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Final report: literature review and needs and feasibility assessment of services for people with younger onset dementia

Anita Westera
*University of Wollongong, westera@uow.edu.au*

David Fildes
*University of Wollongong, dfildes@uow.edu.au*

Cathy Duncan
*University of Wollongong, cduncan@uow.edu.au*

Peter Samsa
*University of Wollongong, psamsa@uow.edu.au*

Jacquelin Capell
*University of Wollongong, jcapell@uow.edu.au*

See next page for additional authors

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Final report: literature review and needs and feasibility assessment of services for people with younger onset dementia

Abstract
This report documents the key findings of the major activities associated with the Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia project funded by the Commonwealth Government. The project was conducted between July 2013 and January 2014, and comprised two key elements: an international literature review, and a needs and feasibility assessment of services for people with younger onset dementia.

Keywords
younger, people, report, onset, services, assessment, dementia, feasibility, final, needs, review, literature

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Authors
Anita Westera, David Fildes, Cathy Duncan, Peter Samsa, Jacquelin Capell, Pamela Grootemaat, and Janet Sansoni

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March 2014
Anita Westera

Dave Fildes

Cathy Duncan

Peter Samsa

Jacquelin Capell

Pam Grootemaat

Jan Sansoni

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The opinions, comments and/or analysis expressed in this document are those of the authors and do not necessarily represent the views of the Australian Government Department of Social Services and cannot be taken in any way as expressions of government policy.

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Most importantly, however, we are thankful for the generosity in time and insights of the people with younger onset dementia who contributed to this project, their carers and family members.
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Executive summary
This report documents the key findings of the major activities associated with the Literature Review and Needs and Feasibility Assessment of Services for People with Younger Onset Dementia project funded by the Commonwealth Government. The project was conducted between July 2013 and January 2014, and comprised two key elements: an international literature review, and a needs and feasibility assessment of services for people with younger onset dementia.

This report brings together findings from a comprehensive review of the international literature, and those of a national consultation process that included face to face meetings, an online survey and email and telephone discussions with people with younger onset dementia, carers, service providers, researchers, policy and program advisers. In summary, we:

- reviewed over 300 journal articles, reports, presentations and websites out of 425 identified from the search strategy;
- interviewed 215 people, including 33 people with dementia and carers, 54 from special interest groups; 77 service providers; 19 peak body representatives; 11 researchers and 21 policy and program advisers (state and territory government representatives); and
- received 29 completed survey responses, out of a total of 97 received.

In recognition of the relatively low level of younger onset dementia specific services that currently exist, the project sought to identify models from other sectors that may be transferable to meet the needs of people at this life stage. Our approach from the outset was to assign a broad definition of ‘younger onset dementia’ to ensure we captured the more well-known diagnostic groups e.g. Alzheimer’s Disease, fronto-temporal dementia, as well as those who may have developed a dementia as a secondary condition associated with another primary diagnosis e.g. HIV/AIDS, Parkinson’s disease, alcohol or drug abuse etc. We also considered the different contextual factors associated with dementia, such as living arrangements, and the social, economic and environmental factors that enable and support people with younger onset dementia.

Conceptual approach
Traditional dementia service models do not sufficiently take into account the life stage at which symptoms of early onset dementia emerge, and therefore are not well equipped to support people with younger onset dementia. Additional supports are required to maximise people’s capacities for participation in the activities that generally occur at this time of life, for example, paid employment, family responsibilities, and social and community activities.

We conceptualised the project across two dimensions: longitudinally as well as systemically. In the first instance we considered the ‘dementia journey’, describing the different stages of the lived experience of dementia and identifying the types of supports and services that may be required. This is depicted in the following diagram:
Five Stages of Younger Onset Dementia

We also took a systems approach to understanding the context within which people with younger onset dementia live and the groups that are influenced by, and have influence on them. This is depicted in the following diagram:

Circles of impact of younger onset dementia

Findings

The service delivery models that offer the strongest evidence for good practice are those that address all elements of the ‘circles of impact’, starting with a focus on the person with younger onset dementia and working outwards to facilitate the enablers within the surrounding spheres of influence. This requires different emphases of effort across the five stages of dementia support.

There was strong alignment of the major issues and practices raised in both elements of the project. In one sense this was a very positive outcome – there seems to be a number of service models that are exhibiting the good practices identified in the literature, including some ‘cutting edge’ examples; however, the systemic deficits identified in the literature appear to be equally evident in the Australian context.
The literature provided revealed a number of Key Service Attributes that facilitate good outcomes for people with younger onset dementia, which were subsequently tested within the context of the Needs Assessment. In the main, there was strong alignment with the attributes identified in the literature; the final Key Service Attributes includes a small number of refinements accordingly. The final list of attributes are summarised in the box below.

**Younger onset dementia service attributes**

**Individualised model of service**
- Listen to people with younger onset dementia and their carers
- Individualised service planning / person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Recognise and respond to the different diagnostic groups and their needs

**Staff attributes**
- Appropriate skills and attitude
- Holistic approach to care and support
- Enabling and consumer centred approach
- Care co-ordination / case management skills
- Effective communication and interpersonal skills
- Flexibility
- Capacity building

**Organisational attributes**
- Integrated specialist diagnostic and ongoing symptom management services
- Organisational change capabilities
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Cater for needs of people in rural and remote communities
- Individualised service planning / person centred approach / continuity
- Respect and consideration for staff and clients
- Manage risk effectively
- Effective exit policies: re suspension and withdrawal of services.
These attributes have been used to make a judgement about the current services available, as well as service models from other sectors that have the potential to be adapted to meet the needs of people with younger onset dementia.

The majority of services used by people with younger onset dementia are those that have emerged from within an aged care context, with a smaller number being delivered by the disability and health sectors. Most of the well-targeted and responsive models of support are those that use a combination of disability and aged care program funding, applied in a flexible manner. For example, some organisations pool respite funding with transport services to create flexible peer group options that included outings as well as centre-based activities.

The Feasibility Assessment (Section 5) contains details of services that meet, or have the potential to meet, Younger Onset Dementia Key Service Attributes. Despite our broad search strategy, both in terms of the literature and the consultation process, the overall number of models in practice are quite small. Overall, the service types include modifications of respite and peer support groups, health and fitness initiatives, employment and vocational options, inter-sectoral partnerships, diagnostic and health pathways, accommodation and residential aged care models. Examples of some of the innovative and potential service models include:

- **Gardening on the Tram Tracks:** A collaboration between LifeCare’s Norman House and the local Council of Unley, this is an eight week program in which men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens. As well as providing the men with a meaningful and rewarding activity it also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.

- **Safe2Walk:** The Safe2Walk system was developed to support people with dementia being able to choose the timing and duration of their walking activities, as opposed to a traditional service delivery which dictates to the person depending on the availability of the worker and the resources available to pay for that service. The program uses a small mobile phone like device with a Global Positioning System (GPS) function that can locate a person to within 10 metres. It has one large button which, when pressed, calls and connects with one of three pre-programmed numbers; it also acts as an SOS as when pressed the location data is sent to the carer’s mobile phone via SMS, enabling carers to log on to a secure website to locate the person. Pilot studies conducted by Alzheimer’s Australia WA and Vic found positive outcomes for many of those who participated. It is possible that people with younger onset dementia may be more likely to benefit from this type of assistive technology, given the increased likelihood of their familiarity with using mobile phones, GPS technology and computer-based programs.

- **Circles of Support:** This is an informal support network whereby a group of people form a network or circle of support, to provide support to a person and their family, work alongside the formal service provider and agree to ‘make time to look out’ for the person. Currently used within a number of disability services nationally, including Western Australia by Planned Individual Networks (PIN), Victoria by UnitingCare...
Community Options (UCCO) and in NSW by Down Syndrome NSW in partnership with UnitingCare Disability Services as part of the Independent Living Support Initiative (ILSI).

- **BANCPASS**: A collaboration between Baptcare Northern, Northwest Aged Care Assessment Service (ACAS) and the Neuropsychiatry Unit (Royal Melbourne Hospital North West Adult Mental Health), BANCPASS is designed to support people with younger onset dementia and their families navigate the health system and initiate service provision from the point of diagnosis of younger onset dementia through to community support and care.

- **The Home Occupiers Mutual Enterprise (HOME)**: A proposed ‘intentional community’ in the Sydney’s Inner West, where ‘people with a disability and people without a disability live in a collaborative and supportive way’. The HOME group is currently seeking finance for a purpose built apartment block of approximately 40 dwellings, of which 15% would be allocated for people with disabilities who have significant support needs which would be met by a partner provider (in this case, UnitingCare Supported Living).

**Key Messages for ongoing service development**

A number of recurring themes emerged across all aspects of this project, and provide a range of lessons for those involved in developing and delivering health, care and support services for people with younger onset dementia, their families and carers:

**Focus on the individual**

Good practice models are those that have a sound understanding of who the person is, including their personal attributes, goals and interests; includes the person in service planning; provides holistic and ongoing assessment of need; is flexible in terms of service delivery; is accessible and affordable; and, works alongside the person in a respectful and considerate manner.

**Timely and accurate diagnosis**

Good practice models include a broad community education and awareness activities; targeted information for primary health care professionals; access to multidisciplinary teams that can provide holistic assessment, treatment and management options.

**Appropriate services**

Good practice models include services which are individually tailored to the needs and interests of the person with dementia, their carer and family; are underpinned with an enabling and well-being approach to service provision; provide ongoing assessment to monitor changes and adapt services accordingly; are accessible in terms of location, transport and cost; are flexible and able to deal with change; have appropriately skilled staff who are supported by a sound business framework that includes ongoing education and risk management policies; and, are culturally appropriate and accommodating of special needs groups.
Integrated care
Good practice models are those that are based on an understanding of the individual’s capacities and preferences and the needs of their immediate support network; have a capacity building approach that draws on personal, social and community networks as well as formal services; are flexible regarding their service provision according to changing needs of the client; have the appropriate skills, education and attitude; and are networked into specialist services and able to draw on expertise as needed.

Continuity of care
Good practice models are those that have an identified ‘case manager’ or ‘care coordinator’ who fully understands the needs and aspirations of the person with dementia and those of their immediate care support network; can work across different services and sectors to build capacity within support and care services, as well as the person’s social and community networks; facilitates the involvement of carers and families across the continuum of the dementia journey, including palliative care and death, for as long as is desired.

Service specific issues – respite care
Good practice models are those that, in addition to the attributes identified above, take into account the specific needs of both the person with dementia as well as the carer; provide meaningful activities that cater for the interests of the person with dementia; are offered in ‘blocks’ of sufficient time to enable carers to engage in their desired activities.

Service specific issues – peer support
Good practice models are those that are those that are designed around the needs of carers as well as people with dementia, in terms of timing, and the nature of activities; are self-directed as much as possible by group members; are accessible in terms of transport and cost; offer opportunities for meaningful engagement amongst one another, and with their local community; and do not enforce arbitrary age thresholds of programs which disadvantage clients.

Policy and program issues
Good policy design is that which does not arbitrarily require people with a diagnosis of dementia to cease particular activities; includes provision for targeted assessment of attributes and capacity pertaining to the relevant activities, e.g. driving, paid employment; acknowledges the interdependence of people with dementia and their carers when considering program eligibility and funding; and, facilitates cross-sector and inter-jurisdictional approaches to supporting people with dual diagnoses and complex health, care and accommodation needs.

Conclusion and recommendations
It is clear that the current service system is not well placed to meet the needs of people with younger onset dementia to remain living and participating in the community. In part, the ability to develop responsive policies and service models has been hindered by a lack of evidence regarding prevalence, presentation and appropriate management strategies; consequently, the default service option has been the aged care system which has
dependency and frailty as its operating paradigms. This report includes a large number of personal stories and experiences that reinforce the need for a new paradigm in terms of the way services are funded, developed and delivered. Paradoxically, this context has also provided the stimulus for the emergence of a number of new and innovative models of health, care, support and employment opportunities that more appropriately take into account the life stage, circumstances and expectations of people with younger onset dementia.

