carers participated	A monthly 90 minute meeting facilitated by tele-health videoconferencing, equipment use training, monthly email telephone reminders and an 18 month in person workshop. The authors found that group interventions for caregivers need to be specialized and, therefore, only include family members caring for individuals with similar diagnoses (e.g. Alzheimer's, FTD) to maximize effectiveness. The group was still in operation after three years.
Shnall et al (2013)	Canada	Development of supportive services for FTD through community engagement: Carer support group	Feasibility study of internet based videoconferencing in which spouses were interviewed about their participation and experiences with the program.	Emerging practice	Carers of people with FTD	Not stated	A video conference group was found convenient for carers who may find it hard to attend a face-to-face group given their various roles on top of their caring role
Shnall et al (2013)	Canada	Development of supportive services for FTD through community engagement: Focus groups with young people	To develop a website, focus groups with children aged 11-18 were used to develop appropriate content.	Emerging practice	Children of people with FTD	14 children over two focus groups	The results of the focus groups were used to develop a website which features content for teens and advice for well parents. An evaluation of the website is planned
Ryder-Jones et al (2012)	United Kingdom	Wii can make a difference	Well- being profiling	Emerging practice	Younger people living with dementia	7	Use of Wii technology to engage people into games. Improvements in social interaction within the group as well interaction with intergenerational family members were observed
Webster and Duncan (2005)	USA	E-mail Connections: An Innovative Communication Network for Families and Persons With Early-onset Alzheimer's	Description of program development. No evaluation. Unsolicited feedback from participants about the program is reported.	Emerging practice	People with young onset Alzheimer's, their carers and family	Currently, there are 134 family units and 42 professionals from 20	The connections database has three lists: care partners (spouses/ significant others), persons with dementia and adult children of persons with YOD. The Care partners connections was the largest of the 3 groups. This was an innovative program using technology that may be accessible for younger age groups who are familiar with

Author & Year	Country/ State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus	Study Nos.	Summary
						states on the database	emails and communicating in this manner. This article describes the development of the program. Benefits and issues are yet to be determined

6.3.1 General program evidence

Batsch and Miller (2009) conducted an assessment of needs of people with Alzheimer's disease and their families/caregivers. They included 19 family members/ caregivers in focus groups separate from their care recipient and were asked to rate the value of 15 different programs. Carers wanted more information about the disease, financial and legal issues, sources of help, and what to expect in the future and understanding from others who know what they're experiencing.

A literature review of psychosocial interventions for carers of people with dementia (Brodaty et al, 2003) also identified a number of successful and unsuccessful program elements. Successful interventions included both the carer and the person with memory loss in structured programs, such as teaching the carer problem solving skills to help in the care of the person with memory loss. Other important aspects included the provision of practical support for the carer, involvement of the extended family, structured individual counselling and a flexible provision of a consistent professional to provide long-term support (Brodaty et al, 2003). The authors found that unsuccessful interventions were short educational programs, support groups alone, single interviews, and brief interventions or courses that were not supplemented with long-term contact.

6.3.2 Individual support for carers

Individualised support for carers includes programs aimed at assisting carers with their specific needs. It was noted from an evaluation of a support group in Sydney (Hayter et al, 2008) that there was a need for a case manager or 'navigator' who could help carers and people with younger onset dementia from the point of diagnosis to the accessing of services. Brodaty et al (2003) also noted that there was a need for a professional who could be there on an ongoing basis (e.g. case manager or key worker) to provide long term support.

The evaluation of the Linking Lives Project (Moore & Renehan, 2011) described in section 6.2.10 above, also examined the benefits of a key worker approach for carers. Although more in depth data on carers was sought for this evaluation the authors were not able to get the feedback they planned. The changes in outcome measures were therefore mixed but there was a strong positive response to the Project from carers.

Charlesworth et al (2008) conducted a randomised controlled trial of whether access to a trained 'befriender facilitator' improve psychological wellbeing and quality of life for carers of people with dementia when compared to usual care. The authors did not find the intervention effective or cost effective with all comparisons between the control and intervention group not reaching significance except for some weak beneficial effects relating to depression at 15 months for the intervention group ($p = 0.044$, unadjusted analysis). This finding did not hold up when scores were adjusted for area, kinship and the Hospital Anxiety and Depression Scale (HADS) (Zigmond et al, 1983) score ($p = 0.67$). The authors recommended a further study relating to the depression findings. It was also noted in section 3.1.1 above that befriending of people with dementia had not proved to be a cost effective intervention (Ratcliffe, 2013).

Although there have been mixed results relating to individualised support there is a case for further research of this approach. There is evidence that programs that respond to carers individuals needs are warranted. A meta-analysis of psychosocial interventions for carers of

people with dementia (Brodaty et al, 2003) included 30 studies of 34 interventions and found that some interventions can reduce the psychological burden of caregivers and this might help people with dementia stay at home longer. The authors found that elements of successful interventions were the inclusion of patients and their families and interventions that are more intensive and modified for the care giver's particular needs.

6.3.3 Group support for carers

Support groups are aimed at meeting the information and support needs of carers of people with dementia. There were few support groups identified for carers of people with younger onset dementia. There were two studies found that reported on an initiative that was specifically for carers of people with younger onset dementia. Both of these groups were facilitated by videoconferencing.

A Canadian study aimed at carers examined how a tele-health videoconference support group could help rural spouses of people diagnosed with atypical early onset dementia (O'Connell et al, 2013). A monthly 90 minute group was facilitated via video-conferencing. The group, consisting of 10 carers, was still in continuation three years after its inception. It was also noted that the group interventions for caregivers need to be specialized, i.e. caregiving in similar circumstances is critical and, therefore, it should only include family members caring for individuals with similar diagnoses to maximize effectiveness. For example, imparting information about dealing with disease specific behaviours was most effective when participants all had experience as a carer of someone with that specific disease. The authors suggested further research to compare the benefits of specialised groups for carers (e.g. Alzheimer's only or younger onset dementia only) to those of carer groups of a more general nature.

Shnall et al (2013) looked at the development of support services for people with fronto-temporal dementia as described in section 6.2.9 above. Part of this was the development of a support group via videoconferencing for spouses of people with fronto-temporal dementia. The videoconference allowed for a remote link at a convenient time. Carers noted that, due to work and other responsibilities, such as caring for children, they would not have been able to attend a face-to-face support group. The on-line group allowed accessibility from a remote location at a convenient time while still being able to provide face-to-face support and education. This type of intervention allowed spouses to gain support when they could not access other types of services.

Shnall et al (2013) also describes a focus group conducted with children of people with fronto-temporal dementia. Results of the focus groups found that children tend to take on the responsibilities of care giving but don't view them as a burden. Children also appeared to mature more quickly and had a more mature understanding of their priorities. They attributed changes in the affected parent to the disease, separating the disease from their parent. Children suffered latent grief concerning the 'loss' of their former parent. Children feared overwhelming the parent without dementia with their own needs and fears. They felt they needed to protect the well parent. Hesitation to express their feelings openly to family members made it more difficult for family members to find common ground. Parents were encouraged to seek help as a way of helping their children to also seek help. The results were

used to develop a website which features content for teens and advice from veteran teen caregivers to well parents. An evaluation of the website is planned.

There were three other studies of support groups that included both the carer and the person with dementia that also reported on outcomes for the carer and not just the person with dementia.

The Living with Memory Loss Program (Bird et al, 2005) noted earlier also provided some encouraging evaluation results in relation to support groups for the carers of people with dementia. The authors collected baseline, 3 month follow-up and 15 month follow-up outcome measures for participants with memory loss and their carer. There was a high level of satisfaction among carers regarding the groups. There was a significant reduction in stress for carers at the end of the LWML groups and at three months follow-up. This change was most likely due to the group itself and was not due to an increase in service use by the carer or changes in cognitive or functional status of the person with memory loss that may have contributed to a reduction carer burden.

An evaluation of a support group located in the inner west of Sydney for people with younger onset dementia and their carers (Hayter, 2008) found that the group met the needs of people with younger onset dementia and their carers. In particular the support group helped to form connections between carers of people with younger onset dementia, allowing them to support each other. This evaluation report also indicated the need for a case manager or 'navigator' that can assist carers (and people with YOD) from the point of diagnosis to the accessing of services.

A support group in the USA called The Memory Club was set up to support people with early stage dementia and their carers (Gaugler et al, 2011). A multi-site pre/post evaluation of the support group found that The Memory Club's most apparent benefits were in offering information and education to care partners (a family member who may or may not be the primary caregiver) in preparing for the future. One of the major benefits of the Memory Club was its ability to motivate and engage care partners in preparing for the future needs of their relatives suffering from early-stage dementia. It was found that including the person with early stage dementia in these information and education sessions may have helped facilitate the carer partner's preparation.

Carr et al (2013) reported on the development of a program in Victoria for carers of people with moderate to severe dementia, Caring for Carers (C4C). The C4C program provided eight weeks of training and 24 weeks of follow-up support. They used an action research approach to evaluate the program, which included 25 carers. Interviews were conducted at the commencement of training, after the training stage and during the follow-up period. The authors reported positive feedback from the carers, with the one-to-one follow-up support provided being the most valued by carers. The program improved communication between carers and formal care workers, thus improving the carer's knowledge of and access to available services. Further research was also recommended by the authors including the integration of the C4C program into community services in Victoria, earlier support for carers, carer support plans and assessing the costs and benefits of the C4C program.

A systematic literature review looking at behavioural interventions for people with fronto-temporal dementia (Kortte & Rogalski, 2013) found that carers can be helped through training in managing behavioural problems and communicating with their family member with fronto-temporal dementia. The authors found that while further research on effectiveness was required it was clear that caregivers benefitted from guidance on how to interpret the behaviour from their loved ones with FTD and by learning ways that they can help their family member through behavioural modification.

Support groups have the potential to reduce carer stress levels, provide needed information and education, help carers prepare for the future and help link carers of people with younger onset dementia with other carers. Using technology such as videoconferencing to overcome barriers such as remoteness and the often busy lives of carers who have many other roles as well have proved successful. Support groups that have a focus on both the carer and the person with dementia also appear to be well received and as noted Brodaty et al (2003), more successful.

6.3.4 Technology to support carers and family members

The use of technology in programs for carers of people with young onset dementia was also observed in the literature. This ranged from telephone-based counselling services to videoconferencing.

An early study of telephone counselling services found that they can help link carers with health professionals and have been shown to be readily taken up by carers of people with young onset dementia with 61% of calls being from carers (Harvey et al, 1998). The authors also found that the service was well used by families of people with younger onset dementia as well as the general public. The authors noted that that among the generic callers requesting clinical advice information, 58% concerned genetics. These calls were mostly from people with a family member affected by dementia who was worried about their own risk of developing the disease.

Webster and Duncan (2005) reported on an innovative communication network for people via email for people with younger onset dementia and their carers and families, who used the email connections program to link with others in similar circumstances.

Two Canadian studies that looked at the use of videoconferencing to facilitate support groups for carers of people with young onset and fronto-temporal l dementia (O'Connell et al, 2013; Shnall et al, 2013) proved to be both successful and sustainable. O'Connell et al (2013) reported that the tele-health connections used were a publicly funded secure network based at a local hospital site. High speed/high quality connection allowed for natural conversation from multiple, simultaneous speakers. Group members were able to navigate the system after one session of on-site individual training. Technical challenges did occur but these were mostly able to be overcome through on-line technical guidance from the facilitators.

An interesting study of young caregivers (aged 11-18 years: 71% female) of people with fronto-temporal dementia was conducted in Canada (Nichols et al, 2013). It was found that young caregivers saw the experience of tending to a parent with early-onset dementia as positive overall but identified opportunities for professionals to assist them in overcoming stigma and managing the challenge of balancing childhood and adolescent development within this

context. A website for young carers was developed using the evidence gathered but has yet to be evaluated.

The only use of other technology found was a reference to the use of Wii technology, a video game console developed by Nintendo. Ryder-Jones et al (2012) noted that introducing people with younger onset dementia to Wii games assisted their engagement with other family members, thereby reducing the level of isolation between family members. This may present an avenue for further research.

Communication technology has the potential to help link carers and family members with other carers and family members as well as facilitate support groups for remotely located or time pressured carers. The development of web-based information for young people in a caring role may need further investigation, although the potential to provide information for a wider group of recipients may also be considered.

6.3.5 Conclusion

A number of the programs identified for carers have to potential to provide those elements described by Batsch and Miller (2009) above, including individual support, support groups, carers training and communication technology. Studies on support groups for carers of people with young onset dementia were mainly rated as emerging or acceptable practice; however, they appear to have some merit. In particular the Living with Memory Loss program showed a reduction in stress levels for carers for at least three months.

The provision of individual support has not yet received a great deal of study and has provided mixed results, however, further study may be warranted given the need expressed for assistance with the process from diagnosis to access of services.

Training for carers has the potential to help carers understand their role and to deal with some of the more challenging aspects of caring. Further study of training needs and training effectiveness may be warranted.

The use of communication technology has been shown to be helpful in linking carers within a support structure and in providing information for carers. Communication technology may be a worthwhile investment in providing support for carers, particularly in remote locations and carers for people with younger onset dementia who may still have many roles (e.g. employment) in addition to their role as a carer.

The available literature relating to programs for the family members of people with younger onset dementia, such as children of people with younger onset dementia was sparse. Programs that did address the needs of family members were exclusively technology based, particularly communication technology. Telephone counselling shows promise and the use of email and websites to link family members and provide tailored information are innovative ideas warranting further study into the impact and effectiveness of these types of support. Other types of technology, such as Wii technology, have the potential to help strengthen family connections and relationships.

Support for other family members who are not the primary carer of the person with younger onset dementia appears to be an area in which more research could occur on how best to support this group through technology use or by other means.

Conclusion

A range of programs were identified for people with young onset dementia, their carers and family members. The majority of programs were aimed at the person with dementia and/or their carer. Only a few programs were aimed at other family members of the person with dementia. The majority of program studies and evaluations only provided a low level of evidence. There were some studies that provided a higher level of evidence but their results were sometimes mixed. Due to the low level of evidence no specific programs can be recommended. There are some types of programs that can be considered helpful or that warrant further research.

Programs that could be considered helpful include tailored physical activity programs and cognitive stimulation. Support programs, particularly those that include both the person with dementia and the carer, also appear to be helpful with promising results identified for the Living with Memory Loss program. People with younger onset dementia and their carers have specific needs that may be different to older populations with dementia and support groups need to be tailored for those needs. Facilitation of support groups through communication technology, such as email and videoconferencing, shows promise.

Programs that warrant further research include programs that provide individual support to people with dementia and their carers, such as case management or a key worker and carer training. Programs that provide active meaningful participation, including horticulture, volunteering or supported workplaces and creative expression programs also warrant further study with people who have younger onset dementia.

7 People with Younger Onset Dementia with Other Special Needs

7.1 Introduction

A relatively small number of people are living with younger onset dementia and as such they can be considered a minority group. However within that group there are even smaller minorities of people who can be considered as special needs groups because of particular characteristics. This section of the literature review discusses issues relating to a range of groups who are considered to have special need, as identified by the Aged Care Act, 1997 (as amended 2013), Section 11-3[1], :

- people from Aboriginal and Torres Strait Islander communities
- people from non-English speaking backgrounds
- people who live in rural and remote areas
- people who are financially or socially disadvantaged; and
- people who are veterans;
- people who are homeless or at risk of becoming homeless; and
- people who are care leavers (people who had been raised in care homes)
- people who are Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI).