The Key Service Attributes and the key messages arising from this project are, on the whole, not new; many have been present within disability services sector for some time. That sector is underpinned by a philosophy of enablement and engagement, which in turn requires an individualised approach to support and service delivery. A number of the new and innovative models described in the feasibility assessment are drawn from, either directly or in part, developments that have been emerging from within disability services.

While these new initiatives hold promise, their ongoing delivery remains precarious; there are uncertainties around future funding and relevance of the models, particularly in light of the implementation of the National Disability Insurance Scheme (NDIS). Many of the more innovative models are driven by the commitment of a few individuals within an organisation, and therefore subject to the vagaries of staff and management changes. The major barriers to implementing good practice services arise from a mix of personal, cultural, organisational and attitudinal factors. Addressing these barriers will require ongoing commitment and collaboration across and between: individuals and their families and support networks; the formal health and community care services; and, the broader political, jurisdictional and community levels.

Recommendations

In order to address the critical issues identified in this report, and encourage the continuation of the positive developments that have occurred within the research, service delivery and policy sectors, the following recommendations are made:

1. Increase community awareness of younger onset dementia to encourage greater awareness of the continuing contribution that people can make, e.g., the ‘Don’t Dis my Ability campaign’.
2. Develop an inter-jurisdictional working group to address the issues identified in the report, in particular: development of integrated assessment, diagnostic and care pathways; improved employment options; and, removal of local policies currently being employed that restrict access to appropriate services in a timely manner.
3. Convene a panel of cross-sector representatives to further develop service delivery models identified in the Feasibility Assessment.
4. Work with relevant health and medical colleges to identify opportunities to increase awareness and improve access to specialist assessment, diagnostic and ongoing management of younger onset dementia.
5. Enhance the opportunity for people with younger onset dementia to be involved in the design, development and delivery of services and policies that affect them through the development of appropriate resources and/or financial incentives.
6. Make this Final Report, and the Literature Review on Younger Onset Dementia, publicly available to encourage the continued development of research, service and policy initiatives that will benefit people with younger onset dementia.
1 INTRODUCTION
Younger onset dementia is defined as dementia which has onset before the age of 65 years. The Australian Institute of Health and Welfare has estimated that around 24,000 people under the age of 65 in Australia have dementia.

Over the last decade or so, there has been an increasing awareness that the critical differences between those with younger onset dementia and those who are older is that their life stage life is substantively different, and therefore the presentation, context and impact of living with dementia is more complex. The 2012 aged care reforms\(^1\) included a range of initiatives that are designed to better address the particular support needs for people with younger onset dementia to continue to live in the community and participate in family and social life for as long as possible.

The aim of this project is to provide an evidence base regarding the needs of people with younger onset dementia and a needs and feasibility assessment of existing services and their capacity to deliver services to people with younger onset dementia. The analysis goes beyond the traditional dementia services paradigm, and examines disability services, community organisations and businesses that employ volunteer services, to explore their capacity to improve the quality of life for people with younger onset dementia.

2 BACKGROUND
In recent years, there has been increased recognition of the different needs, life experiences and expectations, and corresponding support and care requirements of people with younger onset dementia compared to those who are older and develop dementia. The research, advocacy, policy and service provision sectors that have evolved have predominantly operated in either a mental health or aged care paradigm, arising from the overwhelming majority of people with dementia falling into the older age demographic. This paradigm has not catered well for those with younger onset dementia who may experience different expressions of dementia within the context of being at a different life stage, with all its concomitant demands, constraints and expectations.

The Australian Institute of Health and Welfare (AIHW) has estimated that there are approximately 24,000 people under the aged of 65 with dementia living in Australia.\(^2\) As the number of people with dementia is expected to increase, their disease burden (physical, psychological as well as economical) will also impact on their extended network of families, friends and the broader community. The AIHW’s estimates go on to note there are around 200,000 informal carers for people with dementia living in the community, with many of these providing 40 or more hours of care per week.

Increasingly, the distinct issues facing people with younger onset dementia have been clarified and advocates have attempted to influence the research, provider and policy

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\(^{1}\) Formerly known as Living Longer Living Better aged care reforms
\(^{2}\) Australian Institute of Health and Welfare 2012. Dementia in Australia. Cat. no. AGE 70. Canberra: AIHW
agendas. Professional groups also have sought to respond appropriately. The traditional models of assessment, care and service delivery have proved to be inadequate to maximise the abilities of this client group over the generally longer duration of their illness.

Several important developments have occurred in recent years at the broader political and policy level that have highlighted the need for reform, in particular the *Productivity Commission Inquiry into Aged Care (2011)* and submissions to the *House of Representatives Standing Committee on Health and Ageing Inquiry into Dementia: Early diagnosis and Intervention (2012)*. The Australian Government’s 2012 aged care reforms provided a sound foundation for improved responsiveness to the needs of people with younger onset dementia, including funding for the establishment of a National Younger Onset Dementia Key Worker program through Alzheimer’s Australia. The reforms also include objectives of re-ablement and consumer-directed care, factors that are important for this client group.

State and territory governments have also been seeking to better identify the support needs and influence service provision for people with younger onset dementia. One such example is the NSW Government’s Younger Onset Dementia program which is trialling individualised funding options with a person centred approach to improve the quality of life for people with younger onset dementia.

These reforms have been developed in response to a number of pressures arising at both the service delivery and policy levels; in particular, the increasing difficulties experienced by aged care services that are generally tailored for the frail aged population, and the inclusion of younger onset dementia as a client group under the National Disability Insurance Scheme.

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3 LITERATURE REVIEW

The Literature Review formed the first part of this two-stage project which was initiated to inform the development of services and supports for people with younger onset dementia and their families. The second stage of the project, the needs and feasibility assessment of services, was timed to build on the preliminary findings of the review.

This final report includes a brief overview of the literature review methods and results to provide a context for the needs and feasibility discussions contained in this report; more detailed information can be found in the report, Younger Onset Dementia: A Literature Review submitted to the Department in January 2014.

3.1 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 use volunteers.

Likewise, the definition of the term ‘younger onset dementia’ was broadened 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.

3.1.1 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:

- Determining 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;

- Developing search and indexing terms that reflected the research question and were specific to the database being searched;

- Searching of multiple relevant bibliographic databases including EBSCO databases (e.g. Medline, Cinhdl, Academic Research Complete), Scopus, Proquest Central, Informa Healthcare, Cochrane Collaboration, Biomed Central, Summons and Google Scholar;

- Hand searching of specific journals that appeared to contain relevant information pertaining to the project. 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 were 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; and

- 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.

3.1.2 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. It was also helpful in identifying whether specific types of service providers, community groups and organisations were able to build their capacity to deliver services to this client group.

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.

### 3.2 Literature Search results

Our search identified 445 documents of which over 300 were included for review. Academic literature identified included 198 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 34 articles published before 2000. Documents were entered into an Endnote database to manage references.

### 3.3 Key themes emerging from the literature

#### 3.3.1 Types and prevalence of dementia

The focus of this project is to identify the needs of, and potential service models for, people with younger onset dementia. Evidence based policy development and service planning requires a sound understanding of the nature as well as the number of people affected by younger onset dementia. This approach was reflected in the literature search and analyses undertaken, which included consideration of the different types of dementia that are evident in this age group, as well as the science behind the prevalence data.

Numerous research issues and gaps were identified, including those concerning 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.

In summary, the review revealed both a number of similarities and differences in the range of symptoms for the different sub-types of dementia, with behavioural and psychological symptoms (BPSD) of dementia common across most sub-types, adding to their needs and care requirements.

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

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 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.

3.3.2 Current service usage
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.

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. The Consumer Dementia Research Network administered by Alzheimer’s Australia is an example
of a successful mechanism to facilitate consumer input into determining research priorities, processes and funding, which could easily be replicated by those involved in service development and delivery.6

Although it has been estimated that approximately one third of people with dementia live alone there is little data available concerning these people 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.

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 those diagnosed with dementia and their carers and families. There is a need for clear written information to be provided at the point of diagnosis as a matter of routine, including advice regarding a telephone enquiry support service as occurs with CANDID in the UK, and the Alzheimer’s Australia Dementia Helpline in Australia.

3.3.3 Service design
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, integrating diagnostic services, the need 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 whole course of the dementia journey.

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 recommend the introduction of specialist services for people with 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 this disease, 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 specialist 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, it is important the existing dementia and aged care services are

supported by education and training to address the particular needs of potential clients with younger onset dementia, their families and carers.

### 3.3.4 Draft Key Service Attributes

The attributes of service delivery that provided the best evidence were collated into a draft set of Key Service Attributes. These outlined the elements of an individualised model of service, and the staff and organisational attributes that are required for its implementation across a range of service types, both specialist and generic. The features of the service model, staffing and organisational attributes are summarised below, and were tested within the context of the Needs and Feasibility Assessment activities of the project. In the main, there was strong alignment with the attributes identified in the literature; the final Key Service Attributes includes a small number of refinements accordingly.

**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.

### 3.3.5 Programs for people with younger onset dementia

A range of programs were identified 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. These 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 for individually tailored support programs such as case management and key workers is clear, their mode of operation and purported outcomes require further research.

### 3.3.6 Special interest groups

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; lack of 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 a 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.
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.

### 3.3.7 Future research opportunities

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 gaps have been identified in terms of prevalence and outcomes data. As awareness has increased regarding the different manifestations and implications of younger onset dementia, there has been a correlating refinement in the research questions posed, and methodologies employed. The evidence is evolving, with a number of rigorous studies recently completed and currently underway which are likely to improve the way we understand dementia and its impacts, and opportunities, for those diagnosed and their families.

As our understanding of the implications of younger onset dementia has improved over time, so too has our framework for understanding the dementia journey. The literature review was framed from a care and service delivery perspective, derived from the policy paradigm that was in place at the time of commissioning this project. What is missing is an understanding of the factors that will facilitate self-determination and social participation for people with younger onset dementia for as long as possible. We have called this the ‘Adjustment, Enablement and Engagement’ stage which falls after the point of diagnosis, and before the need for formal care services. This was further explored within the consultation phase of this project, and opportunities for further service delivery, policy development and research were clarified through that process.
4 NEEDS ASSESSMENT

The Needs Assessment comprised two key activities: a national consultation process, and an online survey for those who were not able to directly participate in the consultations.

4.1 CONSULTATIONS - METHODOLOGY

The consultations were a critical component of the needs assessment, through which we sought to test the validity of the themes emerging from the literature and clarify the opportunities to maximise the utility of existing infrastructure to better meet the needs of people with younger onset dementia.

The consultation methodology was premised on the need to obtain first-hand the perspectives of those who had a direct experience of living with younger onset dementia i.e., people with younger onset dementia and their carers and /or families. This was facilitated by the very generous support offered by Alzheimer's Australia. They provided the research team with access to their resources enabling us to advertise the consultations. They also provided us with access to the key workers who provided assistance in arranging and conducting the focus groups.

We used a systems approach to understand the context within which people with younger onset dementia lived, and to identify potential opportunities for improvement to enable them to maximise their sense of identity, as well as independence, for as long as possible. Through this process, we identified different stakeholder groups that could inform the project regarding current services available and gaps and opportunities for improvements. These groups are depicted graphically in the ‘circles of impact’ of younger onset dementia in Figure 1.

**Figure 1  Circles of impact of younger onset dementia**

The consultations were designed to capture the perspectives of different stakeholders that formed these ‘circles’, as well as representatives of groups of people who have similar attributes and needs as people with younger onset dementia. These groups included people with disabilities, mental illness and degenerative conditions such as Parkinson’s and Huntington’s diseases. The consultations focussed on the following six stakeholder groups:
1. People with younger onset dementia and carers;
2. Special interest groups;
3. Peak bodies;
4. Service Providers;
5. Researchers; and
6. Policy and Program officers

Approval for the consultation phase of the project was received from the University of Wollongong Human Research Ethics Committee in October 2013.

4.1.1 Consultation themes, questions and management
The key themes for the consultations were clarified from the early findings of our international literature review, as well as feedback from initial key stakeholder meetings with groups such as the Dementia Consumer Advisory Committee. The themes were then considered against the backdrop of the draft Consultation Paper for the National Framework for Action on Dementia 2013-2017, which encapsulated policy directions at the time. Our purpose in setting the consultations within the context of national policy directions was to help frame questions and develop a reporting format that had the potential to facilitate the translation of findings into the policy context.

Consultation Themes
The Draft Consultation Paper identified four key stages of the dementia trajectory against which policy, service provision and research responses are proposed. These four stages are summarised in Figure 2.

Figure 2 Draft National Framework for Action on Dementia

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The stages focussed predominantly on the health and care needs associated with the progression of dementia, and in many respects represented what some call the ‘biomedicalisation’ of dementia.8 Following our review of the literature and early consultations with key stakeholders, it soon became apparent that there was a significant gap in the policy arena, as well as the service and research areas. That is, there is little consideration of the ‘lived experience’ of dementia, particularly for those with younger onset dementia, which can be conceptualised as occurring after the formal diagnosis period and prior to the need for formal support services.

We have called this the ‘Adjustment, Enablement and Engagement’ stage which focuses on that period of life where people have the capacity to continue to participate in routine activities associated with daily living, albeit with progressively declining levels of ability. The duration of this period of time can be many years; and as assessment, diagnostic and treatment options continue to improve, it is likely that the length of time in which people stay in this period will be even longer in the future. The key focus of this stage is to assist individuals and their families to adjust to the diagnosis of dementia, empower and enable them to continue to participate and engage in routine activities such as family life, employment, volunteering and social activities. The way that this ‘Adjustment, Enablement and Engagement’ stage fits in with the Draft National Framework for Action on Dementia is shown in Figure 3.

Figure 3 Five Stages of younger onset dementia support

The five stages provide a clear framework against which to develop the questions. Our initial approach was to build on, as much as possible, the work undertaken by the Social Policy Research Network (SPRC), Alzheimer’s Australia NSW and UnitingCare Ageing NSW. The focus of that study was on support needs, rather than service models, however it was felt that, where possible, we should seek to align the questions in order to compare and contrast findings in the future, should this be desired. Furthermore, their study questions had been subject to a robust consultation and review process, which was not feasible for us to undertake within the time constraints of this current project.

The set of questions were detailed in the Consultation Strategy document provided to the Department in November 2013. Following our first consultation with a group of eight men with younger onset dementia, it was clear that the questions developed were too unwieldy

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8 Beattie et al Op Cit, p360
for the consultations. Developed as a guide for discussion, they were in practice too detailed to be useful within the time constraints and environment of the consumer consultations.

Further refinements were subsequently made to the questions, which were felt to be more feasible for use within the constraints of the consultations. The final five questions focussed on two key themes: what could have made life easier at the beginning; and, what assistance or support can best help in day to day life. The final list of questions is included in the Participant Information Sheet at Appendix 1.

Consultation management

Consultations were undertaken by teams of two project members, at least one of whom has had direct experience communicating and engaging with people with dementia. Teams were allocated different States and Territories and special interest groups, based on their expertise. Each team was responsible for consultations with representatives of the five key stakeholder groups: people with dementia, their carers and families; peak bodies; service providers; researchers; and, policy informants. In addition, teams would also seek out representatives of their designated special interest groups.

The consultations were undertaken using a designated lead that was responsible for the facilitating the discussion, supported by the remaining team member who was responsible for recording (digitally and/or manually) and writing up the discussions.

4.1.2 People with younger onset dementia and carers

After consultation with Alzheimer’s Australia (AA), its Dementia Advisory Committee and other leading stakeholders it was determined that the best way to collect research data from people with younger onset dementia was through a mix of focus groups and surveys using social media.

Focus Groups

Recruitment of people with younger onset dementia was facilitated through working with agencies that had existing relationships with people with younger onset dementia, such as service providers like Alzheimer’s Australia (AA) Younger Onset Dementia Key Worker Program (national), LifeCare (SA) and BlueCare (Qld). Flyers were developed in conjunction with Departmental representatives and distributed via these networks, and ‘Advance notice’ of the consultations was included in the at least two editions of AA HOPE newsletter, a national electronic newsletter distributed to people with younger onset dementia, their carers and families, and service providers (See Appendix 2)

Focus groups were anticipated to be scheduled to coincide with regular scheduled activities, to avoid unnecessary disruption to people’s lives. Importantly, only consumers who self-nominated participated in the groups; consequently it was expected that only those who were in the early to moderate stages of their dementia journey would participate.

Preparation for the focus group included distribution of Participant Information Sheets which included the consent form and list of proposed questions (see Appendix 1). As a guide,
it was anticipated that the duration of the discussions would not exceed one hour, to mitigate against participant fatigue. The usual provisions applied with regards to participants being advised at the outset that they were free to withdraw their consent at any time without any impact on their relationship with their service providers. People with younger onset dementia were invited to include a family member and/or carer as part of the focus group, and a service provider representative who was familiar with the participants was present to support individuals or address any issues that might arise.

In conducting the focus groups we drew on our previous experience working with people with dementia, as well as relevant resources obtained through our literature search to optimise opportunities for consumer participation in these focus groups, including:

- Providing clearly written information about the consultation to allow for preparation and reference;
- Locating the focus group in a quiet venue with good acoustics and minimal distractions;
- Pacing the focus group to provide sufficient time for participants to gather their thoughts and express them; and
- Being flexible to allow for participants to speak up with their views, including ‘out of turn’, to ensure their perspectives are captured whilst front of mind.

Each focus group was attended by two members of the project team, at least one of whom had direct experience working with people with dementia, and both of whom are familiar with the ‘Tip Sheets’ developed by Alzheimer’s Australia (Appendix 3).

4.1.3 Special interest groups
In recognition of the broad range of people expected to be impacted by younger onset dementia, the consultation process included specific measures to incorporate the perspectives of special interest groups, including:

- People from Aboriginal and/or 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
- Veterans
- People who are homeless or at risk of becoming homeless
- People who are care leavers (a person who was raised in a care home)
- People who are Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI).

In addition, we developed strategies to consult with people who would not necessarily identify as having dementia, but may have the same attributes or be at similar life stages including people with disabilities, mental illness and degenerative diseases such as Parkinson’s and neurocognitive impairment associated with HIV/AIDS.
4.1.4 Additional stakeholder groups
In addition to the consumer and special needs consultations, four other key stakeholder groups were approached in each State and Territory: Peak bodies; service providers; researchers; and policy informants.

Peak bodies
Meetings with peak bodies were expected to be an important source of information for the project, being best placed to talk about potential system and service delivery issues and provide advice on consultation opportunities.

Alzheimer’s Australia has been central in facilitating the consultation component of this project, through the following processes:

- Key Workers (KWs) in each participating State and Territory: these were available to facilitate consultations, identify key local stakeholders and service providers who could inform the project, and liaise with consumers regarding the focus groups.

- Consumer advisory committees: the project team attended the National Consumer Advisory Committee (28 September 2013); the National Aboriginal and Torres Strait Islander Dementia Advisory Group (30 October 2013); and the National Cross Cultural Advisory Group (28 November 2013).

Aged and Community Care Services Australia (ACSA), the peak body for faith based and not for profit aged care providers was contacted to identify ‘best practice’ sites.

People with Disabilities Australia (PWDA), the peak body for disability services, in 2010 released its report: ‘Rights Denied’ about abuse and neglect of people with cognitive impairment, was contacted to ascertain the lessons, if any, arising from that project which could be applicable for people with younger onset dementia.

Huntington’s NSW, the peak body for people with Huntington’s disease in NSW was contacted to identify models of support that had the potential to be of benefit for people with younger onset dementia.

Service provider groups
Consultations also involved key service providers which have demonstrated innovative models of services to support people with younger onset dementia, or those with similar needs and circumstances who may not readily regard themselves as being under the dementia umbrella. Examples of service providers include but were not limited to UnitingCare Ageing NSW.ACT, BlueCare and the ACH Group.

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9 Travel destinations were chosen to maximise efficiency of the consultations to obtain as many perspectives as possible on the issues affecting people with YOD rather than jurisdictional representation.
Researchers

Consultations with researchers were undertaken to identify areas of practice that may currently be under development, evaluated and/or the subject of a research study. In the first instance we approached leads of the various Dementia Collaborative Research Centres (DCRCs) and the Dementia Training and Studies Centres (DTSCs) to identify examples of good practice within Australia. We also spoke with researchers in related centres that were also involved in dementia and cognitive impairment studies, such as the Koori Growing Old Well project conducted at the University of New South Wales.

International researchers were also identified during the literature review. To supplement our international findings, an email was distributed with Dementia Sub-group of Contact, Help, Advice and Information Network (CHAIN), an online mutual support network for people working in health and social care that is supported by the National Health Service in the United Kingdom.

Policy and program officers

Meetings were convened with representatives of national, State and Territory Government agencies to discuss jurisdictional responses to younger onset dementia, potential service models as well as exploring the implications for people with younger onset dementia relating to the introduction of the National Disability Insurance Scheme.

4.2 CONSULTATIONS – RESULTS

The national consultations were carried out between October 2013 and December 2013. The consultation schedule was developed to ensure an appropriate mix of perspectives from the six stakeholder groups identified in Section of this report, with priority given to opportunities to meet with people with younger onset dementia, carers and families. Once these were identified, the team sought to meet with other stakeholder groups that could inform on current service models, gaps and opportunities for improved service models. This included, where possible, representatives of services whose clients have similar attributes and needs as people with younger onset dementia, such as people with disabilities, mental illness and degenerative conditions such as Parkinson’s and Huntington’s diseases. Table 1 summarises the numbers of individuals with whom the team consulted. In total 215 people were consulted: 205 were consulted face to face, 7 over the telephone and 3 through email.

Table 1 Summary of consultations

<table>
<thead>
<tr>
<th>Stakeholders</th>
<th>Number</th>
</tr>
</thead>
<tbody>
<tr>
<td>People with younger onset dementia; family members; carers</td>
<td>33</td>
</tr>
<tr>
<td>Special Interest group</td>
<td>54</td>
</tr>
<tr>
<td>Service Providers</td>
<td>77</td>
</tr>
<tr>
<td>Peak body</td>
<td>19</td>
</tr>
<tr>
<td>Research Group</td>
<td>11</td>
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<tr>
<td>State Government</td>
<td>21</td>
</tr>
<tr>
<td>Total</td>
<td>215</td>
</tr>
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</table>
In total, 33 consumers/family members/carers participated in focus groups in four different states and territories (South Australia, Queensland, Victoria and the ACT). These groups included a mix of people who were living as part of a family unit, carers of people who had moved into residential aged care, as well as people who lived alone. Focus groups in other states and territories could not be organised due to difficulties in getting a commitment from consumers/family members/carers within the consultation timeframe.

Our consultation process included specific measures to incorporate the perspectives of special interest groups. A number of different groups were represented in the focus groups, including CALD, ATSI, LGBTI, rural and remote, socially disadvantaged, and veterans. As it was not always possible to meet with people with younger onset dementia, families and carers from special interest groups, discussion of their needs and service models were included in our meetings with service providers, research groups, peak bodies and policy and program officers.

The unique issues relating to people from Aboriginal and/or Torres Strait Islander communities were discussed in every state and territory that the research team visited. It was only possible to include one carer of a person with younger onset dementia in direct discussion; other meetings were scheduled however were unable to proceed at the appointed time. Members of our research team also met with the National Aboriginal and Torres Strait Islander Dementia Advisory Group in Canberra, representatives of those involved in the Koori Growing Older Well project run by Neurosciences Research Australia at the University of New South Wales. Issues relating to Aboriginal and/or Torres Strait Islander communities were also explored with policy and program officers in SA, Qld and WA.