In summary, the literature in relation to dementia and special needs groups was sparse and generally not specific to people with younger onset dementia. The literature identified ranged from emerging practice and expert opinion to mainly qualitative research with small samples. Nonetheless there were common themes identified about the particular issues impacting on these groups which are highly likely to be able to be generalised to people living with younger onset dementia. They include:

- Difficulty in obtaining an accurate and timely diagnosis (Blackstock et al, 2006; Lindeman et al 2010; Brown et al, 2012; Saunders, 2013))
- Denial of diagnosis (Blackstock et al, 2006; Brown et al, 2012)
- Concerns about privacy and confidentiality, and the use of personal information (Blackstock et al, 2006; Birch, 2008)
- Lack of appropriate services, including meaningful and purposeful interventions in day care settings, and culturally, linguistically and socially appropriate services (Saunders, 2013;Lindeman et al 2010; Blackstock et al, 2006; Moriarty, 2002; LoGiudice et al, 2012)
- Lack of available information about existing services (Blackstock et al, 2006; Furniss et al, 2011; Janicki et al, 2010; Saunders, 2013)
- Difficulties accessing existing services because of geographical location, lack of appropriate transport (Blackstock et al, 2006; Lindeman et al, 2010; LoGiudice et al, 2012; Saunders, 2013)
- Lack of appropriately trained staff (Blackstock et al, 2006; Moriarty, 2002; Lindeman et al, 2010; LoGiudice et al, 2012; Saunders, 2013)

[1] http://www.comlaw.gov.au/Details/C2013C00389

- Lack of, and need for person-centred and integrated service provision and personalised care packages (Moriarty, 2002; Blackstock et al, 2006; LoGiudice et al, 2012)
- Poor communication between service providers resulting in a lack of co-ordinated and/or duplicated care (Blackstock et al, 2006; Lindeman et al, 2010; LoGiudice et al, 2012; Saunders, 2013).

Additionally, the literature identified particular needs for some of these groups, as described further below. The literature is listed below in Table 6.

When considering these groups it is imperative to acknowledge that there are people living with dementia that may be classified under multiple special needs groups and therefore may experience disadvantage on a number of fronts (Saunders, 2013).

Table 6 Special Needs Groups

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
ACON (2010)	Australia	Building our community's health and wellbeing	NA -Submission to NSW Health on the Draft NSW Dementia Services Framework 2010-2015iu	Opinion	Dementia clients/carers	LGBTI		Submission providing background on the issues experienced by the GLBT community and people with HIV, recommendations to enable inclusion of these communities in the draft Framework
ADAHPS (2013)	NSW/ Australia	HIV complex case management	NA –project description	NA -	HAD/ADC	HIV/AIDs related dementia		A brief description of a service for the management of people with HIV associated dementia or other complex needs. There is a regional outreach service available provided through a consortium of Sydney based services which is currently being trialled
Alzheimer's Australia (NT) (2009)	Australia	"Looking out for Dementia"	NA - resources	Expert opinion	Dementia	Aboriginal and Torres Strait Islander people		http://www.fightdementia.org.au/northern-territory/looking-out-for-dementia.aspx A suite of themed resources developed to inform Indigenous people living in remote communities of Northern Territory about dementia; developed in English and three Indigenous languages; Djambarrapuyngu, Warlpiri and Kriol
Alzheimer's Australia (2007)	Australia	Dementia: A major health problem for Indigenous people	NA- parliamentary briefing	Expert opinion	Assessment tool - KICA	Aboriginal and Torres Strait Islander people		Briefing prepared for Parliamentary Friends of Dementia, describing evidence about high prevalence rates of dementia in rural and remote Indigenous people, research based on use of the KICA -cog, and six key action areas to be included in the National Indigenous Dementia Strategy; -community awareness and protection; care and support; research; diagnosis, referral and treatment; workforce issues; partnerships and collaborations
Archibald (2006)	UK	Gay and lesbian issues: learning on the (research) job	NA - review	Expert opinion	Dementia clients	LGBTI		The needs of gay and lesbian people are gradually being recognised in dementia care but progress is slow. Recommends that services review a range of issues which might overtly or covertly promote discrimination, including their documentation, training for staff, complaints procedures

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
Australian Bureau of Statistics (2012)	Australia	2071.0 - Reflecting a Nation: Stories from the 2011 Census, 2012–2013	Analysis of 2011 census data		NA	CALD		Cultural diversity in Australia: statistical analysis relating to cultural characteristics of Australians http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013 Who are Australia's Older People? http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features752012-2013
Australian Bureau of Statistics (2010)	Australia	4713.0 - Population Characteristics, Aboriginal and Torres Strait Islander Australians, 2006	Analysis of 2006 census data		NA	Aboriginal and Torres Strait Islander people		http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/759789BB6EAD0F03CA2578DB00283CBB?opendocument This section of the publication provides a broad overview of languages spoken at home by the Aboriginal and Torres Strait Islander (Indigenous) population of Australia using results of the 2006 Census of Population and Housing. The publication as a whole covers Indigenous population structure and distribution; mobility; household composition; language and religious affiliation; education; work; income; and housing and transport. Statistics are provided for Australia, the states and territories and remoteness areas, allowing for analysis of the potential impact of geographical isolation on social and economic outcomes, both within the Indigenous population and in comparison with the non-Indigenous population
Australian Institute of Health and Welfare (2000)	Australia	Disability and ageing Australian population patterns and implications	NA	Expert opinion	Dementia clients/carers	Down syndrome		Individual ageing of people with an early onset of disability – Down syndrome: complex multi-faceted presentation
Bagdonavicius (2009)	Australia	Looking back: looking forward - lessons learnt from redress	NA- conference presentation	Expert opinion	People with decision making disabilities	care leavers		Discussion around implications for people with decision making disabilities who experienced abuse as a child in state care which need to be considered during legal matters. In this case preparation of applications to Redress WA; issue of lack of knowledge among Department for Child Protection case workers across a range of legislation

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
Birch (2008) (for Alzheimer's Australia	Australia	Dementia, Lesbians and Gay Men	NA - overview	Expert opinion	Dementia clients/carers	LGBTI		A wide range of issues affecting lesbian or gay people with dementia or caring for someone with dementia were identified. These include fear of discrimination and actual discrimination; confidentiality and control over personal information; social isolation (particularly in view of numbers living alone); legal issues including changes to anti-discrimination legislation, access to superannuation and wills, advanced care planning issues; service provider issues e.g. discrimination and poor levels of knowledge and understanding about issues relating to LGBTI people
Blackstock et al (2006)	United Kingdom	Living with dementia in rural and remote Scotland: diverse experiences of people with dementia and their carers	Qualitative research	Promising practice	Dementia clients/carers	Rural and remote	31 dementia clients and carers	This study used a purposive sampling approach, seeking a diversity of carers and service users (i.e. those living with dementia) in eight rural areas of Scotland. Service provision in rural and remote areas faces the challenges of service accessibility, both physically (e.g. transport issues) and in terms of the availability of appropriate services which take account of the complex nature of this progressive disease. Other concerns raised included lack of choice of services, issues related to confidentiality and privacy, ambivalence about the relationship between community support and community surveillance and perceptions that the amount of support available may vary as the disease progresses Findings reinforce the argument that service provision for people with dementia and their carers should be need based rather than dictated by existing services and available resources
Broe (2013)	Australia	Preliminary results: Koori Growing Old Well Study	Project Census data	Expert opinion	Dementia clients	Aboriginal and Torres Strait Islander people		Conference presentation 16 May 2013 Alzheimer's Australia's 15th National Conference, Hobart. Three year study into how Aboriginal Australians age: a census of all resident Aboriginal people aged 60 years and over, across five urban and regional Indigenous communities; rate of dementia in Aboriginal Australians is three times that of Australia's non-Indigenous population

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
Brown et al (2012) (Alzheimer's Australia)	Australia	Service and support requirements of people with younger onset dementia and their families	Qualitative	Expert opinion	YOD clients/carers	Aboriginal and Torres Strait Islander people CALD	150 participants -170 contributions	Roundtables, in-depth interviews with people with YOD, family members/carers and service providers; questionnaires for people with YOD and family members/carers. Report is seeking to provide a comprehensive account of the service and support needs of people with YOD and their family members/carers
Calma (2007)	Australia	Social determinants and the health of Indigenous peoples in Australia – a human rights based approach	NA – workshop paper	Expert opinion		Aboriginal and Torres Strait Islander people		Workshop paper presented by Mr Darren Dick on behalf of Mr Tom Calma, Aboriginal and Torres Strait Islander Social Justice Commissioner at International Symposium on the Social Determinants of Indigenous Health, Adelaide, 29-30 April 2007. Social determinants theory recognises that population health and inequality is determined by many interconnected social factors. This paper utilised a human rights discourse to provide a framework for analysing the potential health impacts of government policies and programs on Indigenous peoples. Social determinants of Indigenous health in Australia were discussed in relation to links between health status and socio-economic status / poverty; linkages between perceptions of control and chronic stress; evidence of the health impact of Indigenous community control of health services; traditional ownership of land and health status and social determinants as a contemporary reflection of historical treatment
CLAN (2008)	Australia	A terrible way to grow up. The experience of institutional care and its outcomes for care leavers in Australia	Survey	Expert opinion	Care leavers	Care leavers	291 care leavers	A survey of 291/ 501 care leavers who were members of CLAN at 30 June 2006. Survey explored a range of demographics as well as issues around abuse in care, sexual abuse, working whilst in care, and emotional and behavioural outcomes

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
Clay (2002)	UK & Aust.	Community based respite – reaching rural areas	NA - discussion	NA	YOD	Rural		Description of innovative approaches for YOD services in both rural and metropolitan Western Australia - including mobile respite teams, the development of home clubs and home family respite
Dementia Collaborative Research Centres	Australia	Cognition Assessment Measures	NA - resources	Expert opinion based on literature review	Dementia	NA		http://www.dementia-assessment.com.au/cognitive/index.html Dementia Outcomes Measurement Suite (DOMS) is a Federal Initiative. These tools are designed to assist professionals in assessing dementia and related issues within all environments. The high quality tools provided are recognised as the most current for dementia assessment. Guidelines and scoring information are included to enable the delivery of improved assessment results while remaining easy to use
El-Mallakh et al (1993)	US	Neuropsychiatric program for HIV-infected individuals	Neuropsych assessment of 60 HIV & 20 AIDS patients	Emerging practice	HIV/AIDS clients	HIV/AIDS	60 HIV, 20 AIDS	Need for neuropsychiatric assessment of HIV and AIDS patients. Need to increase awareness of AIDS dementia & for the provision of appropriate service referrals
Furniss et al (2011)	UK	The views of people who care for adults with Down's syndrome and dementia: a service evaluation	Qualitative research	Emerging practice	Dementia clients and carers	Down syndrome	13 Down syndrome carers	Semi-structured interviews used to explore themes about caring and service needs; lack of information about process of diagnosis, course of disease and service availability, concerns for the future of the person being cared for and sustainability of current caring arrangements
Janicki (2010)	USA	Coping with dementia and older families of adults with Down syndrome	Survey	Acceptable practice	Carers	Down syndrome	17 Down syndrome carers	Primary carers of adults with Down syndrome using a range of instruments designed to assess caregiver strain, burden, concern, family health status and caregiver activity
Law Council of Australia	Australia	Australian anti-discrimination laws	NA	Legislation	NA	All Australians - Human rights		Description and links to legislation: Australia has obligations under a number of international human rights treaties to take measures to eliminate discrimination including on the basis of age, race, sex, pregnancy, marital status and disability http://www.lawcouncil.asn.au/lawcouncil/index.php/curre

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
								nt-issues/anti-discrimination
LoGiudice et al (2001)	Australia	Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders	Qualitative – retrospective analysis patient records	Expert Opinion	Clients attending a memory clinic: inclusive of people with dementia	Sample inclusive of CALD and English speaking clients	556 memory clinic clients	148 (28.2%) of clients were from a Non-English Speaking Background, the majority of whom were Italian (12.4%). Patients were classified into categories of dementia, functional psychiatric disorder (including depression), cognitive impairment other than dementia and normal. Clients from a Non-English Speaking Background with dementia presented at a later stage of their disease; were more likely to present with a functional psychiatric disorder (particularly depression) or have normal cognition compared with those from an English Speaking background Clients from a Non-English Speaking Background scored significantly lower on the cognitive assessment compared with the total sample
LoGiudice et al (2012)	Australia	Lungurra Ngoora - a pilot model of care for aged and disabled in a remote Aboriginal community - can it work?	Implementation and evaluation of a model of care over 12 months	Emerging practice	Older people/people with disability and/or mental health problems	Aboriginal and Torres Strait Islander people Rural and remote	22 elderly Indigenous people	A locally designed community service model of care for older people and people with disability and/or mental health problems in remote Aboriginal Australia was developed. The model was implemented and evaluated over 12 months. Provision of community care services increased from 140 to 2,356 services per month over 12 months. A range of benefits were perceived both for care recipients and the community generally with six local people being employed by the project. Care giver and wider community education needs were addressed The project demonstrated a successful collaborative service model which addressed care needs for the identified groups but it was limited by lack of ongoing funding
Marian (2008)	Australia	Paper presented at National "Surviving Care" conference	NA- conference presentation	Expert opinion	Various	Care leavers		Presentation included a report on a small qualitative study conducted in 1993-94 about life outcomes for women 10-15 years post “care” i.e. care for a child outside the family, such as State wards and foster children. A range of themes included increased levels of homelessness, educational deficits, mental health issues, exposure to domestic violence and sexual abuse
Moriarty	Australia	Innovation	Overview	Emerging	YOD & Carers	Rural and		Discussion re good practice for service provision for YOD

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
(2002)		Practice Section		practice		remote		based on examples in remote WA and London. Key points raised were: provision of meaningful and purposeful day activities; consulting clients and carers in designing services and integration with other YOD services.
National LGBTI Health Alliance (2013)	Australia	submission to Senate Standing Committee on Community Affairs	NA- submission to Senate	NA		LGBTI		Comment on Aged Care (Living Longer Living Better) amendment Bill 2013: regarding inclusion of LGBTI people as a special needs group. Older LGBTI people have experienced a lifetime of discrimination and persecution in many cases. Commentary regarding need for inclusivity of service providers
NSW Family and Community Services Ageing, Disability and Home Care (2012)	Australia	Appropriate HACC service models for people with younger onset dementia and people with dementia and behaviours of concern	qualitative research	Expert opinion	Dementia/YOD service providers and carers		78 service providers and carers	Consultation questions and a background paper were widely distributed through regional HACC and dementia networks. Four focus groups were held across the Metro North region of Sydney. Focus group participants included mainly service providers, but also 5 carers. Key message was that flexible service responses are needed to address client's particular needs
NSW Family and Community Services Ageing, Disability and Home Care (2012) CIRCA	Australia	CALD Dementia Strategic Model	literature review, report, model	Expert opinion	Dementia clients/carers	CALD		CIRCA undertook research on behalf of NSW DADHC involving a literature review and consultation with key stakeholders in order to develop a strategic model to support the development of dementia services appropriate to the needs of CALD communities in NSW. Research focussed on three target communities (Italian, Vietnamese and Chinese) in NSW. The literature review found that there was limited research about dementia and the needs of CALD communities and very limited research about dementia and the specific needs of the three target CALD communities. The consultations identified both similarities and differences between the target groups. Findings included that the impact of cultural background on attitudes to dementia were not clear, but cultural background appeared to influence attitudes to, and experiences of, caring

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
NSW Family and Community Services Ageing, Disability and Home Care (2012)	Australia	Look after your brain. A guide to dementia for Aboriginal people	NA - guide	Expert opinion	Dementia clients/carers	Aboriginal and Torres Strait Islander people		Guide to dealing with dementia with knowledge and dignity. Discusses causes, types and signs of dementia; how to reduce chances of getting dementia; how to care for someone with dementia; how to ask for help and where to seek help
Pires (2013)	Australia	DVD resources developed for culturally and linguistically divers communities in Australia	NA – community resource development	Emerging practice	Dementia clients/carers	CALD		Multicultural Communities Council Illawarra commissioned DVD resource for Wollongong's Portuguese community (2007) to address misconceptions about dementia, particularly stigma associated with dementia. Based on the success of this resource, further funding was made available in 2009 to produce resources for Ukrainian, Arabic and Serbian communities
Sansoni et al (2007)	Australia	The Dementia Outcomes Measurement Suite	Report	Literature Review	Dementia clients/ carers	CALD, Indigenous		Chapter 12 of Volume 1 addresses dementia assessment issues for those from a CALD or Indigenous background
Sansoni et al (2010)	Australia	Selecting Tools for ACAT Assessment	Report	Expert opinion	Dementia clients/ carers	CALD, Aboriginal and Torres Strait Islander people		Includes a review of assessment tools appropriate for those from a CALD or Indigenous background
Smith et al (2008)	Australia	High prevalence of dementia and cognitive impairment in Indigenous Australian	Cognitive assessments of rural & remote Indigenous Australians	Acceptable practice	Dementia	Y	363 Indigenous people (remote)	Undertook cognitive screening of 363 rural and remote Indigenous Australians 45 years and above and estimated the prevalence rate to be 12% - about 5* higher than for other Australian prevalence estimates provided by Jorm et al (2005) at 2.4%. Includes both YOD and LOD
Price (2010)	United Kingdom	Coming out to care: gay and lesbian carers' experiences of dementia	Qualitative	Expert opinion	Carers	LGBTI	21 LGBTI carers	Semi-structured interviews explored key themes related to LGBTI people caring for a person with a diagnosis of dementia. Data collection period was protracted (4 year period) as the target population was hard to recruit for a variety of reasons including reluctance to identify as LGBTI

Author & Year	Country / State	Topic	Study Design	Strength of Evidence	Diagnosis & Focus client/carer/other	Special needs groups	Study Nos.	Summary
		services						because of fear of discrimination. Discussion centred on how carers mediated disclosure of their sexualities to health and social care service providers, and wider social networks
Ward (2000)	United Kingdom	Waiting to be heard - dementia and the gay community	NA- review	Expert opinion	Dementia carers and partners	LGBTI		Views and experiences of gay men and lesbians with dementia are largely unrecognised. More research is needed to understand the needs and views of this minority group Service providers need to ensure that staff have appropriate training about sexuality and working with LGBTI within dementia services, and that the service does not inadvertently condone discriminatory practices

7.2 Rural and Remote Areas

From a service provision perspective living in a rural or remote region is likely to be disadvantageous across the board because mainstream services may be scarce or non-existent, restricting both choice and access. Since there are a very small number of people living with younger onset dementia it is highly unlikely that specialised services for this group would be available, particularly in rural and remote areas (Blackstock et al, 2006; Tyson, 2007; Saunders, 2013).

In addition to service access difficulties created by distance and inadequate or non-existent transport networks, existing non-metropolitan dementia specific services face a number of challenges because of the diverse demands on service delivery (Saunders, 2013). These areas also experience difficulties recruiting and retaining appropriately trained staffs who understand the diverse range of issues associated with dementia specific care (Blackstock et al, 2006).

The need for creativity and working with existing networks to find solutions to staff shortages was emphasized in a project run by the Alzheimer's Association (Western Australia), in rural regions where the nearest neighbour could be 50kms away (Clay, 2002; Moriarty, 2002). This nationally funded programme aimed to develop a new service covering three rural regions. Each region was serviced by a Mobile Dementia Respite Team which accepted referrals within a two hour travel radius. The service provided education, support and respite to people with dementia and their carers. The programme involved an eight week assessment period during which time the specialist team focussed on identifying challenging behaviours and developing strategies and practical interventions to reduce the occurrence of these behaviours. The aim of the programme was to reduce carer stress, to maintain carer well- being and enable carers to continue in their role as carer. Where it was possible, ongoing respite was provided by existing organizations. Where no services existed the teams commenced recruiting their own staff and developing respite models in the region. No formal evaluation of this project was identified (Moriarty, 2002).

ADAHPS (2013) provided a brief description of a complex case-management system for people with HIV/Dementia in NSW which includes an outreach service. ADAHPS is a public health service which has teamed up with two other HIV Services in metropolitan Sydney to provide co-case management and staff development in areas with low HIV prevalence in regional and rural NSW. The Sydney services provide clinical support and capacity building in the case management of people living with HIV who have complex needs; for example, one or more physical or mental health conditions, drug and alcohol problems, homelessness. The programme was being trialled for 12 months, from January 2012.

In 2012 Alzheimer's Australia (South Australia) undertook a series of focus group consultations with 162 people living with dementia and their families, with separate groups held with 204 service providers (Saunders, 2013). Findings highlighted the diversity in composition of different communities in country South Australia, including variations across cultural backgrounds, employment levels and socio-economic status. In relation to rural isolation transport issues were identified as a major concern. This included distance from services and support in both metropolitan and regional centres and issues related to the impact of the loss of a drivers licence. Participants, both consumers and service providers, reported that there was a lack of suitable services for people with younger onset dementia. Service providers recommended that there be specific training for care workers about the special needs of those with younger onset dementia.

The importance of culturally appropriate service provision for Aboriginal and Torres Strait Islander people with dementia was identified, including a call for intensive training for Aboriginal and Torres Strait Islander care workers.

Blackstock et al (2006) explored the diverse experiences of people living with dementia and their carers in rural and remote Scotland. Qualitative data was collected from a total of 45 participants (15 service users and 30 carers) using a semi-structured approach which included face-to-face and telephone interviews and focus groups. Their findings identified "hidden" rural voices as well as a diversity of experience, supporting "the drive towards flexible and person centred service provision in rural Scotland" (p.162). The reported experience of living in rural and remote areas was not homogenous, with both positive and negative aspects being discussed by the study participants. Positive comments were made about the level of individualised care resulting from local relationships and the level of informal support for carers and people living with dementia in the community. An example was friends and neighbours watching out for people with dementia who may have wandered, and help with domestic duties and transport. However, these informal networks may not be sustainable if the dementia progresses and particularly if the person with dementia's behaviours become challenging.

Dementia is a complex and multifaceted disease, and dynamic in nature, as are the relationships within communities. By contrast with the positive aspects such as the informal support networks mentioned above, stigma, particularly in small communities, has been identified as a barrier to the timely diagnosis of dementia and social participation (Blackstock et al, 2006; Saunders, 2013).

7.3 Aboriginal and Torres Strait Islander People

'Improving the health status of Indigenous peoples in Australia is a longstanding challenge for governments in Australia. The gap in health status between Indigenous and non-Indigenous Australians remains unacceptably wide. It has been identified as a human rights concern by United Nations committees; and acknowledged as such by Australian governments.

'Social determinants theory recognises that population health and inequality is determined by many interconnected social factors. Likewise, it is a basic tenet of human rights law that all rights are interconnected and that impacting on the enjoyment of one right will impact on the enjoyment of others. Because of this synergy, human rights discourse provides a framework for analysing the potential health impacts of government policies and programs on Indigenous peoples' (Calma, 2007).

Important determinants of Indigenous health inequality in Australia include the lack of equal access to primary health care and the lower standard of health infrastructure in Indigenous communities (healthy housing, food, sanitation etc.) compared to other Australians' (Calma, 2007).

'Indigenous health policy in Australia is guided by the National Strategic Framework for Aboriginal and Torres Strait Islander Health 2003-2013. One of the nine guiding principles of this is that Governments adopt a holistic approach: 'recognising that the improvement of Aboriginal and Torres Strait Islander health status must include attention to physical, spiritual, cultural, emotional and social well-being, community capacity and governance' (Calma, 2007).

This consideration sets the context for the following discussion about younger onset dementia among Indigenous Australians.

Younger onset dementia for Aboriginal people is defined as dementia which occurs before the age of 50 years, compared with 65 years for the non-Aboriginal population (Brown et al, 2012). The number of Aboriginal and Torres Strait Islander people living with dementia may be grossly under reported (Saunders, 2013). Although estimates vary, research has generally concluded that the prevalence of dementia and cognitive impairment is substantially higher among Indigenous than for non-Indigenous Australians (Li et al, 2013; Smith et al, 2008).Preliminary results from the three year Koori Growing Old Well Study conducted by Professor Tony Broe, a Senior Principal Research Fellow at NeuRA (Neuroscience Research Australia) suggested that the rate of dementia in Aboriginal Australians may be three times that of Australia's non-Indigenous population. These results are based on a census of all resident Aboriginal people aged 60 years and over, across five urban and regional Indigenous communities (Broe, 2013). Earlier research in the Kimberley region estimated that the prevalence rate for dementia was nearly five times that for the general Australian population (Smith et al, 2008). This suggests that prevalence may vary depending on a number of factors, for example geographical location and local social context.

Differences in language spoken and literacy rates will impact on a broad range of factors related to diagnosis and management of any health condition. For many Indigenous language speakers, limited communication with mostly English language speaking health professionals has thwarted efforts to provide safe and effective health care education (Trudgen 2003; Taylor and Guerin 2010 – in Lindeman et al, 2010.) Based on the 2006 Australian census there were 52,000 Indigenous people who reported speaking an Australian Indigenous language at home. The majority of Indigenous people (372,000 or 86%) reported speaking English only at home, similar to the level reported by non-Indigenous people (83%). About 12% reported that they spoke an Indigenous language at home and this was much more likely to be reported by those living in geographically remote areas. Very Remote Australia represents much of central and Western Australia (ABS). Over half the Indigenous people living in very remote areas (56%) reported speaking an Indigenous language at home, compared with 1% of those in major cities (ABS, 2010).

It must also be emphasized that Indigenous languages are not homogenous. There are numerous and diverse Australian Indigenous languages most of which have dialects. In addition to traditional Indigenous languages, creoles (which develop from language contact) are also spoken by Indigenous people of northern Australia. Two creole languages spoken by Indigenous Australians have appeared since colonisation. 'Kriol' is spoken in a belt across Northern Australia from the Kimberley through the Katherine region. 'Yumplatok', also called 'Torres Strait Creole' or 'Brokan', is spoken in the Torres Strait and some communities of Cape York Peninsula (ABS, Year Book 2010). This language diversity has clear implications across all aspects of dementia diagnosis, management and service provision.

It is critical that culturally appropriate assessment tools are used to ensure accurate diagnosis. The Kimberley Indigenous Cognitive Assessment (KICA-Cog; Lo Guidice et al, 2006) is the only validated dementia assessment tool for older Indigenous Australians (Sansoni et al, 2007; Sansoni et al, 2010). It is most appropriate for use in primary, community and residential care and in remote communities for those aged 45 and older, when other instruments may not be appropriate (DCRC, 2013).

Proposed possible reasons for undiagnosed younger onset dementia in Aboriginal communities may be that some Aboriginal health workers are not trained to recognise dementia and some general practitioners do not refer to specialists for diagnosis (Brown et al, 2012). Additionally Aboriginal people with dementia may not choose to access mainstream services because they do not identify with the conceptualisation of dementia, or the language used to describe and define it (ibid, 2012). A number of resources have been developed to address this issue. *Look after your brain. A guide to dementia for Aboriginal people* is a resource developed by ADHC (NSW) in consultation with a range of Aboriginal and health agencies. This resource states that the person with dementia is "probably an older person or Elder". However, the information provided, including where to seek help is general in nature and certainly relevant to people with younger onset dementia (ADHC, 2012).

7.3.1 Remote and very remote Indigenous communities

Alzheimer's Australia NT (2009) in partnership with the Dementia Behaviour Management Advisory Services NT (DBMAS) also has produced a range of culturally sensitive dementia resources. *Looking out for Dementia* is a suite of themed resources designed to inform Indigenous people living in remote communities of Northern Territory about dementia. The resources have been developed in English and three Indigenous languages; Djambarrapuyngu, Warlpiri and Kriol (Alzheimer's Australia (NT), 2009).

The evaluation by the Centre for Remote Health of the effectiveness of the *Looking out for Dementia* resource identified some key findings regarding cultural influences, geographic isolation and reasons for the limited use of dementia services for people with dementia in remote communities (Lindeman et al, 2010).

Importantly, the evaluation concluded that 'developing resources in Indigenous languages is important to Indigenous people as it helps validate their cultures, enhances engagement and provides opportunity to develop health vocabularies where there is no existing translatable term' (Lindeman et al, 2010).

The evaluation found that prior to the resource being implemented, although there was some general understanding about brain related problems, issues related specifically to dementia were poorly understood or acknowledged in the study communities. Consequently some individuals remained undiagnosed or unrecognised as being at risk for dementia. Additionally, this lack of knowledge and awareness were viewed as part of the reasons for the relatively low level of service uptake (Lindeman et al, 2010).

Participants in the evaluation identified a number of cultural practices which they related to the prevalence of dementia in remote Indigenous communities with relevance to younger members of the community. In particular, football was one common social activity that the participants related to the incidence of head injury among young men. In conjunction with high levels of alcohol misuse, this was perceived to be a risk factor for dementia. Other participants made a link between dementia and mourning rituals, such as self-inflicted head wounds linked to bereavement, during "sorry business" (Lindeman et al, 2010).

7.4 Culturally and Linguistically Diverse Communities

Cultural and Linguistic Diversity (CALD) refers to the range of different cultures and language groups represented in the population. Definitions vary but commonly refer to a very broad concept encompassing the differences that exist between people, arising out of shared ethnicity, language, dress, traditions, food, societal structures, art and religion. Historically, migrants have made up a large proportion of Australia's population with migration patterns changing over time. Previously the majority of migration was from Europe but increasingly there are more Australians who were born in Asia and other parts of the world (ABS, 2012). In addition to the Anglo-Celtic majority of the Australian population and the Indigenous population the 2011 Census revealed that 26% of Australia's population was born overseas and a 20% had at least one overseas-born parent. It is noted that the term CALD does not refer to Aboriginal and Torres Strait Islander people who are considered as a separate group.

In 2011, 81% of Australians aged 5 years and over spoke only English at home while 2% did not speak English at all. Other than English, the most common languages spoken at home were Mandarin (1.7%), Italian (1.5%), Arabic (1.4%), Cantonese (1.3%) and Greek (1.3%), (ABS, 2012). Particularly in the older groups a very wide range of languages was spoken at home with many languages spoken by relatively small numbers of people, making communication outside the immediate family or language community difficult (ABS, 2012). Inability to communicate because of language differences will clearly impact on the assessment, diagnosis and management of any medical condition, with dementia presenting additional challenges depending on the degree of cognitive impairment and the presence of behavioural issues.

Precise data about the number of people in CALD communities living with younger onset dementia was not readily identifiable in the literature. There are a number of reasons for this, including possible under reporting because of the stigma about dementia in some cultures and the lack of identification with the language used to describe and discuss dementia (Brown et al, 2012).

While no data was able to be identified to provide detail about whether the incidence and/or prevalence of dementia is the same in CALD communities as in the general Australian population, in 2006 it was estimated that in New South Wales about 13% of people living with dementia did not speak English at home and that the actual numbers could be expected to increase substantially as the CALD communities aged. It could also be expected that a change in the CALD group distribution would occur over time, for example an increase in Asian language groups, which may impact on service provision requirements (CIRCA, 2008).

Accurate diagnosis is critical to service provision planning and implementation. Research has indicated that changes in behaviour and presenting symptoms of people with younger onset dementia may not initially be recognised as such. Therefore, diagnosis is often delayed, sometimes for several years, to the detriment of families and family relationships. Misdiagnosis of symptoms, for example as depression or other mental illness, often occurs because younger onset dementia is uncommon (Brown et al, 2012). Additionally, earlier research found that people from non-English speaking backgrounds were diagnosed later after the onset of symptoms than other members of the population (LoGuidice et al, 2001).

An essential element of accurate diagnosis is the use of culturally and linguistically appropriate and validated assessment tools. The impairment of interest must be assessed rather than English

language competency or comprehension of idiomatic expressions. Cultural aspects must be considered both in the design and conduct of assessments. Care is also required with translated materials to ensure that concepts are culturally meaningful (Sansoni et al, 2007).

The Rowland Universal Dementia Assessment Scale (RUDAS) (Storey et al, 2004) was designed to enable the easy translation of the items into languages other than English and to be culturally fair. It is recommended for use with those from culturally and linguistically diverse backgrounds. It is a short cognitive screening instrument designed to minimise the effects of cultural learning and language diversity on the assessment of baseline cognitive performance. As the person being assessed is encouraged to communicate in their first language the use of an interpreter is important. It is noted however, that the RUDAS contains an item on judgement (referring to traffic lights) that may be inappropriate for remote Indigenous situations, for which the KICA-Cog should be used as described above (Sansoni et al, 2007). The RUDAS is appropriate for use in primary, community and residential care (DCRC, 2013).

In order to better understand different cultural groups' attitudes about dementia and their particular service needs the NSW Department of Ageing, Disability and Home Care (DADHC) commissioned the Cultural and Indigenous Research Centre (CIRCA) to conduct research with a focus on the Italian, Vietnamese and Chinese communities in NSW. A total of thirty three in depth interviews were conducted by bilingual researchers with people with mild to moderate dementia and their family/carers. Six round table discussions were conducted with key stakeholders from the aged care and health fields, and representatives working with community organisations in representative Sydney suburbs.