People from culturally and linguistically diverse communities were represented in the focus groups. Members of our research team also attended a meeting of the National Cross Cultural Dementia Network, we also met separately with its Secretariat. Similarly, the issues relating to people with younger onset dementia living in rural and remote areas were addressed in our site visits to Cairns, Alice Springs, Darwin; and discussed with representatives in meetings in Perth, Adelaide, and Sydney.

The perspectives of people who are financially or socially disadvantaged and those who are homeless or at risk of being homeless were included in our focus groups, and specifically through our visit to Wintringham Aged Care in Victoria and meeting with the Homeless Project Officer from the Access and Equity Unit of Alzheimer’s Australia in South Australia. Despite numerous attempts to meet with representatives of care leavers, it was not possible to identify an opportunity for specific consultation with this group within the consultation timeframe.

4.2.1 Circles of Impact of Younger Onset Dementia

As noted previously, the project has been premised on the primacy of the person with younger onset dementia. Using a systems approach we considered the context in which people with younger onset dementia lived and identified the different stakeholder groups
that could inform the project regarding opportunities to maximise their sense of identity, as well as independence, for as long as possible. This is depicted graphically in our Circles of Impact which we used to frame the consultation process, provided in Figure 1. The following section identifies the key outcomes of the consultations which were most relevant for each ‘circle’. Where relevant, we have included some examples illustrative of the point being made in the text, which were identified during the consultations. In the main, these are presented as ‘vignettes’, and use pseudonyms to prevent individuals being identifiable. These are colour coded to align with the Circles of Impact, to enable ready reference for those seeking to identify the target group most likely to benefit from adopting the practice being cited (Table 2).

Table 2 Circle of Impact colour code

<table>
<thead>
<tr>
<th>Colour</th>
<th>Implications for</th>
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</thead>
<tbody>
<tr>
<td>Green</td>
<td>People with younger onset dementia</td>
</tr>
<tr>
<td>Yellow</td>
<td>Family and carers</td>
</tr>
<tr>
<td>Blue</td>
<td>Social participation and networks</td>
</tr>
<tr>
<td>Orange</td>
<td>Formal services e.g., health services, home care and residential care</td>
</tr>
<tr>
<td>Pink</td>
<td>Legislation and policy</td>
</tr>
</tbody>
</table>

4.2.2 Impact on the person with younger onset dementia

When a person is diagnosed with younger onset dementia, their lives are turned upside down. It is the beginning of a number of major losses and adjustments in terms of: their sense of personal identity; roles in their immediate family, workplace and community; and hopes and plans for the future. They face major changes in how they experience and understand the world and how the world understands them.

A number of themes emerged during the consultations regarding the experience of people with younger onset dementia, and how the broader ‘circles of impact’ can assist them maintain their sense of identity, and maximise their ability to remain as independent for as long as possible and contribute to family life and their communities, throughout their life with dementia.

Access to accurate and timely diagnosis

The importance of a timely and accurate diagnosis was an almost universal issue raised in the consultations. The individuals and the people around them often spend a significant period of time in the lead-up to a formal diagnosis seeking to understand the often subtle and the not-so-subtle changes that are occurring. For individuals, their sense of the world is changing, peoples’ responses to them are changing, and when things go wrong they often feel they are ‘at fault’ somehow, but can’t understand why. For families and carers, observing and experiencing these unexplained changes this can result in frustration and uncertainty and impacts on their personal and family relationships. Until a diagnosis is provided, people are often in a grey area about what is happening to them and why, leading some to speculate what the underlying causes could be. One carer reported that she:
hoped that her husband had a brain tumour because we could then do something about it.

The difficulties associated with obtaining an accurate diagnosis were raised at every consultation. The process of diagnosis is often lengthy and frustrating, as doctors seek to rule out other possibilities for the changes people are experiencing. It can include frequent visits to a range of medical specialists from different disciplines: General Practice, Psychology, Psychiatry, Geriatrics, Neuropsychiatry, and Psychogeriatrics; and undergoing a barrage of tests such as: Magnetic Resonance Imaging (MRI), Computed Tomography (CAT Scan) and electroencephalogram (EEG) recordings of brain activities. The time taken to obtain a formal diagnosis amongst those consulted ranged from between one and eight years.

These difficulties are not only due to the complexity of the symptoms and the need to rule out other treatable conditions, but are also attitudinal. One person with younger onset dementia and his carer described the frustrating run-around that they received from health staff – one hospital doctor said that he didn’t believe in younger onset dementia and would not diagnose it! They tried to get a second opinion, but were prevented because hospital rules stated that whilst you were an inpatient in hospital, you could not change doctor. They had to wait until the person with younger onset dementia was discharged before they could seek further help. A highly experienced Geriatrician commented that when she queried a colleague why it had taken so long to receive a referral regarding a person with younger onset dementia, the specialist responded that they ‘could not contemplate’ this diagnosis as an option for someone who was the same age as themselves.

There appears to be variable understanding of the manifestation of younger onset dementia across the breadth of the health profession. One person with younger onset dementia described the refusal by some specialists to consider dementia:

Our GPs are just gobsmacked at a couple of psychiatrists that we have been referred to and their refusal to consider dementia.

A number of participants spoke of their experience of being misdiagnosed. One person had been diagnosed with ‘Executive Stress Burn-out’ seven years ago, which had only recently been diagnosed as fronto-temporal dementia. Others also spoke of being diagnosed with fronto-temporal dementia up to six years previously, but this diagnosis was now being reconsidered as their condition had not deteriorated at the rate expected. The impact of such misdiagnoses and the length of time taken to obtain a more accurate diagnosis raise the real possibility that these people have missed out on potential beneficial treatment and support during that time, and may even have been provided with inappropriate medication over that time.

The consultations also confirmed the difficulties faced by people in regional and rural areas in obtaining an accurate diagnosis, due to limited access to specialists and the scanning technology required. Examples were provided of people living in central Australia who
needed to travel to Melbourne to obtain a formal diagnosis: in one case their diagnosis of Alzheimer’s Disease was confirmed following a period of time at the inpatient Neuropsychiatry Unit at Royal Melbourne Hospital, while another received their diagnosis of fronto-temporal dementia at Eastern Cognitive Disorders Clinic at the Box Hill Hospital. This need to travel to receive diagnostic services is also likely to severely restrict access to these services by Aboriginal and Torres Strait Islander people. Similar issues were raised during our consultations in Western Australia and Queensland.

Likewise, people from cultural and linguistically diverse backgrounds face extra difficulties in obtaining accurate diagnoses. Understanding of younger onset dementia is ‘variable’ amongst different CALD communities, and communication of symptoms to health professionals can be difficult. Even where bi-lingual GPs are available, ‘dementia is not on the radar’. Consultations with cross cultural representatives also revealed problems diagnosing dementia for those members of newly arrived and refugee communities, including difficulties around obtaining an accurate diagnosis of related psychiatric conditions such as stress, depression and post-traumatic stress disorder. They indicated that these issues are also likely to impact on achieving accurate diagnoses of younger onset dementia in such communities.

Response to diagnosis
When a person with younger onset dementia finally receives a formal diagnosis, the responses of themselves and the people around them differ. The diagnosis is often welcome as it helps to explain what has been going on in a person’s life. As one person with younger onset dementia said:

*it is like receiving a death sentence but it is also a relief as it explains what has been going on.*

A number of men who participated in the consultations noted that they were pleased to finally understand that there was a good reason for their decreasing ability to function effectively at work, and that it wasn’t their ‘fault’. As one person with younger onset dementia came to terms with her diagnosis, she noted:

*the best surprise is that Alzheimer’s brings ‘mindfulness’ – being here in the present*

This ‘living in the moment’ was clearly evident during the consultations with people with younger onset dementia, and was manifest by the general openness between and acceptance of each-other despite the often significant differences in terms of their previous occupations, socio-economic status and cultural backgrounds.

By and large, the perceptions amongst carers and family members that participated in focus groups were not as positive. While their support and dedication to their loved one was clearly evident, the tone of discussions appeared to focus on the losses and changes associated with younger onset dementia, in terms of the need for appropriate information, care and support, as well as the changes in personal relationships, roles and responsibilities.
‘Prescribed disengagement’\textsuperscript{10}

Prior to their diagnosis, many people with younger onset dementia were active participants in family life, social activities and paid employment. Upon receiving a diagnosis of dementia, many people experienced what one person described as:

\textit{prescribed disengagement, where you’re expected to give up everything}

A recurring theme was the instructions to ‘quit your job immediately, and put your affairs in order’. In effect, this was a complete negation of the person as an individual, with abilities and capacity to contribute and participate in family, work and community life. For some, this catapulted them into a spiral of despair and depression, compounded by the actions and responses from those around them who were similarly advised. For others, this provided the incentive and determination to ‘fight’ to be recognised for who they were and continue to be.

Many people with younger onset dementia whom we spoke with during the consultations expressed a real desire to continue to work, use their skills and abilities, and contribute to society to the best of their ability. For example, a highly experienced former principal of an elite school, who had been a longstanding employee, felt she could have continued to work at the school, albeit in a less complex role such as in administration and under supervision; her forced retirement upon diagnosis of dementia meant her extensive corporate knowledge and experience were ‘wasted’. In contrast to her experience, a number of people we spoke with were able to continue to be meaningfully employed, which in turn assisted in them maintaining a sense of autonomy and purpose in their lives:

- Michael\textsuperscript{11}, an experienced accountant and business owner. When he could no longer deal with full-time work, he sold the business but continued to work in a less demanding and complex field as an auditor for a number of years. When this became too difficult, he took on the task of bush regeneration near his place of residence;
- Catherine, a senior physiotherapist who resigned once she received her diagnosis. With her desire to continue to ‘do something meaningful’ and ‘use my skills’, she taught ‘movement’ classes with a local community education group for approximately 18 months post diagnosis;
- Patricia was halfway through her university studies when she was diagnosed with dementia. She not only finished that degree, but has recently commenced an on-line master’s degree in Dementia which she calls her ‘own experiment in neuroplasticity’. She is an active advocate for younger onset dementia including writing, public speaking and regular interstate travel;
- Dave, a former butcher who had to sell his business upon diagnosis. He continues to work on a casual basis at his former business, making sausages or other products that don’t require the use of sharp implements or machinery.

\textsuperscript{10} Term attributed to Kate Swaffer, Chairperson: Alzheimer’s Australia Dementia Advisory Committee
\textsuperscript{11} Pseudonyms used
CONTINUING EMPLOYMENT EXAMPLE

Landscape gardening

Anne is married to James who has younger onset dementia and she uses respite care to allow her to continue to run her landscape business part-time. When a pre-booked respite session was cancelled at the last minute, James came along with her to work for the day. Anne initially gave him small, simple tasks, thinking that was all he was capable of; these were all readily completed, albeit at a slow pace. Anne was pleasantly surprised by James’ contribution and, over time, they soon developed a method of working collaboratively whereby he undertook basic tasks and she completed the more complex ones. While it ‘probably didn’t go as quickly as usual’, it was still a positive experience for both of them. Anne commented that:

*the more loving, patient, supportive and positive I am, the more he progresses his skills*

Many other examples were provided of individuals continuing to use their skills, albeit in different ways, circumstances and to different degrees, some of which are detailed in the Feasibility Assessment (Section 5). While some were capable of initiating and driving their activities, others were facilitated through formal services. These include working as volunteers with gardening services, either in a gardening role or providing company for ageing clients while the gardeners attended to their work; participating in Men’s Shed activities which focussed on repairing broken furniture; and working alongside (trained) staff in a large, regional hardware store.

The overwhelming response by these individuals was the importance of their ability to contribute and participate in society in a meaningful manner, for as long as possible; they were not content to be relegated to a passive role for the rest of their life.