The majority of participants living with dementia were older, that is, in their late 70s and 80s, and given the difference in life circumstances of people living with younger onset dementia the applicability of the research is hard to assess. However it would seem likely that many of the findings would be relevant to the younger onset dementia group. These included including poor understanding of the nature of dementia, direct and indirect denial of a dementia diagnosis, cultural influence on the level of understanding about dementia and reported stigma and associated shame. Language and literacy will impact on the ability to gain information, for example about health related matters and available services, even if materials are available in a suitable language.

In 2011 DADHC commissioned Alzheimer's Australia NSW to research the service and support requirements for younger people living with dementia in NSW. The research included interviews, surveys and roundtable discussions across metropolitan and regional areas with people living with younger onset dementia, their family/carers and service providers. A total of 44 people living with younger onset dementia, 101 family members/carers and 25 service providers contributed to the research. However, the researchers noted that despite their efforts using purposive sampling (e.g. through key service providers, networks and contacts) few people from CALD and Aboriginal backgrounds wanted to participate. Therefore the sample of CALD participants was very small (Brown et al, 2012).

One CALD service provider suggested that people from some CALD backgrounds did not seek a diagnosis because of lack of knowledge about dementia, and the stigma attached to that diagnosis. Inconsistent access to interpreters at the time of assessment could also complicate matters.

Additionally, the service provider reported that some General Practitioners preferred to treat the person with dementia themselves, rather than referring to a specialist and thus delaying accurate diagnosis.

The research found that in some CALD groups there was an expectation that the family was solely responsible for care, thus reducing the likelihood that appropriate services would be sought, in the unlikely event that such services were in fact available (Brown et al, 2012).

As noted above, the challenge of dispelling myths and misconceptions about dementia and its causes may be compounded by low literacy levels. In order to effectively reach these communities to educate them about dementia appropriate resources with community acceptance are required. An example is the DVD resources commissioned by the Multicultural Communities Council Illawarra (MCCI). The DVDs were developed for a range of communities, including the Portuguese, Ukrainian, Arabic, Serbian, Croatian, Assyrian and Cambodian refugee communities. Although not specifically designed for people with younger onset dementia these resources could be helpful in providing accurate information about dementia generally and assist with dispelling the belief that dementia is a normal part of ageing. They could provide families with information about culturally appropriate services, helping them to see that asking for help is not contrary to family obligation, and addressing the stigma associated with dementia in these diverse communities (Pires, 2013).

7.5 Lesbian, Gay, Bisexual, Transgender and Intersex people

Information about the actual numbers of gay men and lesbian women in Australia is not well established, for a range of reasons including the lack of a relevant and reliable data collection and a potential reluctance to identify as such because of concerns around privacy and confidentiality (Birch, 2008). Consequently, research literature relating to lesbians and gay men, bisexuals, transsexuals and other member of sexual minorities is scant and that identified was not specific to people with younger onset dementia or their carers and included research articles and opinion pieces (Price, 2010; ACON, 2010; Birch, 2008; Archibald, 2006; Ward, 2000). The identified research was limited by small sample sizes with a lack of socio-economic and cultural diversity.

Alzheimer's Australia commissioned Birch (2008) to write a paper to promote informed discussion about the issues relevant to Lesbian, Gay, Bisexual, Transgender and Intersex people (LGBTI). Although the paper focussed on older LGBTI, it was noted that the issues of concern and needs are likely to be the same for younger gay men and lesbian women. It is also noted that while many of the impacts of dementia will be the same for all people, regardless of sexuality, there are some particular issues of concern for LGBTI.

Concerns around confidentiality and control over personal information were identified by a number of authors (Price, 2010; ACON 2010; Birch, 2008; Archibald, 2006; Ward 2000). This issue was relevant not only for the person with dementia, but also for same sex partners and friends who may have chosen to keep their sexual identity and relationships private for a number of reasons. Inadvertent disclosure by a partner with dementia, of their own and other's sexuality, could compromise privacy that had been carefully guarded for a variety of reasons over many years with unknown consequences.

One of the concerns raised about having carers enter one's home was about whether disclosure of sexual identity might impact on service provision (Price, 2010; Birch, 2008). Choice of whether and how to disclose one's sexuality to a service provider was reported to be affected by a range of

factors. For example some service users were reported to have chosen direct disclosure of information to service providers in order to correct assumptions about the relationship with one's same sex partner. This was viewed as a high-risk strategy as the service providers' responses could not be predicted. One respondent chose not to disclose to the local support group he attended because he thought this might compromise the support he received, which he greatly valued (Price, 2010).

Fear of discrimination if service providers knew of their sexuality (Birch, 2008) and actual discrimination by service providers are other issues of concern.

Price (2010) used semi-structured interviews to explore the experiences of 21 gay and lesbian women who cared, or had cared, for a person with dementia to try and understand the impact of their sexuality on that experience. A major theme which emerged from this study was their concern around service providers' anticipated reactions to disclosure of their sexuality. Service providers' reactions were found to vary considerably, and seemed to be dependent on personal attitudes rather than "being a matter of professional obligation (ibid p.166).

The consequences of discrimination as described in the literature were multi-faceted. Archibald (2006) reported a case study of an older lesbian woman with dementia and mental health problems in residential care, who experienced a change in care staff behaviour when her sexuality became apparent. This included residential care workers providing the minimum of touch necessary to complete care activities, with a reduction in quality of life for the care resident as a result of the minimal interaction with staff leading to distress and isolation (Archibald, 2006). Birch (2008) and the National LGBTI Health Alliance (2013) similarly reported cases where LGBTI clients had been subject to discrimination including less attention and negative comments from care workers. Examples included clients being roughly handled during bed washes, left without being washed, and a lack of information being provided to same sex partners.

There has also been long-standing systematic discrimination against LGBTI because of Australian legislation, although it is noted that there have been changes in recent years. As an example homosexuality was not decriminalised in most Australian states until the 1980s and 1990s and it was only in 2008/2009 that federal legislation was reformed to recognise same-sex de-facto partnerships. Until relatively recently, same sex couples were treated very differently to heterosexual couples (de facto and married), when dealing with certain superannuation entitlements and retirement planning needs. Some superannuation funds did not recognize same-sex partners as dependents, resulting in financial disadvantage for the remaining partner who was unable to access these funds on their partner's death. Previously, there have been other serious consequences because of state and territory based legislation, including denial of wills and power of attorney. Legislation about substitute decision making for a person who has lost the capacity to make their own decision also varies across the states and territories (Birch, 2008).

Reportedly some older LGBTI people are fearful about accessing faith-based aged care services because of fear of discrimination based on their sexuality. Provisions to limit the ability of Commonwealth-funded aged care services from being able to discriminate in the provision of services were introduced in the Commonwealth Human Rights Anti-Discrimination draft bill (November 2012), and numerous faith based providers have publicly declared their non-discriminatory policy towards LGBTI clients. In March 2013, the Commonwealth Government

announced that it would not be introducing legislation based on the draft Human Rights and Anti-Discrimination Bill at this time and would instead be pursuing reforms to the Sex Discrimination Act (Law Council of Australia, 2012). However, there are still concerns among some older LGBTI people that they will experience discrimination and this becomes particularly pertinent in areas where there is a limited choice of service providers.

Another issue of concern raised by the available literature is that there are about twice as many LGBTI that live alone compared with the Australian heterosexual population, although the situation is unclear for a number of reasons including lack of data and under-reporting due to non-disclosure in the available data. This situation suggests that in the absence of family support/carer support there maybe additional support requirements for this group.

7.6 Down syndrome

People living with intellectual disabilities represent another minority group. Down syndrome is a frequently occurring chromosomal disorder associated with intellectual disability. There is considerable documentation of the earlier onset and higher incidence of Alzheimer's disease in people with Down's syndrome (AIHW, 2000). This group experience the effects of ageing sooner than the general population and although having a generally reduced life span compared with the general population their life expectancy has progressively increased. There is a multiplicity of challenges for people with Down syndrome and their carers. The existing challenges of caring for someone with an intellectual disability are compounded by dementia and the wide range of possible associated behaviour changes associated with progressive decline.

Janicki et al (2010) found that parents "expressed a profound commitment" to keeping their child at home (p.398). Family carers expressed a strong commitment to the person they cared for, and a desire to keep the person at home for as long as possible (Furniss et al, 2011; Janicki et al, 2010). The amount of time required for care-giving may substantially increase as the adult child's needs increase and carers' abilities to continue to provide care could be compromised if their own health declined (Janicki et al, 2010).

Furniss et al (2011) conducted thirteen semi-structured interviews with family carers, relatives and staff caring for people who had Down syndrome and were diagnosed, or highly suspected of having Alzheimer's disease, to explore their views about the services they received and the issues around caring for people with multiple diagnoses. The ages of the people with Down syndrome for whom they cared ranged from 40 -65 years, two of whom lived with their families and the other eleven living in residential care. All of those interviewed identified the lack of knowledge about dementia, and how this might impact on the person with Down syndrome over time, as an issue. Family carers and relatives identified a lack of information, and lack of awareness of available information, about the diagnosis process and service availability as issues of concern. They also reported finding that the number of professionals involved was confusing and were concerned about future care needs arrangements for the person as their condition progressed (Furniss et al, 2011).

7.7 Care Leavers

The term "care leavers" refers to people who grew up in what was called "care", outside of their families, but who have left that "care". It includes people who were State wards, foster children, Home children (in homes run by State governments, religious orders and charitable organizations), and sometimes all three.

No relevant literature specific to younger onset dementia, or generally to dementia for this group of people was found. However, this group contains a high proportion of people with potentially multiple levels of vulnerability which could impact on care needs. As a group, care leavers have reported extreme psychological, physical and sexual abuse at the hands of carers, which is currently the subject of the Royal Commission into Institutional Responses to Child Sexual Abuse. A survey by CLAN (Care Leavers Australia Network) in 2006 yielded a sample of 291 respondents out of a possible total of 501 CLAN members. The results indicated that this group experienced high levels of disadvantage post care across a very wide range of areas. These included homelessness, mental health issues, incarceration, educational deficits with consequent effects on future employment potential and earning capacity, substance abuse and exposure to domestic violence. This group also reported significantly higher levels of suicidal thoughts and attempted suicide than the general population.

One of the issues for this group of people is that as a result of disconnection from family and social networks those who have diminished decision-making capacity may have no support systems to assist them with decisions impacting on financial, legal and health matters. Consequently, although the underlying presumption is that people have a right to make decisions that should not be taken away unless it is absolutely necessary; this vulnerable group may have a critical requirement for assistance from a substitute decision maker such as the Public Advocate (Bagdonavicius, 2009; Marian, 2008).

7.8 Conclusion

Although the research literature about younger onset dementia relating to the defined special needs groups is scant the available literature, including grey literature, emphasises that the needs of these groups are complex, multifaceted and dynamic and become more so with the onset of dementia, reinforcing the call for person-centred, culturally appropriate, flexible service options. This point is further emphasized when the substantial variation within these groups is taken into consideration. Geographical location plays a role in the prevailing culture, for both Indigenous and non-Indigenous Australians, with subsequent impact on a wide range of factors related to the diagnosis and management of dementia. Additionally, geographical location is a crucial aspect of service availability and accessibility.

Based on the literature the following recommendations are made to promote the provision of meaningful services which will benefit the person with younger onset dementia and their family/carers:

- It is critical that assessment is conducted using culturally and linguistically appropriate tools to provide an accurate diagnosis, and thus assist with service provision planning and implementation
- Information about available services must be provided in culturally and linguistically appropriate forms
- Service provision must revolve around individually tailored programmes
- Service providers must ensure that staff have training about dementia, its many and varied presentations, the characteristics of special need groups, the disadvantage experienced by special needs groups, the impact of multiple special needs on service requirements, anti-discrimination legislation and the practical application of this training in daily service provision

- Service provider staff training needs must be regularly reviewed to ensure that all staff members, particularly those new to the service, receive appropriate training which incorporates current theoretical and practical components based on “best available” evidence. This is critically important for services which have high staff turnover
- Inter-agency communication is essential to reduce duplication or fragmentation of services
- Funding is required to enable a State or Territory based coordinator to promote collaboration and partnerships with the special needs groups, including Aboriginal and Torres Strait Islander and CALD organisations, about issues related to younger onset dementia
- Models of care to support rural service provision, for example via an outreach model designed to provide clinical support and capacity building must be further explored.

8 Conclusion and Recommendations

The aim of this project is to undertake a literature review into the service needs of people with Younger Onset Dementia (YOD) and to undertake a needs and feasibility assessment of services for this group. A rigorous search strategy has been employed to identify literature related to services and needs of people with younger onset dementia.

The introductory overview describes the different types of younger onset dementia and has noted the similarities and differences in the range of symptoms for these subtypes. It is noted that behavioural and psychological symptoms (BPSD) of dementia are common across most sub-types adding to the need and care requirements of people with younger onset dementia. The provision of programs to assist carers to address these issues has been found to be helpful.

The overlapping of some symptoms across younger onset dementia types has made differential diagnosis complex and difficult. The problems and delays experienced by people with younger onset dementia in obtaining an accurate diagnosis remain a common theme in the younger onset dementia literature and is a major issue for continued service improvement.

Some types of younger onset dementia (e.g. Huntington's disease, Down syndrome, and some forms of Alzheimer's disease) carry a high level of genetic transmission or are strongly associated with genetic risk factors and for groups so affected provision of genetic counselling and clear information is of prime importance.

Some types of younger onset dementia are potentially more preventable, such as alcohol related brain damage or alcohol related dementias (ARBD), and yet more recent prevalence studies indicate this is more common in Australia than elsewhere. This is an area where health promotion and prevention campaigns would seem warranted.

The literature available indicates there is quite a long period from onset of symptoms to permanent residential care placement for people with younger onset dementia (e.g. 6 to 9 years) and that the level of informal care provided is high which places a significant burden on these families/carers. Although some studies indicate a relatively high use of institutional services for this group (e.g. hospital admissions, nursing home respite etc.) authors also report that community service use is relatively low for this group. In view of this many authors suggest the need for a central gateway to services for people with younger onset dementia or the adoption of case-management and key worker approaches. However, there are few studies that comprehensively examine service utilisation and the costs of illness for the younger onset dementia group or that include consideration of social and informal care costs. There is a need for further research concerning these factors.

Although it has been estimated that approximately one third of people with dementia live alone there is little data available concerning those that live alone in the younger onset dementia research literature and yet this is a group that is likely to have high service needs. It might well be that premature placement in residential care facilities may be an issue for this group and this needs to be further explored.

Numerous other research issues and gaps have been identified in this overview including those concerning prevalence, incidence, life expectancy and the proportions of people with younger

onset dementia that are diagnosed with the various sub-types of younger onset dementia. More accurate and up to date Australian estimates will be critical for service planning purposes.

The experience, issues and stated need of people with younger onset dementia, their carers and families have been explored by many authors although the sample sizes were generally small. As a result some authors recommend further research on the 'experience' of people with younger onset dementia, their family and carers. However, 'more of the same' research is actually not required. What is required are a few well-funded studies with better research designs, larger sample sizes, a triangulation of methods of outcome assessment, and consideration of the control of extraneous variables/ confounding factors. The previous studies have provided valuable insights but the level of evidence is 'weak'. However, what should become part of routine practice is the involvement and participation of people with younger onset dementia in service design, development and evaluation.

Many of these studies also noted the lack of a clear diagnostic pathway and the lack of appropriate referrals to support services during the diagnostic process and its immediate aftermath. This is important as more effective and earlier use of community support services may have the potential to delay institutionalisation.

Despite the numerous attempts by organisations such as Alzheimer's Australia to provide comprehensive information across a range of forums, including the internet, the need for clear information and advice is still mentioned as a major unmet need for carers and patients. It would also be desirable if people with younger onset dementia and their families were routinely provided with clear written information at the point of diagnosis and consideration could be given to a telephone enquiry support service as occurred with CANDID in the UK.

The literature on service design and development highlights two key themes regarding services for people with younger onset dementia:

- At the system level, the overwhelming evidence from the literature identifies service integration as being critical. There is a need to integrate diagnostic services and to streamline the pathway to diagnosis and to relevant service support. The use of multi-disciplinary team approaches and the development of more effective links between the range of services providing assistance to people with younger onset dementia, their carers, and families along the course of the dementia journey is required.
- At the service level, people with younger onset dementia need to be directly consulted in the design and delivery of services designed to support them. Underpinning an individualised approach is the need for flexibility, to accommodate individual and family circumstances as they change over time.

A number of authors also recommend the introduction of specialist services for younger onset dementia and such services are increasingly available internationally and some specialist services have begun in metropolitan areas of Australia more recently. However, given the geographic nature of Australia with its vast areas of sparse population, and given the relative rarity of younger onset dementia, the provision of specialist services outside major metropolitan areas presents some challenges. It will be important in the development of specialist services that effective outreach strategies are included in the design of these services with an associated use of such facilities as teleconferencing/video conferencing/web links to

assist in providing support in rural and remote areas. However, given that many people with younger onset dementia may not be able to directly access specialist services, local services for dementia and aged care will also need to become more aware of younger onset dementia. Education and training will be required to assist such services to address the particular needs of younger onset dementia clients.

The key service design attributes that have been identified in the literature are able to be applied across a range of service types, both specialist and generic. The features of the service model, staffing and organisational attributes are described below, and could readily be incorporated into many mainstream services for the improvement of all clients, not just those with dementia.

Individualised model of service:

- Listening to people with younger onset dementia and their carers
- Individualised service planning / person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognition of the diversity among the many younger onset dementia diagnostic groups and the special needs of individuals.

Staff attributes:

- Appropriately skilled and suitable staff
- An holistic approach
- An enabling and consumer centred approach
- Case management skills
- Effective communication
- Flexibility.

Organisational attributes:

- Access to integrated specialist diagnostic and ongoing symptom management services
- Capacity for organisational change/responsiveness
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Ability to cater for the needs of people in rural and remote communities
- Individualised service planning / person centred approach
- Respect and consideration for clients and carers

- Capacity building - Involve people capable of effecting change in the process of service development.
- Effective Risk Management strategies
- Appropriate exit policies relating to the suspension and withdrawal of services.

The literature on non-pharmacological interventions and programs for people with younger onset dementia provided limited evidence concerning the effectiveness of these programs and much of this literature could be described as 'emerging evidence'. Some promising approaches identified were cognitive stimulation, physical exercise/activity programs and support programs such as the Living with Memory Loss programs. Further research should be undertaken for programs that provide individual support for people with younger onset dementia and their carers as well as programs that provide active, meaningful participation. However, it is important that a culture of outcome evaluation for many of these programs/interventions is developed within services. When service interventions are developed there is a need to design the evaluation process prior to program introduction and for appropriate consideration to be given to the use of standardised outcome measures as well as qualitative approaches to evaluate effectiveness.

The literature in relation to dementia and special needs groups was sparse and generally not specific to people with younger onset dementia. The literature identified ranged from emerging practice and expert opinion to mainly qualitative research with small samples. Although the research literature about younger onset dementia in relation to the defined special needs groups is scant the available literature emphasises that the needs of these groups are complex, multifaceted and dynamic and become more so with the onset of dementia. This reinforces the call for person-centred, culturally appropriate, flexible service options.

The focus of the literature review has been to find examples and evidence of best practice in care and support for people with younger onset dementia and their families. In undertaking this exercise, a number of research gaps have been identified. As awareness has increased regarding the different manifestations and implications of younger onset dementia, there has been an associated refinement in the research questions posed, and the methodologies employed. The evidence is evolving, and there are a number of more rigorous studies recently completed or currently underway which are likely to improve the way we understand dementia and its impacts, and the opportunities, for those diagnosed and their families.

As our understanding of the implications of younger onset dementia has improved, our framework for understanding the dementia journey has also changed. The four stages of dementia that were included in the former draft National Framework for Action on Dementia 2013-2017, with its focus on service delivery and health and care, does not sufficiently address self-determination and social participation aspects of dementia amongst people who are younger. Consequently, we have introduced an additional 'stage' for this cohort, to assist us to move our thinking from purely a 'care and support' paradigm to one that focuses on enabling people to participate and engage in community life for as long as possible. We have called this the 'Adjustment, Enablement and Engagement' stage, and will be exploring this in more detail through the consultation phase of the project.

The issues identified through this literature review are currently being tested within the context of national consultations with a mix of consumers, providers, researchers, clinicians and policy advisers. Importantly, the consultation strategy has been structured to ensure that the voices of people with younger onset dementia and their spouses, carers and families are prioritised. The extent to which these findings align with the reality of the Australian care and support sector will be explored in our next report, which will also include examples of service models that demonstrate the principles of best practice.

9 Reference List

Access Economics (2005). Dementia estimates and projections: Australian states and territories. Canberra, Alzheimer's Australia.

ACON (2010). Building our community's health and wellbeing. Submission to NSW Health on the Draft NSW Dementia Services Framework 2010-2015. Surry Hills, ACON Health Ltd**:** 6 p.

Ageing Disability & Home Care (ADHC) (2012). Forum on younger onset dementia: fact sheet July 2012. Sydney, NSW Department of Family and Community Services**:** 1-5.

Ageing Disability & Home Care (ADHC), Alzheimer's Australia NSW, et al. (2013). Roundtable on younger onset dementia with international expert clinician and researcher, Christian Bakker, 12 March 2013. Sydney.

Agnihotri, S. (2009). Expressive arts as a social and community integration tool for adolescents with acquired brain injuries. Master of Science M.Sc., University of Toronto (Canada).

AIDS Dementia and HIV Psychiatry Service (ADAHPS). (2013). "HIV complex needs case management project." 2013, from http://www0.health.nsw.gov.au/adahps/index.asp.

Aldridge, J. and S. Becker (1993). "Children as carers." Archives of Disease in Childhood **69**(4): 459-462.

Aldridge, J. and S. Becker (1993). "Punishing children for caring: the hidden cost of young carers." Children & Society **7**(4): 376-387.

Allen, J., J. R. Oyebode, et al. (2009). "Having a father with young onset dementia: the impact on well-being of young people." Dementia **8**(4): 455-480.

Alt Beatty Consulting (2008). Appropriate HACC service models for people with younger onset dementia & people with dementia and behaviours of concern: issues for Aboriginal and Torres Strait Islander people and people from culturally and linguistically diverse backgrounds. Mosman, Alt Beatty Consulting for Community Care (Northern Beaches) Inc.**:** 60 p.

Alvarez, N. (2012, 2 March 2012). "Alzheimer disease in Down Syndrome." Medscape, from http://emedicine.medscape.com/article/1136117-overview.

Alzheimer's Association (USA). (2013a). "Traumatic brain injury: dementia and traumatic brain injury." What is dementia? Retrieved November, 2013, from http://www.alz.org/dementia/traumatic-brain-injury-head-trauma-symptoms.asp#dementiaandinjury.

Alzheimer's Association (USA). (2013b). "Down Syndrome and Alzheimer's Disease." What is dementia? Retrieved November, 2013, from http://www.alz.org/dementia/down-syndrome-alzheimers-symptoms.asp.

Alzheimer's Australia. (5 December, 2013). "Fight Dementia." from http://www.fightdementia.org.au/default.aspx.

Alzheimer's Australia (2007). Dementia: a major health problem for indigenous people. Briefing prepared for Parliamentary Friends of Dementia. Paper No. 12. Canberra, Alzheimer's Australia**:** 6 p.

Alzheimer's Australia. (2009). "2009 Younger Onset Dementia Summit." Retrieved 19 July 2013, 2013, from http://www.fightdementia.org.au/services/2009-younger-onset-dementia-summit.aspx.

Alzheimer's Australia. (2012a). "Down syndrome and Alzheimer's disease." Retrieved 28 November, 2013, from

http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_15_DSandAD.pdf.

Alzheimer's Australia. (2012b). "HIV associated dementia." Retrieved 28 November, 2013, from http://www.fightdementia.org.au/common/files/NAT/2012_NAT_HS_AD_19_HIV.pdf.

Alzheimer's Australia. (2013). "2013 Younger Onset Dementia Summit: a new horizon." Retrieved 19 July 2013, 2013, from http://www.fightdementia.org.au/services/2013-younger-onset-dementia-summit-a-new-horizon.aspx.

Alzheimer's Australia NT. (2009). "Looking out for dementia." Retrieved November, 2013, from http://www.fightdementia.org.au/northern-territory/looking-out-for-dementia.aspx.

Alzheimer's Innovation Institute. (2012). "Help for Alzheimer's and Dementia." Ashby Memory Method Retrieved 4 December, 2013, from http://www.alzheimersinnovation.com/.

Alzheimer's Society UK (2005). Younger people with dementia: a guide to service development and provision. London, Alzheimer's Society UK**:** 41 p.

Alzheimer's Society UK. (2012). "Rarer causes of dementia." Retrieved November 2013, from http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=135.

Alzheimer's Society UK. (2013). "HIV-related cognitive impairment." Retrieved November 2013, from http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=61.

Aminzadeh, F., A. Byszewski, et al. (2007). "Emotional impact of dementia diagnosis: exploring persons with dementia and caregivers' perspectives." Aging & Mental Health **11**(3): 281-290.

Arai, A., T. Matsumoto, et al. (2007). "Do family caregivers perceive more difficulty when they look after patients with early onset dementia compared to those with late onset dementia?" International Journal of Geriatric Psychiatry **22**(12): 1255-1261.

Archibald, C. (2006). "Gay and lesbian issues: learning on the (research) job." Journal of Dementia Care **14**(4): 21-23.

Arends, D. and S. Frick (2009). "Without warning(TM) lessons learned in the development and implementation of an early-onset Alzheimer's Disease Program." Alzheimer's Care Today **10**(1): 31-38 10.1097/ACQ.1090b1013e318197463f.

Armitage, G. D., E. Suter, et al. (2009). "Health systems integration: state of the evidence." International Journal of Integrated Care **9**(2): 1-11.

Australian Bureau of Statistics. (2010). "Language." ABS 4713.0 - Population characteristics, Aboriginal and Torres Strait Islander Australians, 2006 Retrieved 28 November, 2013, from http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/759789BB6EAD0F03CA2578DB00283CBB?opendocument.

Australian Bureau of Statistics. (2012). "Cultural diversity in Australia." ABS 2071.0 - Reflecting a nation: stories from the 2011 Census, 2012-2013 Retrieved 28 November, 2013, from http://www.abs.gov.au/ausstats/abs@.nsf/Lookup/2071.0main+features902012-2013.

Australian Government Department of Health and Ageing (DoHA). (17 April 2013). "Consultation paper: national framework for action on dementia 2013-2017."

Retrieved November, 2013, from http://www.health.gov.au/internet/main/publishing.nsf/content/dementia-nfad2013-2017-consultation.

Australian Government Department of Health and Ageing (DoHA). (31 July 2013). "Dementia." Retrieved November, 2013, from http://www.health.gov.au/internet/main/publishing.nsf/Content/Dementia-1.

Australian Government Department of Health and Ageing (DoHA). (11 July 2013). "Home Care Package Program guidelines - August 2013." Retrieved November, 2013, from http://www.livinglongerlivingbetter.gov.au/internet/living/publishing.nsf/Content/home-care-packages-program-guidelines.

Australian Government Department of Health and Ageing (DoHA). (25 November 2013). "Reports on the Operation of the Aged Care Act 1997." Retrieved November, 2013, from http://www.health.gov.au/internet/main/publishing.nsf/Content/ageing-reports-acarep.htm.

Australian Government Department of Health and Ageing (DoHA). (2012). "Commonwealth HACC program manual." Retrieved November, 2013, from http://www.health.gov.au/internet/main/publishing.nsf/Content/1BA3D0B8011DCB06CA257BF0001BB02B/$File/HAAC%20Manual_web.pdf.

Australian Government Department of Social Services (DSS). (21 November 2013). "National disability strategy." Retrieved November, 2013, from http://www.dss.gov.au/our-responsibilities/disability-and-carers/program-services/government-international/national-disability-strategy.

Australian Institute of Health and Welfare (2000). Disability and ageing: Australian population patterns and implications. AIHW cat. no. DIS 19. Canberra: AIHW (Disability Series).

Australian Institute of Health and Welfare (2007). Dementia in Australia: national data analysis and development. Canberra, AIHW**:** 315 p.

Australian Institute of Health and Welfare (2012). Dementia in Australia. Canberra, AIHW**:** 240 p.

Bagdonavicius, P. (2009). Looking back: looking forward - lessons learnt from redress. Families in Law: Investigation, Intervention and Protection. 29th Annual Australian and New Zealand Association of Psychiatry, Psychology and Law (Western Australia) Congress. Fremantle, WA.

Bakker, C. (2013). Young onset dementia: care needs and service provision, Radboud University.

Bakker, C., M. E. de Vugt, et al. (2013c). "Unmet needs and Health-Related Quality of Life in young-onset dementia." The American Journal of Geriatric Psychiatry(Online First).

Bakker, C., M. E. de Vugt, et al. (2013a). "Predictors of the time to institutionalization in young- versus late-onset dementia: results from the Needs in Young Onset Dementia (NeedYD) study." Journal of the American Medical Directors Association **14**(4): 248-253.

Bakker, C., M. E. de Vugt, et al. (2013b). "The use of formal and informal care in early onset dementia: results from the NeedYD study." American Journal of Geriatric Psychiatry **21**(1): 37-45.

Bakker, C., M. E. de Vugt, et al. (2010). "Needs in early onset dementia: a qualitative case from the NeedYD study." American Journal of Alzheimer's Disease and other Dementias **25**(8): 634-640.

Baldwin, R. C. (1994). "Acquired cognitive impairment in the presenium." Psychiatric Bulletin **18**(8): 463-465.

Banerjee, S., R. Willis, et al. (2007). "Improving the quality of care for mild to moderate dementia: an evaluation of the Croydon Memory Service Model." International Journal of Geriatric Psychiatry **22**(8): 782-788.

Batsch, N. L. and R. V. Miller (2009). "An assessment of needs for serving individuals diagnosed with Alzheimer's Disease and related dementias in the early stages." Alzheimer's Care Today **10**(3): 140-155 110.1097/ACQ.1090b1013e3181b1015d1099b.

Beattie, A., G. Daker-White, et al. (2004). "'How can they tell?' A qualitative study of the views of younger people about their dementia and dementia care services." Health & Social Care in the Community **12**(4): 359-368.

Beck, A. T. and A. Beamesderfer (1974). Assessment of depression: the depression inventory. Psychological measurements in psychopharmacology. P. P. R. Olivier-Martin. Oxford, England, S. Karger**:** 267.

Bentham, P. and J. La Fontaine (2008). "Services for younger people with dementia." Psychiatry **7**(2): 84-87.

Birch, H. (2008). Dementia, lesbians and gay men. Alzheimer's Australia Paper 15. Canberra, Alzheimer's Australia**:** 28 p.

Bird, M., T. Caldwell, et al. (2005). Alzheimer's Australia early stage dementia support and respite project. Final report on the national evaluation. Queanbeyan, Greater Southern Area Mental Health Service**:** 52 p.

Blackstock, K. L., A. Innes, et al. (2006). "Living with dementia in rural and remote Scotland: diverse experiences of people with dementia and their carers." Journal of Rural Studies **22**(2): 161-176.

Boldy, D., M. Davey, et al. (2005). "Host family respite: description and assessment of a program." Australasian Journal on Ageing **24**(2): 94-97.

Boutoleau-Bretonnière, C., M. Vercelletto, et al. (2008). "Zarit burden inventory and activities of daily living in the behavioral variant of frontotemporal dementia." Dementia and Geriatric Cognitive Disorders **25**(3): 272-277.

Bradshaw, J. (1972). "The concept of social need." New society **496**: 640-643.

Bray, J. R. (2012). Young carers in receipt of Carer Payment and Carer Allowance 2001 to 2006: characteristics, experiences and post-care outcomes. Canberra, Department of Families, Housing, Community Services and Indigenous Affairs**:** 156 p.

Brodaty, H. and A. Cumming (2010). "Commentary: Dementia services in Australia." International Journal of Geriatric Psychiatry **25**(9): 887-895.

Brodaty, H., A. Green, et al. (2003). "Meta-analysis of psychosocial interventions for caregivers of people with dementia." Journal of the American Geriatrics Society **51**(5): 657-664.