**Stigma associated with dementia**

The ability of people to continue to participate in a meaningful manner in society was significantly constrained by the stigma associated with dementia. As noted above, a number of people reacted strongly to the perceived stereotypes that accompany the label of dementia. As one participant said, they felt that they were ‘thrown on the scrap heap’ even though they could still do a lot of things.

The stigma associated with dementia led one man, working in a senior management position, to develop strategies to hide the fact that changes were occurring. As his disease progressed over a period of 12 years, he gradually lost his ability to continue to function at that level. No-one at his work had any idea that that there was anything wrong with him but ‘underneath, I was falling apart’. After he chose to give up work, the major issue for him was who amongst his friends and family could he tell or trust with that information so that he would not be stigmatised:
I was concerned over whom do I tell, who do I trust, due to lack of knowledge about dementia. People in the community are scared about this because they think it only happens to old people.

Many people raised this issue of stigmatisation during the consultations. This affected not only their close personal relationships but also interactions with the broader community. The overwhelming message from people with younger onset dementia was that they were still the same person, and wanted to be treated as such. However, a recurring theme was the way friends started to reduce contact over time, ‘as if they feared the dementia was contagious’.

Many people with younger onset dementia experience apathy as one of its symptoms, making it hard for them to feel motivated to continue to engage with those around them; a number commented how the stigma and reactions from other people made this even more difficult. There was considerable support for the idea of programs in the community and schools to educate and inform people about younger onset dementia.

**Access to information**

Once diagnosed, people with younger onset dementia reported facing a bewildering service system. While some experienced positive referrals to information and services such as that provided by Alzheimer’s Australia, these were in the minority. A recurring theme throughout the consultations was the difficulty in accessing reliable and appropriately targeted information. One person described the process as an ‘emotional journey’, and others ‘didn’t know where to go’.

The context in which the diagnosis was made, and the way ongoing management is delivered were key factors in whether people felt they were informed about the disease process and care options. Some people received their diagnosis by health professionals such as psychologists who work in private practice, and are not linked into the existing service and referral networks. Similarly, a number noted that their GPs often did not know anything about younger onset dementia or relevant support services. One person contrasted their situation to someone who had had received a cancer diagnosis:

> If this was a diagnosis of cancer, you would get immediate referral to support groups and other places.

Increasingly, people with younger onset dementia are accessing information over the internet, including social media. While there are a number of Facebook sites where people with younger onset dementia can share information, it is unclear whether the information posted is monitored to ensure it is evidence based or up to date. A similar initiative was established by AA NSW, including a website and blog for people with younger onset dementia. However, staff reported that it had been less patronised than expected.
The absence of information and services for people with younger onset dementia was sometimes turned into an opportunity. One person from a regional town, upon finding no specific services available locally, took it upon himself to inform the community about his condition and associated needs. He establishes challenges for himself every day, one of which involves communicating with someone in his community about dementia. As a result, he continues to utilise local services and participate in community activities as the regular bus drivers, shop assistants etc., all understand his condition and how they can support him.

**Access to appropriate services**

In parallel with the limited information available, participants experienced significant difficulties accessing age-appropriate services. The vast majority of dementia services that have been established to date have been designed for older people, whose needs, circumstances and attributes are significantly different to that of younger people. Also, people with younger onset dementia did not want to be identified as being ‘old’ simply because of their condition.

Not only are the services often inappropriate, but the complexity of factors that are associated with this period of life often compounds the need for and the variety of services required. There was much anticipation of the potential for improved coordination of services with the establishment of the Younger Onset Dementia Key Worker positions within Alzheimer’s Australia. Given the relatively brief time that such positions had been operating at the time of the consultations however, there were very few people who could comment on their direct experience of these positions. One person said that after the diagnosis the person with younger onset dementia:

> should have a pathway straight away – the GP should say ‘here’s a booklet, here’s where you need to go and people to talk to’. Meanwhile you’re losing your whole way of life. Everything is an issue, dealing with Centrelink, standing in queues, not knowing what is going one – Like Oliver asking for a bit more and we shouldn’t have to.

In some jurisdictions, people identified models such as that developed in Western Australia for people with Huntington’s disease, where strong and clear pathways from diagnosis to service providers have been developed. The only coherent pathway for people with younger onset dementia that was identified in the consultations was the Neuropsychiatry Unit at the Royal Melbourne Hospital, which provides assessment and diagnosis, counselling (personal and family) as well as, if needed, the capacity to fast track access to appropriate services. Once discharged, people remain clients of the Unit, receiving ongoing assessment and care management for the term of their life regardless of their location or residence.

The need for some facilitation in negotiating the service system is particularly important given the array of agencies that may be involved in providing support, each with its own target groups, rules and regulations. Carers in particular expressed their concern that they could not be sure that they were providing the best support to the person with dementia because of the service system’s complex nature and not understanding how it works. As one person with younger onset dementia said:

You don't know what you don’t know.

One strategy to improve access to services and information by people with younger onset dementia was the use of case managers or care co-ordinators such as the recently established Key Workers. In many cases, people wanted a case manager to come and look at their situation in a holistic way, taking into account the needs of the person with younger onset dementia and their family. The family may appear to be functioning adequately to people outside but as one carer said:

Our household had become dysfunctional; we needed a lot more support because no-one knew. Our GP didn’t help much – all we got was a referral to a marriage counsellor.

Some people with younger onset dementia had been in contact with the Key Workers from Alzheimer Australia and reported that these workers had been extremely helpful in assisting them with information and strategies about coping with younger onset dementia.

Changing relationships

It is clear from the consultations that dementia places immense pressures on couples and families. The patterns of unexplained and sometimes bizarre behaviours before diagnosis sometimes lead to relationship breakdowns with partners and children. Even when families stay together, the changes in family relationships can be devastating. One carer said that there is a ‘huge need for relationship support’:

Nobody knows that we are not functioning but our lives are collapsing around (us).

A number of participants reported that their children were particularly affected by the changes associated with dementia. Several noted their adolescent or young adult children were being treated with depression; while it was unclear whether this had developed because of their parent’s dementia, all acknowledged it made treatment much more complex. Some attributed the depression to being unable to effectively grieve for the loss of a parent while the parent was still alive and present in the family home. This, in turn, made some feel a sense of guilt over the impact of their dementia on the mental health of their children. The father of one teenager, himself experiencing depression, was foregoing his own treatment due to financial costs, saying he needed to prioritise the treatment of his daughter’s depression over his own. Another described his alienation from his adult children due to his spouse’s negative perspectives of him since diagnosis; she would warn them that ‘you are going to die if you get in the car with him’ even though he still had a valid driver’s licence.

A number of people experiencing relationship difficulties had benefited from counselling services that were provided through the Alzheimer’s Australia network, Relationships Australia and other agencies and private practitioners.
Driving and transport

One of the consequences of a diagnosis of dementia is the implications for maintaining a person’s driving licence. In some jurisdictions in Australia, a diagnosis of dementia means automatic loss of a person’s driving licence. The loss of independence associated with this further isolates the person with dementia from access to economic, social and service activities. This is often compounded in rural and remote areas, where there is little or very limited alternative public transport.

A number of people with dementia spoke of ‘enforced isolation’ associated with this automatic loss of licence, particularly for those who live alone and have no carer. A number of people with dementia indicated that they felt they should be able to have access to at least a limited-range licence that could enable them to continue to drive to amenities in their local area. An example was provided of the social benefits of people still being able to drive; several women from a peer support group, some of whom lived alone, had formed a ‘cinema club’ which involved regular outings to the local cinema, with members transported by one of their own who still had her licence. This activity was not part of any formal service but organised amongst the group, allowing the women to continue to have a sense of independence and autonomy as well as much needed social company and stimulation.

While community transport may be available in some regions, it was reported that in some places it was only available to people aged 65 years and over, either as a result of eligibility criteria or perceived additional risks associated with having someone so physically able with a cognitive impairment. The limited availability of community transport, in some cases only available Monday to Friday, was also found to restrict people’s ability to participate in family activities that might be scheduled during a weekend.

The loss of licence can also impact on leisure activities. One man spoke of his boating licence having to be revoked following his diagnosis of dementia. This man lived on his own, and derived much pleasure from fishing, particularly spending time on his 18ft boat. Although no longer able to pilot the boat, he was in the fortunate position of having close neighbours who also enjoyed fishing and would take him out on his boat regularly.

As a result of losing their driving license, most people with younger onset dementia have to rely on some sort of community transport. Our discussions revealed that access to such service can be challenging, particularly in regional and rural Australia. For example, one man living in a regional town reported that while he has access to a transport subsidy scheme, it is of little use to him as the local taxi service is unreliable. It was also revealed that other forms of community transport can be unreliable as you have to fit your activity in with the pre-determined schedules of the transport provider. Other people with younger onset dementia preferred not to use community transport as it is traditionally associated with older people.

The difficulties associated with driving and transport was cited as a key reason for the sense of isolation experienced by many people with younger onset dementia, particularly if their partner is at work and children are at school. As noted previously, a number of people identified the apathy that was associated with their dementia, and said their enforced isolation was a defining factor in this developing into depression.
Financial impacts

All people with younger onset dementia involved in the consultations had experienced job losses as a direct result of their dementia; for some, this occurred prior to a formal diagnosis and arose from the changes in behaviour and/or productivity that was occurring, while others ceased employment upon receipt of a formal diagnosis of dementia. The resulting loss of income often occurs at a time in their lives when many are planning to pay off their mortgages and debts, and accumulate funds for their retirement. These plans are now no longer feasible, as additional financial pressure is placed onto them and their families. While a small number of workplaces sought to continue to accommodate the person with younger onset dementia these were isolated and definitely not the norm.

This resulted in a number of impacts for spouses and/or family members, with some needing to take on additional employment to make up for the lost income, while others having to cut back on their work to provide care for the person with younger onset dementia, further compounding the financial difficulties. A number reported the need to sell the family home and move to more modest accommodation.

Many people with younger onset dementia and their carers reported difficulties in drawing on their insurance policies or superannuation funds. In one case, the person with dementia had been a self-employed health professional with income protection insurance; the insurance company was contesting his claim due to his oversight of a small number of questions when completing his initial application. Similarly, an army veteran reported considerable difficulties in accessing his pension early. In another situation, a former teacher quit her job and accessed her superannuation upon diagnosis, as directed to by her health professional; when she did not deteriorate at the rate she initially anticipated, and sought casual employment in a related workplace (albeit at reduced capacity) she found that agreement she signed in order to access the superannuation early precluded her from any further employment. One positive experience was recounted during the consultations, whereby the friend of a person with younger onset dementia who was a financial adviser found that within the small print of the insurance policy was a definition of ‘trauma’ that included dementia, and therefore he was eligible to receive a payout under the policy.

The income changes that occur following a diagnosis of dementia mean that for most people they are required to establish and maintain regular dealings with Centrelink. A recurring theme in the consultations was the difficulties people experienced with Centrelink, some describing it as a ‘nightmare’ with the numerous and often confusing signage, the requirement to queue and keep tabs on the different monitors to ensure ‘you don’t miss it when your number comes up’. Others commented that the Centrelink staff were generally unwilling or unable to be flexible in helping them:

unless you know what questions you need to ask, you won’t get any useful information.

A number commented that it took several months before their applications for assistance was approved, involving ‘continual going backwards and forwards’ while extra information
or reports had to be obtained. This was felt to be an unnecessary burden on people whose lives had ‘already been turned upside down’.

There was one occasion, however, where the feedback on Centrelink was more positive. This was provided by a service provider who had developed an effective working relationship between themselves and the local Centrelink Community Team that was specifically designed to short-circuit the often lengthy queues and approval times.