Brodaty, H., K. Seeher, et al. (2012). "Dementia time to death: a systematic literature review on survival time and years of life lost in people with dementia." International Psychogeriatrics / IPA **24**(7): 1034-1045.

Broe, T. (2013). "Koori growing older well study." Retrieved October 2013, from http://www.neura.edu.au/aboriginal-ageing.

Brown, A. and P. Roach (2010). "My husband has young-onset dementia: A daughter, wife and mother's story." Dementia **9**(4): 451-453.

Brown, J.-A., K. Sait, et al. (2012). Service and support requirements of people with younger onset dementia and their families. Final report. Sydney, NSW Department of Family and Community Services, Ageing, Disability and Home Care**:** 164 p.

Bunn, F., C. Goodman, et al. (2012). "Psychosocial factors that shape patient and carer experiences of dementia diagnosis and treatment: a systematic review of qualitative studies." PLoS Medicine **9**(10): 1-12.

Burgener, S. C., L. L. Buettner, et al. (2009). "Effectiveness of community-based nonpharmacological interventions for early-stage dementia: Conclusions and recommendations." Journal of Gerontological Nursing **35**(3): 50-59.

Burrell, J. (2012). What is younger onset dementia? Concord, Neuroscience Research Australia.

Callahan, C. M., H. C. Kales, et al. (2013). The historical development and state of the art approach to design and delivery of dementia care services. Designing and Delivering Dementia Services. H. De Waal, C. Lyketsos, D. Ames and J. O'Brien. Chicester, Wiley-Blackwell**:** 17-30.

Calma, T. and D. Dick (2007). Social determinants and the health of indigenous peoples in Australia - a human rights based approach. International Symposium on the Social Determinants of Indigenous Health, 29-30 April 2007. Adelaide.

Calsyn, R. J., W. D. Klinkenberg, et al. (2004). "Recruitment, engagement, and retention of people living with HIV and co-occurring mental health and substance use disorders." AIDS Care **16**: S56-S70.

Calvete, E. and E. L. de Arroyabe (2012). "Depression and grief in Spanish family caregivers of people with traumatic brain injury: the roles of social support and coping." Brain Injury **26**(6): 834-843.

Carling-Jenkins, R., J. Torr, et al. (2012). "Experiences of supporting people with Down syndrome and Alzheimer's disease in aged care and family environments." Journal of Intellectual and Developmental Disability **37**(1): 54-60.

Carr, A., H. Kimberley, et al. (2013). Caring for carers: evaluation of a support program for carers of people with dementia. Fitzroy, Brotherhood of St Laurence**:** 38 p.

Carson, J. D. and J. M. Ashby (2008). "Preservation of cognitive functioning in persons with mild to moderate dementia using informal caregiver resources." Alzheimer's & Dementia **4**(4, Supplement): T146-T147.

Casey, J. (2004). "Early onset dementia: Getting out and about." Journal of Dementia Care **12**(4): 12-13.

Chapman, N. J., T. Hazen, et al. (2005). "Encouraging development and use of gardens by caregivers of people with dementia." Alzheimer's Care Today **6**(4): 349-356.

Charlesworth, G., L. Shepstone, et al. (2008). "Does befriending by trained lay workers improve psychological well-being and quality of life for carers of people with dementia, and at what cost? A randomised controlled trial." Health Technology Assessment **12**(4).

Chaston, D. (2010). "Younger adults with dementia: a strategy to promote awareness and transform perceptions." Contemporary Nurse **34**(2): 221-229.

Chaston, D. (2011). "Between a rock and a hard place: exploring the service needs of younger people with dementia." Contemporary Nurse **39**(2): 130-139.

Chemali, Z., S. Schamber, et al. (2012). "Diagnosing early onset dementia and then what? A frustrating system of aftercare resources." International Journal of General Medicine **5**(Journal Article): 81-86.

Chesla, C., I. Martinson, et al. (1994). "Continuities and discontinuities in family members' relationships with Alzheimer's patients." Family Relations **43**(1): 3-9.

Clay, G. (2002). "Community-based respite – reaching rural areas." Dementia **1**(2): 256-259.

Clemerson, G., S. Walsh, et al. (2013). "Towards living well with young onset dementia: an exploration of coping from the perspective of those diagnosed." Dementia.

CommunityWest. (2013). "WA HACC Wellness Approach." Retrieved November, 2013, from http://www.communitywest.com.au/Wellness/introduction-to-the-wellness-approach-in-wa.html.

Cook, F. (2011). Medway Horticultural Project for younger people with dementia. Canterbury, St Martin's.

Cooper, C., A. R. Tandy, et al. (2010). "A systematic review and meta-analysis of ethnic differences in use of dementia treatment, care, and research." The American Journal of Geriatric Psychiatry **18**(3): 193-203.

Coppus, A. M. W., H. M. Evenhuis, et al. (2010). "Early age at menopause is associated with increased risk of dementia and mortality in women with Down Syndrome." Journal of Alzheimer's Disease **19**(2): 545-550.

Cosgrave, M. P., J. Tyrrell, et al. (1999). "Age at onset of dementia and age of menopause in women with Down's syndrome." Journal of Intellectual Disability Research **43**(6): 461-465.

Council of Australian Governments (COAG). (2011). "National Health Reform Agreement." Retrieved November, 2013, from http://www.coag.gov.au/node/96.

Cultural & Indigenous Research Centre Australia (CIRCA) (2008). CALD dementia strategic model: literature review, report, model. Leichhardt, NSW Department of Ageing, Disability & Home Care**:** 91 p.

Cummings, J. L., M. Mega, et al. (1994). "The Neuropsychiatric Inventory: comprehensive assessment of psychopathology in dementia." Neurology **44**(12): 2308-2314.

Dartington, T. (2007). "Two days in December." Dementia **6**(3): 327-341.

Davies-Quarrell, V., R. Marland, et al. (2010). "The ACE approach: promoting well-being and peer support for younger people with dementia." The Journal of Mental Health Training, Education, and Practice **5**(3): 41.

de Vugt, M. E., S. R. Riedijk, et al. (2006). "Impact of behavioural problems on spousal caregivers: a comparison between Alzheimer's disease and frontotemporal dementia." Dementia and Geriatric Cognitive Disorders **22**(1): 35-41.

de Waal, H., C. Lyketsos, et al. (2013). Designing and delivering dementia services. Chichester, Wiley-Blackwell.

Dearden, C. and S. Becker (1999). "The experiences of young carers in the UK: the mental health issues." Mental Health Care **2**: 273-276.

Delany, N. and H. Rosenvinge (1995). "Presenile dementia: sufferers, carers and services." International Journal of Geriatric Psychiatry **10**(7): 597-601.

Deloitte Access Economics (2011). Dementia across Australia: 2011-2050. Canberra, Deloitte Access Economics Pty Ltd.

Denny, S. S., D. Morhardt, et al. (2012). "Caring for children of parents with frontotemporal degeneration: a report of the AFTD task force on families with children." American Journal of Alzheimer's Disease and other Dementias **27**(8): 568-578.

Draper, B., D. Gibson, et al. (2010). "Age effects upon general hospital admissions of persons with dementia: longer admissions in young-onset dementia." Alzheimer's & Dementia: The Journal of the Alzheimer's Association **6**(4): S334-S335.

Draper, B., C. Peisah, et al. (2010). "Early dementia diagnosis and the risk of suicide and euthanasia." Alzheimer's & Dementia : The Journal of the Alzheimer's Association **6**(1): 75-82.

Ducharme, F., M.-J. Kergoat, et al. (2013). "The unique experience of spouses in early-onset dementia." American Journal of Alzheimer's Disease and other Dementias **28**(6): 634-641.

Eagar, K. and A. Owen (2002). Ongoing needs identification in NSW Primary Health and Community Care: how and why. University of Wollongong, Centre for Health Service Development.

Easton, A. (2011). Are younger people with dementia and their carers being informed and supported appropriately at the time of diagnosis? The Alzheimer's Australia 14th National Conference. Brisbane.

Ehrlich, F. (1994). "Planning for young adults with brain damage in New South Wales." Journal of Intellectual and Developmental Disability **19**(4): 293-306.

Elliott, T. and K. Read (2011). "Early onset dementia: developing strategies." Journal of Dementia Care **9**(5): 17-18.

Ellis, R., D. Langford, et al. (2007). "HIV and antiretroviral therapy in the brain: neuronal injury and repair." Nature Reviews Neuroscience **8**(1): 33-44.

El-Mallakh, R. S., D. Okoneski, et al. (1993). "A neuropsychiatric program for HIV-infected individuals." Maryland Medical Journal **42**(6): 565-570.

Evans, D. and E. Lee (2013). "Impact of dementia on marriage: a qualitative systematic review." Dementia.

Evers, C. (2009). "Cognitive dysfunction in multiple sclerosis." 2013, from http://www.alzheimer-europe.org/Dementia/Other-forms-of-dementia/Other-Rare-Causes-of-Dementia/Cognitive-Dysfunction-in-Multiple-Sclerosis#fragment-1.

Ferran, J., K. Wilson, et al. (1996). "The early onset dementias: A study of clinical characteristics and service use." International Journal of Geriatric Psychiatry **11**(10): 863-869.

Florence Centre for Specialised Care in Early Onset Dementia (2011). Caring for people in a respectful manner. Florence Centre for Specialised Care in Early Onset Dementia. The Hague, Netherlands.

Folstein, M., S. Folstein, et al. (1975). "Mini-mental state". A practical method for grading the cognitive state of patients for the clinician." Journal of Psychiatric Research **12** (3): 189-198.

Freyne, A., N. Kidd, et al. (1999). "Burden in carers of dementia patients: higher levels in carers of younger sufferers." International Journal of Geriatric Psychiatry **14**(9): 784-788.

Furniss, K. A., A. Loverseed, et al. (2011). "The views of people who care for adults with Down's syndrome and dementia: A service evaluation." British Journal of Learning Disabilities **40**(4): 318-327.

Garbutt, N. J. (2006). The experience of having a parent with young-onset dementia during transition to adulthood. Dissertation/Thesis, University of Leeds.

Gaugler, J. E., K. Gallagher-Winker, et al. (2011). "The Memory Club: providing support to persons with early-stage dementia and their care partners." American Journal of Alzheimer's Disease and other Dementias **26**(3): 218-226.

Gélinas, I., L. Gauthier, et al. (1999). "Development of a functional measure for persons with Alzheimer's disease: the disability assessment for dementia." The American Journal of Occupational Therapy **53**(5): 471-481.

Gelman, C. R. and C. Greer (2011). "Young children in early-onset Alzheimer's disease families: Research gaps and emerging service needs." American Journal of Alzheimer's Disease and other Dementias **26**(1): 29-35.

Georges, J., S. Jansen, et al. (2008). "Alzheimer's disease in real life – the dementia carer's survey." International Journal of Geriatric Psychiatry **23**(5): 546-551.

Gilbert, J. (1992). "Huntington's disease - community care? A carer's tale." Journal of Public Health Medicine **14**(4): 385-388.

Gilliard, J. (1999). Young carers: individual circumstances and practice consideration in dementia care giving. Younger people with dementia: planning, practice, and

development. S. Cox and J. Ready. London, Jessica Kingsley Publishers: 196-202.

Goldberg, E. L. (2011). "Filling an unmet need: a support group for early stage/ young onset Alzheimer's disease and related dementias." The West Virginia Medical Journal **107**(3): 64, 66-68.

Grabowski, D. C. (2006). "The cost-effectiveness of noninstitutional long-term care services: review and synthesis of the most recent evidence." Medical Care Research and Review **63**(1): 3-28.

Greenhalgh, T. and R. Peacock (2005). "Effectiveness and efficiency of search methods in systematic reviews of complex evidence: audit of primary sources." BMJ (Clinical Research ed.) **331**(7524): 1064-1065.

Hain, D., T. A. Touhy, et al. (2010). "What matters most to carers of people with mild to moderate dementia as evidence for transforming care." Alzheimer's Care Today **11**(3): 162-171 110.1097/ACQ.1090b1013e3181eb1098f1090.

HammondCare. (2013). "Specialised residential and respite care for younger people with dementia: Younger Onset Dementia Program Streeton Cottage." Retrieved November, 2013, from http://www.hammond.com.au/services/younger-onset-dementia.

Harris, P. B. (2004). "The perspective of younger people with dementia." Social Work in Mental Health **2**(4): 17-36.

Harris, P. B. and J. Keady (2009). "Selfhood in younger onset dementia: Transitions and testimonies." Aging & Mental Health **13**(3): 437-444.

Harvey, J. (1998). The impact of young onset dementia: a study of the epidemiology, clinical features, caregiving and health economics of dementia in younger people. Doctor of Medicine, University of London.

Harvey, R. J., P. K. Roques, et al. (1998). "CANDID - counselling and diagnosis in dementia: a national telemedicine service supporting the care of younger patients with dementia." International Journal of Geriatric Psychiatry **13**(6): 381-388.

Harvey, R. J., M. Skelton-Robinson, et al. (2003). "The prevalence and causes of dementia in people under the age of 65 years." Journal of Neurology, Neurosurgery & Psychiatry **74**(9): 1206-1209.

Hayter, C. (2008). Flexible and responsive: evaluation of the younger onset dementia social support and respite program Leichhardt, Carrie Hayter Consulting: 37 p.

Hean, S., N. Nojeed, et al. (2011). "Developing an integrated memory assessment and support service for people with dementia." Journal of Psychiatric and Mental Health Nursing **18**(1): 81-88.

Heaton, R. K., J. H. Atkinson, et al. (2010). "HIV-associated neurocognitive disorders persist in the era of potent antiretroviral therapy: CHARTER Study." Neurology **75**(23): 2087-2096.

Hellström, I., M. Nolan, et al. (2007). "Sustaining `couplehood': spouses' strategies for living positively with dementia." Dementia **6**(3): 383-409.

Hewitt, P., C. Watts, et al. (2013). "Does a structured gardening programme improve well-being in young-onset dementia? A preliminary study." The British Journal of Occupational Therapy **76**(8): 355-361.

Hodges, J. R., C. Gregory, et al. (2009). Quality dementia care series: Younger onset dementia a practical guide. Quality Dementia Care Series. Sydney, Alzheimer's Australia: 38 p.

Hunt, D. C. (2011). "Young-onset dementia: a review of the literature and what it means for clinicians." Journal of Psychosocial Nursing and Mental Health Services **49**(4): 28-33.

Husband, H. J. and M. N. Shah (1999). "Information and advice received by carers of younger people with dementia." Psychiatric Bulletin **23**(2): 94-96.

Ikejima, C., F. Yasuno, et al. (2009). "Prevalence and causes of early-onset dementia in Japan: a population-based study." Stroke **40**(8): 2709-2714.

Iverson, G. L. (2012). "Mild traumatic brain injury and risk for Alzheimer's Disease." International Brain Injury Association, from http://www.internationalbrain.org/articles/mild-traumatic-brain-injury-risk-for-alzheimers-disease/.

Janicki, M. P., A. Zendell, et al. (2010). "Coping with dementia and older families of adults with Down syndrome." Dementia **9**(3): 391-407.

Jenkins, N. (2013). "Piloting the use of drama to explore experiences of early onset dementia and priorities for developing specialist support services.", from http://www.alzscotdrc.ed.ac.uk/index.php/news-a-events/latest-news/115-alzheimer-scotland-dementia-research-centre-funds-innovative-theatre-based-researach-in-young-onset-dementia#_ENREF_11.

Johannessen, A. and A. Möller (2013). "Experiences of persons with early-onset dementia in everyday life: a qualitative study." Dementia **12**(4): 410-424.

Jokinen, N., M. P. Janicki, et al. (2013). "Guidelines for structuring community care and supports for people with intellectual disabilities affected by dementia." Journal of Policy and Practice in Intellectual Disabilities **10**(1): 1-24.

Jorm, A. F., K. B. G. Dear, et al. (2005). "Projections of future numbers of dementia cases in Australia with and without prevention." Australian and New Zealand Journal of Psychiatry **39**: 959–963.

Kaiser, S. and P. K. Panegyres (2007). "The psychosocial impact of young onset dementia on spouses." American Journal of Alzheimer's Disease and other Dementias **21**(6): 398-402.

Kaplan, L. (2001). "A couplehood typology for spouses of institutionalized persons with Alzheimer's Disease: perceptions of "We"-"I"." Family Relations **50**(1): 87-98.