For people with younger onset dementia who were engaged in social activities, there were costs that had to be dealt with:

*Providing social activities cost money too – snooker and lunch – paid for by person with younger onset dementia.*

Some people struggled to afford these additional costs, resulting in them withdrawing from the activities, which further increased their sense of isolation. While a number of service providers indicated that subsidies were available for these social activities, they were not able to do so in every situation, thereby resulting in people missing out on the full range of social activities that they may require.

**Peer support**

The relationship changes and social alienation that many people with younger onset dementia experience means that opportunities to meet and socialise with people in similar circumstances are extremely important. The operation of peer support groups is a very popular strategy for people with younger onset dementia, allowing people to share their experiences and to learn from each other.

Peer group activities range from gym groups, coffee clubs to general outings. The choice of activity or destination for an outing is predominantly determined by the members’ interests and choosing rather than pre-planned and structured according to the decisions and convenience of the service provider. This not only reinforced the sense of autonomy of participants, but also allowed for flexibility to meet the members’ fluctuating symptoms and capacities.

A number of service providers highlighted the importance of peer support for people living in rural and regional areas, where there are fewer formal services and lesser opportunities for social or family activities. Similarly, people who live alone or have limited family and social support networks around them were considered to particularly benefit from peer group activities.

The peer groups also appear to provide a ‘safe’ environment for people with younger onset dementia, where they can talk and communicate relatively freely (where able) without being constrained by others expectations. It was clear to the research team that members’ background, socio-economic status, employment history, culture and even limited understanding of English were not barriers to their obvious enjoyment of being together.
INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY

Peer support

Andrew enjoys attending his weekly peer-support group which is run by his local Alzheimer’s Australia service. The group includes 8 - 10 people with younger onset dementia. The group is activity based which usually consists of various outings to the local botanic gardens, aviation museum, winery, art gallery and even dolphin cruises. The group has been meeting for a while and in Andrew’s words is ‘tight knit’. He felt he was starting to ‘fall into a hole’ and attending the social group was good for his ‘psyche’ and he loved the fact that everyone in the group was positive. Over time, a real sense of camaraderie developed between the members as they began to have a better understanding of each other. He knew he had something good planned for the week and looked forward to his group outings, ‘Regular and meaningful activities in a supportive group is what is needed’.

Members encouraged each other to contribute, even when this was clearly a difficult and laboured process. The motto of the AA ACT Walking Group sums up nicely the benefits of peer networks for people with younger onset dementia:

Friendship doubles our joy and divides our sorrow

INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY

Photography

Attendance at a Living with Memory Loss program linked up a group of men with a shared interest in photography. This was recognised by two local service providers who collaborated to provide tailored respite to this group of men. At the photography respite sessions the men would plan their ‘shoots’ including the subject as well as location. They all soon learned to use a digital camera and then learnt how to use Photoshop. Within no time the men were producing calendars for their friends and families.

4.2.3 Impact on families and carers

As evidenced above in Section 4.2.2, the experience of younger onset dementia has significant implications for families and carers. Not surprisingly, many of the themes that emerged regarding impacts on families and carers were consistent with, or extensions of, those raised by people living with dementia.
Information relating to diagnosis, management and service options

Echoing the concerns of people with dementia, families and carers also spoke of the frustrations associated with the difficulties and time taken to receive an accurate diagnosis, in particular the experience of trying to navigate the medical system. For example, a young couple living in a regional town said they had consulted with a couple of GPs, numerous psychologists, five psychiatrists and two neurologists before receiving a formal diagnosis after a period of 12 months of investigations. Relating to this experience, the wife commented:

*If we were trying to get a diagnosis for cancer, referral and support is much greater...getting a diagnosis for younger onset dementia is like battling the medical system...you need to be tenacious.*

The importance of health professionals’ having good communication skills was particularly pressing during the diagnostic process and in the period immediately following. Where the person with dementia was still living as part of a family unit, participants highlighted the need for engaging with the whole family to keep them informed and provide them with the opportunities to ask questions about the array of issues they are likely to confront as a result of the condition, not just the medical aspects.

For Aboriginal and Torres Strait Islander people, the communication with family needs to occur prior to the engagement with the person suspected of having dementia. Representatives of these communities indicated that relationships need to be established with the broader family and kinship unit, to allow family members to trust the health care worker and entrust their person into their care. The assessment, diagnosis and ongoing support for the person with dementia involves significant networking and coordination to ensure family members are able to be involved in supporting the person with dementia, and to assist them come to terms with the fact that things may not be ‘right’.

Response to diagnosis

It is clear from the consultations that the immediate period following diagnosis is often a time of inordinate stress and strain for carers (most of whom are spouses or partners) and families. For many, they are entering a period of consolidation in their lives: having positions of responsibility at work, paying off the mortgage, their children becoming teenagers and young adults, having established friendships and networks, and generally planning for the future. These foundations are shaken, as carers and families are faced with a number of immediate challenges, which are likely to continue into the foreseeable future.

As with people living with younger onset dementia, carers and families had mixed responses to its formal diagnosis. Many of those attending the focus groups reported that it was a relief to finally get the diagnosis, as it helped explain previous behavioural and personality changes that had been occurring over the preceding period. A number commented on feeling positive about the diagnosis, as ‘at last’ they could ‘finally get help’. On the other hand, however, many carers found it extremely distressing, as they faced a ‘changed future’ that was ‘filled with uncertainty’ and the ‘overwhelming responsibility’ for caring for their loved one with dementia. In a number of cases it was evident that, even several years down
the track, some were still exhibiting signs of stress and fatigue, as well as anxiety and guilt about their situation.

Impact on relationships

Health professionals spoke of relationship difficulties that had set in due to the changes in personality and behaviour that had emerged in the period leading up to the diagnosis, with some couples in ‘crisis’ by the time this occurred. Service providers also mentioned that ‘marriage break-ups are common’ as a result of this process. On a number of occasions, the stress experienced by carers was so evident that as members of the research team we could not walk away unaffected. In one instance, the spouse was extremely forthright and appeared to be highly resentful and anxious about the financial pressures and lifestyle changes that had occurred after her husband’s illness; another consultation included a woman who had relinquished care of her partner, but was openly tearful as she spoke of the physical and psychological impacts of making that transition. Yet another expressed sadness that her plans for this stage of her life had changed as a result of her husband developing dementia:

All my friends are travelling, enjoying retired life, I am a fulltime carer.

The husband of a woman with fronto-temporal dementia commented:

People say that having dementia is dreadful, but sometimes I think it’s worse for the carer

Consequently many people in our consultations referred to the importance of some sort of relationship counselling. A number of people spoke of the support services provided by Alzheimer’s Australia, in particular its Dementia Helpline, education and information services and peer support activities. These are regarded as important foundational services for carers of people with younger onset dementia, although there was some variability nationally. For more substantial emotional and psychological counselling, Alzheimer’s Australia referred clients to organisations such as Relationships Australia, private psychologists and, on one occasion, Carers Australia counselling service.

The impact on relationships is not only on couples, but also includes the broader family unit. Of particular importance was the impact on the children of people with younger onset dementia. Depending on their ages and pre-diagnosis family dynamics, the effect on children can manifest in different ways. A common concern raised by parents (both people with dementia and their spouses) was the impact on children of ‘losing’ their parent ‘while they are still there’, i.e., dealing with the personality changes, behavioural issues, cognitive and physical decline that occurs over time, the increasing care needs and eventual transition to residential care and death. Children’s experience of a relationship with the parent with dementia is one of contraction over time, whereas their peers are often experiencing a time of growth and development. The biggest impact appeared to be on children still living at

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12 On these occasions the research team immediately informed the relevant host service providers who were able to take them aside and work through some solutions
home; at least two families we spoke with had children who were being treated with depression, and several service providers spoke about aggressive and withdrawn behaviours they had observed amongst young children of parents with younger onset dementia. Examples were also provided of children who had to move schools due to the parent/s having to give up paid employment and therefore no longer able to pay school fees, or limit the amount of extra-curricular activities in which they could be involved.

A number of health professionals suggested that marriage and relationship counselling and family therapy should be provided as a matter of course at the time of diagnosis, as well as offered on ongoing basis to prevent further crises arising further down the track and to improve the chances of maintaining the person with younger onset dementia in their own homes.

The need and emotional support of children are often overlooked by service providers, primarily due to the program funding being directly attached to the person with dementia or their carer. Most information and education about younger onset dementia is targeted at adults and often doesn’t include consideration of the broader family in either its content or delivery. For example, a health professional noted that, whilst memory clinics provide a great service to the person with younger onset dementia and the primary carer, no work is being carried out with children. This health professional further highlighted the need for adolescent education about dementia specific issues, particularly when genetic factors may be the cause of the parent’s dementia; this could be ‘quite terrifying’ to contemplate, and education is desperately needed around genetic testing and reproductive choice.

**Managing Behaviours**

The need for counselling and support is particularly important in those carer and family situations where the person with younger onset dementia begins to display difficult behaviours. These can range from apathy, obsessive and repetitive behaviour, anger and shadowing to sexual disinhibition and physical violence. These were clearly issues of concern for a number of carers attending the consultations. As one service provider noted:

*If these behaviours are not effectively managed in many cases the carers and other family members (including children) can be at risk of serious harm.*

While some appeared to have developed strategies for reducing the frequency of the behaviours, there were others who appeared to be struggling and did not know what to do. A number spoke of the ‘trial and error’ approach to resolving behaviours and of the importance of peer support for this purpose. Several had found the ‘Living with Memory Loss’ program provided by Alzheimer’s Australia to be helpful and a number were accessing counselling services to identify management strategies as well as helping them deal with the stress caused by the behaviours.

However, it was clear that a number of carers were not aware of potential management strategies and felt quite bereft at how to respond to these. It is possible that information was provided at an earlier stage in the dementia process, where the need was not so pressing or carers had other priorities they were dealing with, and was not taken on board. In one case, the husband of a wife with fronto-temporal dementia had not received any
formal assistance in managing behaviours, as he had assumed that the information provided by groups such as Alzheimer’s Australia was only for older people with Alzheimer’s Disease and would not be relevant for the issues he was facing.

**Targeted education**

This highlights the importance of having access to information and support regarding behaviour management, which was raised by a number of health professionals during the consultations. An interesting insight around ‘behaviour management’ was raised by a service provider from a rural and remote community, who said that in many cases the modification of behaviour has to occur *in the carer* and not the person with younger onset dementia; i.e., carers need to realise that the person’s illness is changing their behaviour and it is not their fault; the person with younger onset dementia is not deliberately causing problems or being difficult.

In order to fully assist carers, the education should start off with basic understanding of the dementing process and how the brain may be affected, and how circumstances which may trigger changed behaviour in individuals. Carers then need to learn to identify the underlying causes of the behaviours (e.g., frustration and boredom associated with limited physical activity) to be able to apply the optimum management strategies (e.g., provide opportunities for the person to be physically active). A number of service providers reinforced the relationship between providing meaningful and purposeful activities for a person with dementia, and their general state of well-being, which in turn can minimise the development or escalation of some behaviour. This echoes the views expressed by people with dementia discussed previously. Consequently, there was general consensus amongst health professionals and service providers that the optimum approach for carers was a combination of education and skills development, combined with the availability of counselling and support services.

Health professionals spoke of the specific challenges for families and carers of Aboriginal and Torres Strait Islanders with dementia, in particular the potential dangers of wandering behaviour in remote communities. They had observed a number of innovative strategies that families had devised, including installing a bell on the outside doors to alert them if their family member wanders outside, and where possible having fenced yards in good repair to eliminate risk of them wandering off. A number of carers living in urban communities spoke about the tracking devices that were available, such as Medi-Trac and the Safe2Walk program run by AA Vic and AA WA. These were not applicable for people living in remote communities due to the lack of reception (needed for GPS monitoring); in addition, these were generally considered culturally inappropriate because they relied on people wearing a pendant or watch, and most Aboriginal and Torres Strait Islanders living in those communities had never worn either of these things in their life.