Kay, D. W. K., D. P. Forster, et al. (2000). "Long-term survival, place of death, and death certification in clinically diagnosed pre-senile dementia in northern England: Follow-up after 8-12 years." The British Journal of Psychiatry **177**(2): 156-162.

Keady, J. and M. Nolan (1994). "Younger onset dementia: developing a longitudinal model as the basis for a research agenda and as a guide to interventions with sufferers and carers." Journal of Advanced Nursing **19**(4): 659-669.

Keady, J. and M. Nolan (1999). Family care giving and younger people with dementia: dynamics, experiences, and service expectations. Younger people with dementia: planning, practice, and development. London, Jessica Kingsley**:** 203-222.

Keady, J. D. (1998). The dynamics of dementia: a modified grounded theory study Dissertation/Thesis PhD, University of Wales.

Keenan, K. F., Z. Miedzybrodzka, et al. (2007). "Young people's experiences of growing up in a family affected by Huntington's disease." Clinical Genetics **71**(2): 120-129.

Kelley, B. J., B. F. Boeve, et al. (2008). "Young-onset dementia: demographic and etiologic characteristics of 235 patients." Archives of Neurology **65**(11): 1502-1508.

Kelly, C. (2008). "Memory clinics." Psychiatry **7**(2): 61-63.

Kenny, R. and E. Wilson (2012). "Successful multidisciplinary team working: an evaluation of a Huntington's disease service." British Journal or Neuroscience Nursing **8**(3): 137-142.

Killick, J. (1999). 'Dark head amongst the grey': experiencing the worlds of younger persons with dementia. Younger people with dementia: planning, practice and development. S. Cox and J. Keady. London, Jessica Kingsley**:** 153-172.

Kinney, J. M., C. S. Kart, et al. (2011). "'That's me, the goother': Evaluation of a program for individuals with early-onset dementia." Dementia **10**(3): 361-377.

Knapp, M., L. Thorgrimsen, et al. (2006). "Cognitive stimulation therapy for people with dementia: cost-effectiveness analysis." The British Journal of Psychiatry **188**(6): 574-580.

Koedam, E. L., Y. A. Pijnenburg, et al. (2008). "P3-023: Comparison of mortality risk between early- and late-onset dementia." Alzheimer's & Dementia **4**(4): T523-T523.

Koopmans, R. T., D. Thompson, et al. (2013). Services for people with young onset dementia. Designing and Implementing Successful Dementia Care Services. H. De Waal, C. Lyketsos, D. Ames and J. O'Brien. Oxford, John Wiley & Sons Ltd**:** 33-45.

Kortte, K. B. and E. J. Rogalski (2013). "Behavioural interventions for enhancing life participation in behavioural variant frontotemporal dementia and primary progressive aphasia." International Review of Psychiatry **25**(2): 237-245.

Laudate, T. M., S. Neargarder, et al. (2012). "Bingo! Externally supported performance intervention for deficient visual search in normal aging, Parkinson's disease, and Alzheimer's disease." Aging, Neuropsychology, and Cognition **19**(1-2): 102-121.

Lechich, A. J., D. Lovecky, et al. (2008). "Survey of community-based programs serving U.S. families with Huntington's disease: perceived barriers and facilitators in the residential placement process." Care Management Journals **9**(2): 65-74.

Letts, L., M. Edwards, et al. (2011). "Using occupations to improve quality of life, Health and wellness, and client and caregiver satisfaction for people with Alzheimer's disease and related dementias." American Journal of Occupational Therapy **65**(5): 497-504.

Leuty, V., J. Boger, et al. (2013). "Engaging older adults with dementia in creative occupations using artificially intelligent assistive technology." Assistive Technology **25**(2): 72-79.

Leutz, W. (2005). "Reflections on integrating medical and social care: five laws revisited." Journal of Integrated Care **13**(5): 3-12.

Leutz, W. N. (1999). "Five laws for integrating medical and social services: lessons from the United States and the United Kingdom." Milbank Quarterly **77**(1): 77-110.

Li, S. Q., S. L. Guthridge, et al. (2013). "Dementia prevalence and incidence among the indigenous and non-indigenous populations of the Northern Territory, using capture-recapture methods." The Medical Journal of Australia **In Press**.

Liebson, E., P. Rauch, et al. (2005). "Early-onset dementia: diagnostic considerations and implications for families." Harvard review of psychiatry **13**(2): 102-102.

Lim, J., J. Goh, et al. (2012). "Why do patients and their families not use services for dementia? Perspectives from a developed Asian country." International Psychogeriatrics **24**(10): 1571-1580.

Lindeman, M., K. Taylor, et al. (2010). Evaluation of a dementia awareness resource for use in remote indigenous communities. Darwin, Centre for Remote Health, Alzheimer's Australia Research**:** 42 p.

Lindén, A., J. Lexell, et al. (2010). "Perceived difficulties using everyday technology after acquired brain injury: Influence on activity and participation." Scandinavian Journal of Occupational Therapy **17**(4): 267-275.

Livingston, G. and C. Cooper (2013). The need for dementia care services. Designing and Delivering Dementia Services. H. de Waal, C. Lyketsos, D. Ames and J. O'Brien. Oxford, John Wiley & Sons, Ltd: 3-16.

Lloyd, B. T. and C. Stirling (2011). "Ambiguous gain: uncertain benefits of service use for dementia carers." Sociology of Health and Illness **33**(6): 899-913.

Lloyd-Yeates, T. (2013). "Working one-to-one with iPads." Australian Journal of Dementia Care **2**(4): 8.

Lobo, A., J. Martinez-Lage, et al. (2000). "Prevalence of dementia and major subtypes in Europe: a collaborative study of population-based cohorts." Neurology **54**(11): S4-S9.

Lockeridge, S. and J. Simpson (2012). "The experience of caring for a partner with young onset dementia: How younger carers cope." Dementia.

LoGiudice, D., A. Hassett, et al. (2001). "Equity of access to a memory clinic in Melbourne? Non-English speaking background attenders are more severely demented and have increased rates of psychiatric disorders." International Journal of Geriatric Psychiatry **16**(3): 327-334.

LoGiudice, D., K. Smith, et al. (2006). "Kimberley Indigenous Cognitive Assessment tool (KICA): development of a cognitive assessment tool for older indigenous Australians." International Psychogeriatrics **18**(2): 269-280.

LoGiudice, D. C., K. Smith, et al. (2012). "Lungurra Ngoora - A pilot model of care for aged and disabled in a remote Aboriginal community - Can it work?" Rural and Remote Health **12**(4).

Logsdon, R., S. McCurry, et al. (2007). "Evidence-based interventions to improve quality of life for individuals with dementia." Alzheimer's Care Today **8**(4): 309-318.

Luscombe, G., H. Brodaty, et al. (1998). "Younger people with dementia: diagnostic issues, effects on carers and use of services." International Journal of Geriatric Psychiatry **13**(5): 323-330.

Mackay, N. and A. Marriott (2000). "Young onset dementia: carer's experiences of services." PSIGE Newsletter(72): 3-5.

MacRae, R. and S. Cox (2003). Meeting the needs of people with alcohol related brain damage: a literature review on the existing and recommended service provision and models of care. Stirling, Scotland, University of Stirling.

Manly, J. J. and R. Mayeux (2004). Ethnic differences in dementia and Alzheimer's disease. Critical perspectives on racial and ethnic differentials in health in late life. Washington, DC, National Academies Press: 95-141.

Marian, C. (2009). Forgotten Australians still searching for 'The Road Home'. National Surviving Care Conference, 3 October 2008. Sydney.

Martin, F., A. Turner, et al. (2013). "Conceptualisation of self-management intervention for people with early stage dementia." European Journal of Ageing **10**(2): 75-87.

Maslow, K. (2006). Early-onset dementia: a national challenge, a future crisis. Washington DC, Alzheimer's Association: 14 p.

McCallion, P., R. W. Toseland, et al. (2004). "Increasing the use of formal services by caregivers of people with dementia." Social Work **49**(3): 441-450.

McCarron, M., M. Gill, et al. (2005). "Alzheimer's dementia in persons with Down's syndrome: predicting time spent on day-to-day caregiving." Dementia **4**(4): 521-538.

McLeod, S. A. (2007). "Maslow's hierarchy of needs - Simply Psychology." Retrieved November, 2013, from http://www.simplypsychology.org/maslow.html.

Meadows, J., K. Le Maréchal, et al. (1999). "The burden of care: the impact of HIV-associated dementia on caregivers." AIDS Patient Care and Stds **13**(1): 47-56.

Mendez, M. F. (2006). "The accurate diagnosis of early-onset dementia." International Journal of Psychiatry in Medicine **36**(4): 401-412.

Menne, H. L., J. M. Kinney, et al. (2002). "'Trying to continue to do as much as they can do': Theoretical insights regarding continuity and meaning making in the face of dementia." Dementia **1**(3): 367-382.

Metcalfe, M. (2013). "Making sense of relationships." Australian Journal of Dementia Care **1**(4): 26-27.

Minkman, M. M. N., S. A. Ligthart, et al. (2009). "Integrated dementia care in The Netherlands: a multiple case study of case management programmes." Health & Social Care in the Community **17**(5): 485-494.

Miranda-Castillo, C., B. Woods, et al. (2013). "The needs of people with dementia living at home from user, caregiver and professional perspectives: a cross-sectional survey." BMC Health Services Research **13**(1): 1-10.

Mitchell, H. (2012). Coping with young onset dementia: perspectives of couples and professionals. Dissertation/Thesis, ProQuest, UMI Dissertations Publishing.

Miyamoto, M., D. R. George, et al. (2011). "Government, professional and public efforts in Japan to change the designation of dementia (chihō)." Dementia **10**(4): 475-486.

Mocellin, R., A. Scholes, et al. (2013). Quality dementia care: Understanding younger onset dementia. Quality Dementia Care Series:. Melbourne, Alzheimer's Australia**:** 52 p.

Molloy, D., E. Alemayehu, et al. (1991). "Reliability of a Standardized Mini-Mental State Examination compared with the traditional Mini-Mental State Examination." American Journal of Psychiatry **148**(1): 102-105.

Moore, K. and E. Renehan. (2011). Evaluation of Linking Lives Pilot: supporting younger people with dementia. Final Report. Melbourne, Alzheimer's Australia Victoria**:** 46 p.

Morhardt, D. (2011). "Accessing community-based and long-term care services: challenges facing persons with frontotemporal dementia and their families." Journal of Molecular Neuroscience **45**(3): 737-741.

Moriarty, J. (2002). "Innovative practice section." Dementia **1**(2): 255-264.

Mourik, J., S. Rosso, et al. (2004). "Frontotemporal dementia: behavioral symptoms and caregiver distress." Dementia and geriatric cognitive disorders **18**(3-4): 299-306.

National LGBTI Health Alliance (2013). Submission to senate committee inquiry on care and management of younger and older Australians living with dementia and behavioural and psychiatric symptoms of dementia (BPSD). Parliament of Australia.

Newens, A. J., D. P. Forster, et al. (1995). "Dependency and community care in presenile Alzheimer's disease." The British Journal Of Psychiatry **166**(6): 777-782.

Nichols, K., D. Fam, et al. (2013). "When dementia is in the house: needs assessment survey for young caregivers." Canadian Journal of Neurological Sciences **40**(1): 21-28.

Nicolaou, P. L., S. J. Egan, et al. (2010). "Identifying needs, burden, and distress of carers of people with Frontotemporal dementia compared to Alzheimer's disease." Dementia **9**(2): 215-235.

NSW Department of Family and Community Services (2012). Look after your brain: a guide to dementia for Aboriginal people. Sydney, NSW Dept of Ageing Disability & Home Care**:** 1-31.

Nurock, S. (2000). "Carers and young onset dementia." Journal of the British Society of Gerontology (Generations Review)(10): 7-9.

O'Connell, M. E., M. Crossley, et al. (2013). "Development and evaluation of a telehealth videoconferenced support group for rural spouses of individuals diagnosed with atypical early-onset dementias." Dementia **published online 4 February**(1-14).

O'Connor, D., A. Phinney, et al. (2007). "Personhood in dementia care: developing a research agenda for broadening the vision." Dementia **6**(1): 121-142.

Obata, K. and J. Lee. (2010). "Languages of Aboriginal and Torres Strait Islander peoples - a uniquely Australian heritage." ABS 1301.0 - Year Book Australia, 2009-10 Retrieved 28 November, 2013, from http://www.abs.gov.au/ausstats/abs@.nsf/Previousproducts/1301.0Feature%20Article42009%E2%80%9310?opendocument&tabname=Summary&prodno=1301.0&issue=2009%9610&num=&view.

Penglase, J. and L. Sambrook (2008). A terrible way to grow up: the experience of institutional care and its outcomes for care leavers in Australia. Bankstown, Care Leavers Australia Network (CLAN)**:** 17 p.

Phillips, J., D. Pond, et al. (2011). Timely diagnosis of dementia: can we do better? A report for Alzheimer's Australia: Paper 24. Canberra, Alzheimer's Australia**:** 44 p.

Phillips, L. J. and V. S. Conn (2009). "The relevance of creative expression interventions to person-centered care." Research in Gerontological Nursing **2**(3): 151-152.

Phinney, A. and E. M. Moody (2011). "Leisure connections: benefits and challenges of participating in a social recreation group for people with early dementia." Activities, Adaptation and Aging **35**(2): 111-130.

Pipon-Young, F. E., K. M. Lee, et al. (2012). "I'm not all gone, I can still speak: The experiences of younger people with dementia. An action research study." Dementia **11**(5): 597-616.

Pires, S. (2013). "It's not a disgrace.....it's dementia." Australian Journal of Dementia Care **2**(4): 10-11.

Pitkälä, K. H., M. M. Pöysti, et al. (2013). "Effects of the Finnish Alzheimer disease exercise trial (FINALEX): a randomized controlled trial." JAMA internal medicine **173**(10): 894-901.

Price, E. (2010). "Coming out to care: gay and lesbian carers' experiences of dementia services." Health & Social Care in the Community **18**(2): 160-168.

Prince, M. and J. Jackson (2009). World Alzheimer Report. London, Alzheimer's Disease International**:** 93 p.

Putnam, M., J. G. Pickard, et al. (2010). "Stakeholder perspectives on policies to support family caregivers of older adults with dementia." Journal of Family Social Work **13**(2): 173-190.

Ratcliffe, J., L. Pezzullo, et al. (2013). Health economics, healthcare funding and service evaluation: international and Australian perspectives. Designing and Implementing Successful Dementia Care Services. H. De Waal, C. Lyketsos, D. Ames and J. O'Brien. Oxford, John Wiley & Sons Ltd**:** 126-138.

Ratey, J. J. and J. E. Loehr (2011). "The positive impact of physical activity on cognition during adulthood: a review of underlying mechanisms, evidence and recommendations." Reviews in the Neurosciences **22**(2): 171-185.

Reed, J., C. Cantley, et al. (2002). "Services for younger people with dementia: problems with differentiating needs on the basis of age." Dementia **1**(1): 95-112.

Reed, P. and S. Bluethmann (2008). Voices of Alzheimer's Disease: a summary report on the nationwide Town Hall meetings for people with early stage dementia. Washington DC, Alzheimer's Association**:** 33 p.

Reynolds, T., G. Thornicroft, et al. (2000). "Camberwell Assessment of Need for the Elderly (CANE). Development, validity and reliability." The British Journal of Psychiatry **176**(5): 444-452.

Riedijk, S., M. De Vugt, et al. (2006). "Caregiver burden, health-related quality of life and coping in dementia caregivers: a comparison of frontotemporal dementia and Alzheimer's disease." Dementia and Geriatric Cognitive Disorders **22**(5-6): 405-412.

Roach, P., J. Keady, et al. (2008). "Subjective experiences of younger people with dementia and their families: implications for UK research, policy and practice." Reviews in Clinical Gerontology **18**(2): 165-174.

Robertson, J., D. Evans, et al. (2013). "Side by Side: A workplace engagement program for people with younger onset dementia." Dementia **12**(5): 666-674.

Rose, K., F. Yu, et al. (2010). "Care considerations for persons with early-onset dementia: a case studies analysis." Alzheimer's Care Today **11**(3): 151-161.