**Peer support**

As for people with younger onset dementia, opportunities for carers and families to meet with people in similar situations are very important. A number commented on the friendships that had been established and the personal support they had experienced from
fellow carers. Peer support groups for carers were particularly popular, as they helped overcome the social isolation many carers experienced due to their caring responsibilities. This was particularly beneficial for those who had given up work to better care for their loved one, or when social activities had to be scaled back due to challenging behaviours. Examples were provided where service providers organised social outings and dinners designed specifically to allow couples continue to socialise ‘without fear of what other (diners) might think’. As well as this social function, peer support groups provided carers with the opportunity to ‘debrief’, and learn from others’ experiences through discussions and being able to ‘toss around ideas’ between themselves.

**Funded services**

The mechanisms for social support may be provided by both formal services, as well as informally amongst individuals or couples. The majority appear to have been established and maintained by service providers with funding provided through respite and related community service programs. A popular peer activity is the ‘dementia cafe’ where people meet in a local coffee shop, the service provider’s facility or at a designated location, which provides an informal atmosphere for members to chat and relax. These may also include occasional information and education sessions with guest speakers; sessions have ranged from explaining relaxation therapy, ‘navigating Centrelink’, understanding the roles of Medicare Locals, to assisting carers organised their own carer respite.

A good example of a peer-support group for families and carers is provided by a respite centre in South Australia. This particular service organises monthly peer-support meetings and is supported by a newsletter. The group is mostly activity based and might involve a bus trip supported by two service staff. This provides the carers with an ideal opportunity to share information, socialise and offer each other support. Where there may be reluctance on the part of carers to participate, an inducement is offered by means of being offered two hours free centre-based respite for their participation in the monthly meeting. Every three months the respite centre holds a special event attended by both family/carers and the person with younger onset dementia.

While the advantages for peer support were evident, their limited availability was a recurring theme throughout the consultations. As the major source of funding for such initiatives is through aged care programs, carers of people with younger onset dementia are often ineligible to participate in established and local peer programs, and not able to benefit from the peer network, due to the age differences. A number of health professionals indicated the need for peer support to be available to children and families of people with younger onset dementia; however, there were no such services identified during the consultations. A further issue was the absence of support available to carers once the person for whom they are caring enters residential aged care. Many carers spoke of the emotional and physical toll associated with caring for a person with dementia, and of the often even greater stress and heartache experienced in the process of relinquishing full time care. However, as pointed out by a number of service providers, these carers were deemed no longer eligible for support by services provided through Home and Community Care (HACC) or National Respite for Carers (NRC) Programs, the main sources of funding for peer activities.
Informal networks

Informal support tends to follow once the connections have been made between families and carers. In one example, a group of four families affected by younger onset dementia that were originally introduced through a State-wide networking service have continued to meet regularly independently of the service provider; the inclusion in this group of a couple from a regional town meant that it’s not always possible for them to attend the regular, centrally located peer support meetings. This group continues to meet independently and they remain in regular contact both through formal get togethers (such as regular weekend retreats) and informal chats over the telephone.

Respite

In order to facilitate peer support for carers and families, a key factor is the availability of respite – someone to look after the person with younger onset dementia while carers attend their day to day and social activities. Age-appropriate respite services that were flexible and provided in longer blocks of time were also vital for carers to participate in employment and family activities that often feature during this time in people’s lives.

Service types and purposes

Many types of both short-term, long-term, in-home, community and centre based respite are available around the country. The two common forms of respite that were used by consultation participants were in-home care provided by a paid care worker, and attendance at a centre-based service. These services were generally extensions of existing ones funded under the HACC and NRC Programs, and were mostly targeted at frail older people. Thus, the environments of the centre-based services, and the attributes of the in-home carers were not tailored to the different needs and interests or physical attributes of someone who has younger onset dementia. Similarly, the periods of time offered for respite care were often inadequate for the needs of the carers and families to participate in paid employment, attend school presentation nights, travel for family weddings and meet the health and care needs of the wider family, such as ageing parents, children with mental health issues etc.

The stress of some carers was palpable during the consultations. Many cited their need to be able to have ‘down time’ and be able to do their ‘own thing’. For a wife in a regional town, the in-home respite provided two days per week allowed her to undertake things that she otherwise would not have time to do such as riding her horses; others mentioned the importance of catching up with friends over dinner, or going to the movies as being important for their own mental health. Importantly, the respite provided needs to be targeted to both the carer’s needs as well as the interests the person with dementia.
INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY

Respite

Ted was supported at home for 8 years after being diagnosed with younger onset dementia. He was able to remain living with his family primarily through the provision of respite services which were activity based, and included vocational elements such as assistance to undertake the family’s grocery shopping as well as recreational activities such as outings, photography etc. The respite service use was attuned to Ted’s individual needs and interests and remained at low to modest level of provision over the eight year timeframe.

These services were initially provided under HACC and the National Respite for Carers program and later incorporated into an EACH package.

Appropriate respite

A common theme throughout the consultations was the anxiety of carers and families about leaving loved ones in an appropriate environment and in the care of someone who understands their needs.

For example, one woman required in-home respite for her husband in order for her to continue in paid employment; her husband presented well, and continued to be relatively articulate. In the first occasion of in-home respite, the husband did not ‘get on’ with the carer and asked them to leave, and believing they were respecting the clients’ wishes, duly did as asked. It was clear the carer had limited understanding of their client, and no strategies that could be employed to better engage with him. The issue only arose when the wife rang later in the day to find her husband alone, as the care worker had failed to advise his employer of the situation. In the several months since that occasion, the couple had trialled six different care workers before finding one that the husband got on with, and was willing to spend his days with while the wife went to work. An additional complication for this couple was the limited hours that were available with the funding allocated, requiring them to find alternative, self-funded respite for the remaining hours that were required to enable her to participate in paid employment.

For others, their concern is whether the environment suitably supports their person, particularly those who experience sleep disturbances as part of their dementia. In such cases it is particularly important that the person with dementia is able to move freely and expend energy as needed, rather than remain passive through-out the respite period. A constraint of most centre-based services was the limited space and ability for people to freely move between settings (e.g., indoors and outdoors) resulting in frustration for the person with dementia, which can then escalate into ‘challenging behaviours’. A number of service providers commented on the disruptions this causes, including unsettling some of the more frail elderly clients in attendance, as well as potentially putting them, and the staff, at risk if the situation is not managed well.
INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY

Respite

Brian used to be a fit man, but since his diagnosis of younger onset dementia has spent most of his days sitting at home watching television. Following a change of carer providing in-house respite, Brian was asked about his likes and dislikes and after some time, he spoke of his love for the ocean. His ‘in-home’ respite is now provided ‘out-of-doors’ as a walk along the local paths overlooking the ocean, enabling Brian to keep fit as well as tiring him out and thereby assisting with his sleeping patterns; all while ‘stimulating his senses’. In the words of his carer:

*He really enjoys the experience and ‘milks it for everything’*

A key message from participants was the need for respite services to be tailored to the needs of the person with younger onset dementia, and the context within which they live, i.e., whether the carer is working, children are still at school etc. Common expressions included ‘holistic care’, ‘relationships’, ‘seeing the person as an individual’ and ‘tailored activities’ when describing the desired attributes of respite services. This was echoed across the spectrum of those consulted, including service providers and policy and program advisers speaking of the importance of ‘building relationships with clients and their families’ and considering ‘the needs of the client and the carer at the same time and assess their needs as a unit. To deliver this type of respite, staff need to be trained and supported, not ‘set in their ways’ but rather be ‘creative’, ‘intuitive’ and ‘flexible’. There was clear agreement of the need to have received education around the different types of younger onset dementia, the impacts on carers and families, as well as appropriate care and management strategies; their personal attributes were considered equally, if not more-so, important.

*Overnight respite*

Based on our consultations, cottage respite seems to be the most popular for people with younger onset dementia. In one example, the cottage offers overnight respite for clients four nights per week and also allows family members/carers to stay in the respite centre. This was thought to be particularly useful by one spouse who was transitioning her husband into residential aged care. Others highlighted the importance of overnight respite, especially for those with disturbed sleep patterns which were impacting on the health and well-being of other household members. On the whole, though, overnight respite was predominantly raised by service providers rather than carers themselves, possibly due to their limited availability and carers’ lack of familiarity with the model. For example we were advised that there is no access to overnight respite in Perth. It is not clear whether this is due to local policy decisions, or provider concerns around financial viability of these services (this latter issue was raised by a number of service providers). Similarly, we were advised that in Queensland it is often difficult to gain access to overnight cottage respite in an emergency.
situation and even when access to overnight respite is gained, it is generally only offered on a short term basis for a couple of nights. The only option for longer term overnight respite is through residential respite care and this is not considered age-appropriate and is costly as the carer has to pay the ‘gap’.

**INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY**

**Peer support**

SA Health has collaborated with an established respite cottage to provide a model of care tailored specifically for people with younger onset dementia. On one day per week access to the cottage is set aside exclusively for people with younger onset dementia. The Department stipulates that clients attending must have an official diagnosis of younger onset dementia and funds the program through the National Respite for Carers Program.

The cottage facilitates a client-centred approach and the younger onset dementia day is attended by up to 17 male clients. The men usually participate in group based activities such as supervised swimming at the local pool and table tennis, but there are no ‘compulsory activities’. The men are free to read the paper and spend time relaxing on their own should they wish. The men have a strong sense of camaraderie and there are high retention rates of clients with ‘only one client dropping out’ since the program began.

**Accessing services**

Several examples were provided of Local Government Area (LGA) boundaries being used to limit access to younger onset dementia respite services. In these cases, the service was operated by the local council, and only available to those residing within the LGA; several people attending the consultations lived in neighbouring areas but were not able to use these services, despite no alternatives being available within their own LGA.

Access to culturally appropriate respite services remains a critical issue amongst such communities. For example, we were advised that Aboriginal and Torres Strait Islander families will not even consider respite services as the concept itself is culturally inappropriate.

**Financial and legal impacts**

A major cause of stress for carers and families is the financial and legal impacts of younger onset dementia.

**Financial impacts**

As discussed previously, once a person receives this diagnosis they invariably have to give up their paid employment often with immediate and ongoing detrimental financial consequences, particularly if that person is the primary breadwinner of the household. This
situation is made worse over time as the care needs of the person with dementia increases, and their spouse or partner has to reduce their work hours or give up work completely to look after them.

While some carers use respite services to enable them to continue to work, the inflexibility and limited availability of these services meant they needed to be supplemented with additional private services to provide sufficient coverage. This additional cost is clearly only feasible for those carers who are in relatively well-paid positions, and able to work fixed hours; one carer had been a shift worker all her life and was forced to leave that job and network of colleagues for a lesser paid position that had regular hours, to ensure she could take advantage of the respite services available in her area.

INDIVIDUALISED SERVICE EXAMPLE – RESIDENTIAL

Cleaning and gardening

Vernon is a big man with younger onset dementia who lives with his daughter at home. Unfortunately for Vernon, he experienced a progressive decline with his behaviour and had to be placed in a residential aged care facility. However, the staff at the facility were unable to handle his behavioural issues due to Vernon’ size and strength and he lasted only a few days before being discharged. Consequently he had to return home to live with his daughter again. It looked like Vernon’s daughter would have to give up her part-time work as he could not be left alone at home all day. After further discussion, the aged care facility agreed to take Vernon in for respite during her work days. The facility became more proactive with Vernon and got him involved in cleaning and gardening activities. He has now been attending regularly for six weeks and they have not experienced any problems with his behaviour.

Residential care is predominantly set-up for frailty for those who ‘can’t do’, younger people like Vernon are fit and strong and ‘can do’ and very much ‘want to do’.

A young couple described the impact of dementia on their household income. Prior to the dementia, both were working full time, and their children attending day care. Following his diagnosis, the husband had to quit work altogether, and the wife moved to part-time work to enable her to provide care for her husband. That is, the household income went from two full-time wages to one part-time wage virtually overnight.