Rosen, W., R. Mohs, et al. (1984). "A new rating scale for Alzheimer's disease." American Journal of Psychiatry **141**(11): 1356-1364.

Rosenberg, L. and L. Nygård (2013). "Learning and using technology in intertwined processes: a study of people with mild cognitive impairment or Alzheimer's disease." Dementia.

Rosness, T. A., P. K. Haugen, et al. (2008). "Support to family carers of patients with frontotemporal dementia." Aging and Mental Health **12**(4): 462-466.

Rota-Bartelink, A. (2009). Consider Robert. Ageing Safely Forum. Adelaide.

Rota-Bartelink, A. and B. Lipmann (2007). "Supporting the long-term residential care needs of older homeless people with severe alcohol-related brain injury in Australia: The Wicking Project." Care Management Journals **8**(3): 141-148.

Ryder-Jones, C., A. Bullock, et al. (2012). "Wii can make a difference." Australian Journal of Dementia Care **1**(2): 10-11.

Sait, K. (2012). "Service and support requirements of people with younger onset dementia and their families." Younger Onset Dementia Forum Retrieved November, 2013, from http://www.fightdementia.org.au/common/files/NSW/20120720-NSW-PRES-YODForum-ServiceSupportResearch-Sait.pdf.

Sait, K. (2013). Living alone with dementia (Discussion Paper No. 7). North Ryde, Alzheimer's Australia NSW**:** 44 p.

Sampson, E. L., J. D. Warren, et al. (2004). "Young onset dementia." Postgraduate Medical Journal **80**(941): 125-139.

Sansoni, J., N. Marosszeky, et al. (2010). Selecting tools for ACAT assessment: a report for the Expert Clinical Reference Group, Aged Care Assessment Program, Department of Health and Ageing. University of Wollongong, Centre for Health Service Development**:** 212 p.

Sansoni, J., N. Marosszeky, et al. (2007). Final report: dementia outcomes measurement suite project. University of Wollongong, Centre for Health Service Development**:** 511 p.

Sansoni, J., P. Samsa, et al. (2012). A Model and Proposed items for the New Assessment System for Aged Care, Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong.

Santangelo, D. (2012). "Younger onset dementia initiative." Retrieved November, 2013, from http://www.fightdementia.org.au/common/files/NSW/20120720-NSW-PRES-YODForum-ServiceMapping-StAngelo.pdf.

Saunders, C. (2012). Memory Boost Slows Dementia. The West Australian. Perth. **September 6:** http://au.news.yahoo.com/thewest/lifestyle/a/-/lifestyle/14768761/memory-boost-slows-dementia/

Saunders, P. (2013). Get your voice heard: living with dementia in country SA report. Glenside, Alzheimer's Australia SA**:** 71 p.

Schlosberg, E., C. Browne, et al. (2004). "What users and carers think of a service for younger people." Journal of Dementia Care(Jan/Feb).

Scott, D. and M. Donnelly (2005). "The early identification of cognitive impairment: a stakeholder evaluation of a 'Dementia Awareness Service' in Belfast." Dementia **4**(2): 207-232.

Seddon, D. (1999). Negotiating care-giving and employment. Younger People with Dementia: Planning, Practice and Development. S. Cox and J. Keady. London, Jessica Kingsley**:** 173-195.

Selwood, A., K. Johnston, et al. (2007). "Systematic review of the effect of psychological interventions on family caregivers of people with dementia." Journal of Affective Disorders **101**(1): 75-89.

Shnall, A., A. Agate, et al. (2013). "Development of supportive services for frontotemporal dementias through community engagement." International Review of Psychiatry **25**(2): 246-252.

Silverman, W. (2010, 20 Jan 2010). "Dementia among adults with down Syndrome: individual differences in risk and progression." Aging and End of Life Webinar Series, 2013, from http://aaidd.org/education/education-archive/2010/01/20/dementia-among-adults-with-down-syndrome-individual-differences-in-risk-and-progression#.Uo5MtSe6njZ.

Silverstein, N. M., C. M. Wong, et al. (2010). "Adult day health care for participants with Alzheimer's disease." American Journal of Alzheimer's Disease & other Dementias **25**(3): 276-283.

Sixsmith, A. (2006). "New technologies to support independent living and quality of life for people with dementia." Alzheimer's Care Today **7**(3): 194-202.

Skirton, H., J. K. Williams, et al. (2010). "Huntington disease: families' experiences of healthcare services." Journal of Advanced Nursing **66**(3): 500-510.

Smith, K., L. Flicker, et al. (2008). "High prevalence of dementia and cognitive impairment in Indigenous Australians." Neurology **71**(19): 1470-1473.

Soltysiak, B., P. Gardiner, et al. (2008). "Exploring supportive care for individuals affected by Huntington disease and their family caregivers in a community setting." Journal of Nursing & Healthcare of Chronic Illnesses **17**(7B): 226-234.

Sperlinger, D. and M. Furst (1994). "The service experiences of people with presenile dementia: a study of carers in one London borough." International Journal of Geriatric Psychiatry **9**(1): 47-50.

Spring, J. A., M. Viera, et al. (2013). "Is gardening a stimulating activity for people with advanced Huntington's disease?" Dementia.

Stansell, J. (2001). "A volunteer program for people with dementia." Alzheimer's Care Today **2**(2): 4-7.

Stern, R. A., D. O. Riley, et al. (2011). "Long-term consequences of repetitive brain trauma: chronic traumatic encephalopathy." PM & R : the journal of injury, function, and rehabilitation **3**(10 Suppl 2): S460-S467.

Storey, J. E., J. T. J. Rowland, et al. (2004). "The Rowland Universal Dementia Assessment Scale (RUDAS): a multicultural cognitive assessment scale." International Psychogeriatrics **16**(1): 13-31.

Sussman, T. and C. Regehr (2009). "The influence of community-based services on the burden of spouses caring for their partners with dementia." Health and Social Work **34**(1): 29-39.

Svanberg, E., A. Spector, et al. (2011). "The impact of young onset dementia on the family: a literature review." International Psychogeriatrics **23**(3): 356-371.

Svanberg, E., J. Stott, et al. (2010). "Just helping: children living with a parent with young onset dementia." Aging and Mental Health **14**(6): 740-751.

Svanstrom, R. and K. Dahlberg (2004). "Living with dementia yields a heteronomous and lost existence." Western Journal of Nursing Research **26**(6): 671-687.

Swaffer, K. (2012). "Prescribed Dis-engagement: what is it?" Retrieved 14 October, 2013, from http://kateswaffer.com/2012/11/25/prescribed-dis-engagement/.

Teng, E. and H. Chui (1987). "The Modified Mini-Mental State (3MS) Examination." Journal of Clinical Psychiatry **48**: 314-318.

Thompson, D. (2011). "Service and support requirements for people with younger onset dementia and their families: literature review." Social Policy Research Centre (SPRC) Publications.

Thompson, S. B., T. D. Coates, et al. (2006). "Interdisciplinary clinic for adults with early onset dementia in a mental health NHS Trust." Clinical Gerontologist **29**(4): 99-104.

Tindall , L. and J. Manthorpe (1997). "Early onset dementia: A case of ill-timing?" Journal of Mental Health **6**(3): 237-250.

Tolhurst, E., S. Bhattacharyya, et al. (2012). "Young onset dementia: The impact of emergent age-based factors upon personhood." Dementia.

Troy, K. and D. Zisis (2012). Case management for younger onset dementia: an enabling approach. Younger Onset Dementia Forum. Sydney, Alzheimer's Australia NSW.

Truscott, M. (2003). "Life in the slow lane." Alzheimer's Care Today **4**(1): 11-17.

Tyson, M. (2007). Exploring the needs of younger people with dementia in Australia. Canberra, Alzheimer's Australia**:** 96 p.

van Baalen, A., A. J. J. M. Vingerhoets, et al. (2011). "How to evaluate quality of care from the perspective of people with dementia: an overview of the literature." Dementia **10**(1): 112-137.

van Vliet, D., C. Bakker, et al. (2010a). "Research protocol of the NeedYD-study (Needs in Young Onset Dementia): a prospective cohort study on the needs and course of early onset dementia." BMC Geriatrics **10**.

van Vliet, D., M. E. de Vugt, et al. (2012). "Prevalence of neuropsychiatric symptoms in young-onset compared to late-onset Alzheimer's disease - part 1: findings of the two-year longitudinal NeedYD-study." Dementia and Geriatric Cognitive Disorders **34**(5-6): 319-327.

van Vliet, D., M. E. de Vugt, et al. (2011). "Caregivers' perspectives on the pre-diagnostic period in early onset dementia: a long and winding road." International Psychogeriatrics **23**(9): 1393-1404.

van Vliet, D., M. E. de Vugt, et al. (2010b). "Impact of early onset dementia on caregivers: a review." International Journal of Geriatric Psychiatry **25**(11): 1091-1100.

Vieira, R. T., L. Caixeta, et al. (2013). "Epidemiology of early-onset dementia: a review of the literature." Clinical Practice and Epidemiology in Mental Health **9**(Journal Article): 88.

Ward, R. (2000). "Waiting to be heard - dementia and the gay community. The views and experiences of lesbians and gay men with dementia, and their carers, are largely unrecognised." Journal of Dementia Care **8**(3): 24-25.

Ward, R., M. Howorth, et al. (2012). "Supporting the friendships of people with dementia." Dementia **11**(3): 287-303.

Ware, J. E., M. Kosinski, et al. (2000). How to score version 2 of the SF-36 Health Survey Lincoln, RI, QualityMetric Incorporated.

Warren, J. (2013). "Younger onset dementia key worker program." HOPE Newsletter **15**: 7-9.

Webster, J. J. and M. A. Duncan (2005). "Best practices. E-mail connections: an innovative communication network for families and persons with early-onset Alzheimer's." Alzheimer's Care Quarterly **6**(3): 197-200.

Werner, P., I. Stein-Shvachman, et al. (2009). "Early onset dementia: clinical and social aspects." International Psychogeriatrics / IPA **21**(4): 631-636.

Whitfield, K. (2006). Health service planning with individuals with dementia: towards a model of inclusion. NR17485 Ph.D., University of Waterloo (Canada).

Williams, I. (2000). "What help do GPs want from specialist services in managing patients with dementia?" International Journal of Geriatric Psychiatry **15**(8): 758-761.

Williams, T., I. Cameron, et al. (2001). "From pillar to post - a study of younger people with dementia." Psychiatric Bulletin **25**(10): 384-387.

Williamson, T. (2008). Dementia: out of the shadows. London, Alzheimer's Society UK**:** 72 p.

Willis, R., J. Chan, et al. (2009). "People with dementia and their family carers' satisfaction with a memory service: a qualitative evaluation generating quality indicators for dementia care." Journal of Mental Health **18**(1): 26-37.

Withall, A. (2013). "The challenges of service provision in younger-onset dementia." Journal of the American Medical Directors Association **14**(4): 230-232.

Withall, A. and B. Draper (2010). "Alcohol-related dementia: A common diagnosis in younger persons." Alzheimer's & Dementia **6**(4): S188-S189.

Woolley, R. (2013). "Younger Onset Key Worker Program Update: meet the Key Workers." HOPE Newsletter **16**: 3-6.

Wylie, M. A., A. Shnall, et al. (2013). "Management of frontotemporal dementia in mental health and multidisciplinary settings." International Review of Psychiatry **25**(2): 230-236.

Xie, J., C. Brayne, et al. (2008). "Survival times in people with dementia: analysis from population based cohort study with 14 year follow-up." BMJ (Clinical research ed.) **336**(7638): 258-262.

Zarit, S. H., N. K. Orr, et al. (1985). The hidden victims of Alzheimer's disease: families under stress. New York, New York University Press.

Zigmond, A. S. and R. P. Snaith (1983). "The hospital anxiety and depression scale." Acta Psychiatrica Scandinavica **67**(6): 361-370.

10 Appendices

10.1 Appendix 1: Academic Literature Search

The literature searched included both Australian and International peer reviewed academic literature, alongside 'grey literature' such as relevant government documents and web-based information. The literature reviewed was initially limited to the years 2000 to present. Relevant papers were obtained by searching across the following databases:

- EBSCO: Medline, Cinahl, Academic Research Complete, Psychology & Behavioural Science Collection, Health Source: Nursing / Academic edition
- Scopus
- Proquest Central
- Informa Healthcare
- Cochrane Collaboration
- BioMed Central
- Summons
- Google Scholar.

The *Alzheimer's Care Today* journal and the *Dementia* journal were also "hand searched" as they were journals that kept reappearing in the database search results.

All searching was limited from the year 2000 to the year 2013.

Initially, the searching focused on Young/Early Onset Dementia and Special Needs groups, such as rural & remote, Aboriginal & Torres Strait Islanders, LGBTI, Huntington's disease, Alzheimer's, HIV/AIDS, Down Syndrome, and alcohol related dementia. The searching focussed on the community support and care available rather than the clinical and diagnostic side of early onset dementia associated with these groups.

Once a search across a database was performed, the list of documents would be then sorted by relevance so that the most relevant items appeared to the beginning of the results list.

Searches were performed using a combination of the following terms across the above mentioned databases. The results of each search are outlined in Table 1 below.

Table 1 Electronic database search terms and results

Primary Terms	Secondary Terms	Database	Result hits	Downloaded from results
(young OR early) onset Dementia Presenile "special needs" Cognitive* impair* Huntington's Neurocognitive Lesbian Homosexual* "Person centre care"	support OR community service activity community participation community care community support AND NOT clinical AND NOT (aged OR elderly OR older)	**EBSCO**: Medline, Cinahl, Academic Research Complete, Psychology & Behavioural Science Collection, Health Source: Nursing / Academic edition	633	52
(young OR early) onset Dementia Cognitive* impair* Acquired brain injury*	Community care Community participation Community service Indigenous Employment participation Rural Support services AND NOT hospital	Scopus	737	86
(young OR early) onset Dementia Cognitive* impair*	Community participation	Proquest Central	25	5
Young Dementia	Community support	Informa Health	962	5
(young OR early) onset Dementia		Cochrane		0
(young OR early) onset Dementia	Living Lifestyle	BioMed Central	49	2
Early onset Young onset	Community Support Employment	Alzheimer's Care Today Journal	302	30
Early onset Young onset	Community care Services	Dementia Journal	50	21
Early onset Young onset Dementia	Community care Support service Participation Employment	Google/Google Scholar & Summons		47 (these results included many reports and webpages)

In total, 248 articles were downloaded from the above searching. These articles were then reviewed and sorted into groups of:

- High priority
- Medium – high priority
- Medium priority; and
- Low priority.

10.2 Appendix 2: Grey Literature Sources

Government Department websites:

- Department of Health and Ageing (DoHA)
- Ageing Disability and Home Care (ADHC)
- State & Territory Departments/Ministry of Health
- Department Families, Housing, Community Services and Indigenous Affairs (FaHCSIA)
- Victorian Government Health Information: Cognitive, Dementia and Memory Service
- Australian Institute for Health and Welfare
- Australian Human Rights Commission

Parliamentary Committee Websites, e.g.

- House of Representatives Standing Committee on Health and Ageing
- Senate Standing Committee on Community Affairs
- Relevant State and Territory ageing/social policy/community affairs committees

Relevant Australian Organisations

- Alzheimer's Australia
- Younger Onset Dementia Association Inc.
- Hammond Care & the Dementia Centre
- Eastern Australia Dementia Training Studies Centre, UOW
- Social Policy Research Centre, University of New South Wales
- Primary Health Care Research Information Service (PHC RIS)
- Australian Federation of AIDS Organisations
- ACON (Formerly AIDS Council of NSW)
- Federation of Ethnic Communities' Councils (FECCA)
- Mental Health Council of Australia
- People With Disabilities Australia (PWD)
- GLBTI Retirement Association Inc. (GRAI)
- Volunteering Australia
- National Rural Health Alliance Inc.

Relevant International Organisations such as:

- The Campbell Collaboration Library
- Alzheimer's New Zealand
- Alzheimer's Society UK
- Young Dementia UK
- Alzheimer's Disease International

- Alzheimer's Association (USA)
- Alzheimer Society Canada
- Alzheimer Europe
- National Institute of Mental Health (NIMH)
- National Health Service (NHS)
- Canadian Health Services Improvement Foundation