Income support

Accessing income support is clearly a major issue for many families, however many people spoke of the difficulties working with Centrelink. A carer from a regional town spoke of a nine month delay in processing her application for the Carer Allowance; the couple above
were eventually able to receive some financial support, but also only after a long and clearly frustrating experience:

*Navigating Centrelink is an absolute nightmare...it took three months for them to process my claim...it seems if you don’t know the right questions to ask, you don’t get the right answers.*

During the consultations, we were informed of a disturbing anomaly that appears within the Centrelink guidelines: several married couples had been advised by their local Centrelink branch that they should consider filing for divorce, to enable the person with younger onset dementia to be considered financially disadvantaged and thereby increase their access to services.

Participants at each of the focus groups also stressed the importance (often in in hindsight) of some sort of income protection. It is not uncommon for persons with younger onset dementia to experience difficulties in accessing pensions or insurances. In Section 4.2.2 we included the example of the health professional diagnosed with dementia whose income protection insurance was being challenged by the insurance company because he had missed a number of questions when filling in his application form (possibly as a result of his dementia prior to formal diagnosis). His spouse was very concerned not only of the immediate ramifications financially, but also further down the track when residential care might be needed. The difficulty accessing life insurance was also highlighted, particularly regarding access to payment on the basis of the person with dementia having a terminal illness. The difficulties arise from the definition of ‘terminal’, with some insurance companies only paying out when the person has 12 months to live. The trajectory of dementia is difficult to predict with accuracy, and medical reports are often unclear about timeframes, given some people can live with younger onset dementia for ten years or more.

**Legal issues**

A number of legal issues were also raised during the consultations, predominantly around processes regarding Powers of Attorney and Guardianship. These vary considerably between jurisdictions, and are often not well understood by family solicitors. A number of participants noted the additional difficulties for people from fronto-temporal dementia, who may have no insight into their dementia and refuse to engage in these legal processes.

**Transport**

Access to transport is a huge issue for carers and families of people with younger onset dementia. As noted previously, for many people there is an automatic loss of licence if diagnosed with dementia. The vast majority of people with younger onset dementia who attended the focus groups were male and in many cases were also the traditional family driver. The loss of driving licence therefore significantly impacted on the other family members’ routines and roles, as well as their opportunities for respite. For example, one couple living in a regional community had lined up the husband’s attendance at a local Men’s Shed to enable the wife to have some much-needed respite. His dependence on her having to drive him to and from the Shed, however, meant that this limited the time she
could actually spend attending to her own activities, thereby countering any potential positive benefits the respite was supposed to provide. The husband subsequently had to stop his attendance at the Shed as he did not want to further burden his wife.

While community transport is available nationally, access to it is often problematic for people with younger onset dementia and their carers, particularly those living in regional and rural areas. In addition, staff and volunteers are generally not trained or skilled in supporting people with dementia. As one service provider noted, many community transport providers generally have an ageing volunteer workforce that is undertrained with issues regarding dementia. The physical attributes, such as strength and agility, of many younger people often are a cause of concern for these volunteers, particularly if behaviours are an issue. As one program and policy adviser noted:

*nobody ‘owns’ the problem, and there is a general assumption that the carer will provide transport...this is clearly problematic with younger onset dementia where the carer may be working or there may not be a carer.*

### 4.2.4 Impacts on social networks

Human beings are, on the whole, social creatures; we derive a great sense of purpose, pleasure and identity through the relationships with those around us. People with younger onset dementia, and the carers and families surrounding them, not only face the personal challenges described above (Sections 4.2.2 and 4.2.3); their social networks and participation rates are also significantly impaired.

#### Community awareness and stigma

The main reason for the changes in social participation arise from the lack of community awareness about younger onset dementia, and the stigma associated with dementia generally.

#### Social impacts

In the period preceding a formal diagnosis of dementia, many people have experienced reduced social engagement, primarily due to the changing behaviours and cognition they are experiencing. Those living with dementia may begin to isolate themselves as they start to realise there is ‘something wrong’, with a number of participants speaking of the sense of shame they experienced when the could no longer function as effectively as they had done previously.

Family members also experience changes in social patterns, with children not wanting to invite friends over because of potential embarrassing behaviours on the part of the parent with the (as yet undiagnosed) dementia. Similarly, invitations to attend social events often start to reduce, as others increasingly find their behaviours difficult to understand; in many cases people spoke of others thinking they were deliberately avoiding company or being rude and inappropriate in social situations. As one service provider noted:
**We focus on gaps in the service delivery system but the biggest gap is the lack of community awareness**

The experience for many is that once a diagnosis of dementia is confirmed, the damage to relationships is often beyond repair, and those surviving relationships are often strained further, due to a lack of understanding and awareness about dementia and uncertainty about its manifestations. Even amongst those well informed about dementia, there can be scepticism about the diagnosis and blaming the individual for laziness or lack of effort to improve themselves. For example, a representative of a peak body suggested, confidentially, that they ‘doubted’ that a person with younger onset dementia had a ‘true diagnosis’ of dementia, because their decline had not been as swift as expected. Others spoke of friends who ceased contact as they ‘suspected I wasn’t trying hard enough’ to keep up with the friendship. As one participant commented:

*If you get cancer you get a casserole, if you are diagnosed with younger onset dementia people run away!*

**Perceptions of dementia**

In addition to increasing the isolation experienced by many people with dementia, carers and families, this lack of awareness can also result in people missing out on receiving the support that is currently available. As noted previously, several people indicated they had not considered approaching Alzheimer’s Australia as their partner was diagnosed with fronto-temporal dementia, not Alzheimer’s Disease. Others associated the term with older people, and therefore did not think the services it offered would be relevant for their situation. Several carers noted that their reluctance to approach AA was based primarily on their own difficulty in coming to terms with the fact that their person had dementia, or that they themselves could not cope and needed help. One carer, a health professional, admitted she thought she knew all there was to know about dementia and assumed she would be able to coordinate any support she might need through purchasing services privately; she had assumed that AA and similar services were only for those who could not afford to pay privately.

There was widespread agreement of the need to invest in a broad range of community awareness activities, supported by targeted approaches to the infrastructure supporting people and their families, such as health professionals, schools, employer groups and unions, as well as general community services. An example of a positive community awareness campaign was the ‘Don’t Dis my ABILITY’ ([http://www.dontdismyability.com.au/](http://www.dontdismyability.com.au/)) campaign that has been developed by the NSW Government. The campaign celebrates the diversity and ability of people with disability and uses the United Nations International Day of People with Disability to showcase their achievements.

**Focus on the positive**

A number of people cited the importance of raising awareness of the continued potential of people with dementia, rather than focusing on their losses:
I am constantly being told what I can’t do instead of focusing on what I can do

The stigma that many people experience as a result of having younger onset dementia was captured by another participant:

I am pigeon-holed...people view me as different

The ‘prescribed disengagement’ described in Section 4.2.2 often commenced at the point of diagnosis, and continued throughout the dementia journey; it was attributed primarily to health professionals’ perspectives that often underpinned the care and support services that have been developed over recent times. An example was provided of a senior health professional who sought to redress this negative perception, and started referring to his patients as having a ‘brain disease’ rather than using the term ‘dementia’. His rationale was that, if people came to view dementia as a disease process just like any other disease, they would be less ‘scared’ of it, and not be so quick to stereotype people. The service provider relating this example observed that this had a positive outcome not only for people with dementia and carers, leaving them feeling more empowered and less stigmatised, but also for workers in the related health services who started to perceive these people more positively.

One person with dementia noted that, while they saw the political logic in promoting a negative perspective as a means of advocating for additional funding for much needed services and research, this came at a cost in terms of the portrayal of people living with dementia:

There is a need for more positive stories...we are normal people who have a disease...we still have a lot to contribute and want to participate

A number of participants raised the impact of dementia on cultures and communities which were already disenfranchised due to negative stereotypes:

If you are Aboriginal you have a double stigma...you are Aboriginal and you have dementia!

Employment and volunteering

As noted previously in Section 4.2.2, people with younger onset dementia are generally required to give up their employment when they receive their diagnosis. The impacts of this abrupt cessation are not only felt by the person with dementia, in terms of reduced income and self-esteem as well as increased isolation, but also for their broader relationship network (Section 4.2.3). The need to feel useful and contribute was a recurring theme amongst discussions with people with dementia, service providers and some health professionals. Expressions such as ‘meaningful’, ‘engaged’ and ‘vocational’ were used to describe the type of activities that people with dementia could do, and wanted to be engaged in. That is, activities that had a purpose, and added value to participants and others. For most people, this usually describes the job they are doing. Given the limited
options available for paid employment for people with dementia, there has been an emerging focus on the role that volunteering can play in fulfilling this need.

Employment opportunities

For a number of people who participated in the consultations, such as the former judge, doctor, nurse and senior armed forces officer, their ceasing work was without question, as their impaired decision-making would have placed other people at risk. However, like others we spoke with, this did not mean they no longer had anything to contribute; there was an overwhelming feeling that people with younger onset dementia still had much to offer and many felt disappointed that they were not offered the support to continue working in a reduced capacity, with supervision.

A number of examples of people taking their own initiative and continuing to identify employment or other opportunities to contribute to their community have been cited previously in Section 4.2.2. On the whole, though, there seemed to be a lack of awareness amongst employers of the potential for the person with younger onset dementia to continue to contribute to a workplace. Through-out the national consultations we came across only one example of an employer which supported their employee to continue working with their business after they were diagnosed.

CONTINUING EMPLOYMENT EXAMPLE

Trucking company

John, a truck driver working for a regional trucking company felt that he was not ready to finish work after his diagnosis. He communicated these feelings to the company who, after much discussion, assigned John to a job with lesser demands that were more suitable for him. Over time as John’s cognitive abilities deteriorated, he was reassigned to other jobs. This went on for 6 years allowing him to maintain a job and colleagues, and receive an income.

A number of service providers spoke of the potential for organisations such as Disability Services Australia, Commonwealth Rehabilitation Services (CRS) or other employment agencies to be more proactively used in assessing people with younger onset dementia and identifying possible employment opportunities. No-one could provide any examples of this being trialled, with most saying they expected that these organisations probably were too busy with their own client base to consider taking on another diagnostic group.

Vocational activities

Service providers reported an emerging understanding of the importance of vocation for people with younger onset dementia. The benefits are obvious in terms of the pleasure people show at participating in doing things that have relevance to them. There were many examples in our consultations of where people with younger onset dementia likened attending respite to going to ‘work’:
Joan attends a day respite centre twice a week and helps out with the mobility of the older clients and coordinates mealtime activities.

Fred, a former ‘jack of all trades’, attends his local respite centre with his toolkit and, under supervision, does maintenance jobs around the centre.

John is the ‘gardener’ at his local respite centre.

Dave, the butcher mentioned previously in Section 4.2.2, lives alone and attends his local respite centre two days a week, returning on the other three days to ‘help out’.

Service providers spoke of the ‘therapeutic benefits’ of enabling people to continue to be actively involved in some way or other, such as reducing agitation and difficult behaviours, and creating a happy and positive environment for themselves and others. In one example, a former Director of Nursing, who was having great difficulty settling into the residential care facility, was provided with the ‘job’ of greeting visitors as they arrived in the unit; she presents so well that many assume she is one of the staff, and she is much more settled in her new environment. In another example of someone having difficulty transitioning to residential care, a man who had been ‘very social’ prior to his dementia was encouraged to assist in the activities which residents participated, which not only gave him great pleasure, but also brightened up others in his secure unit through being provided with the opportunity to share in his gregarious nature.

**INDIVIDUALISED SERVICE EXAMPLE - TRANSITIONS**

**Moving between community and residential**

Stan received respite services in a local residential aged care facility. Eventually, as his symptoms deteriorated, he needed full-time care and took up residence in the facility where he had received respite services. This transition seemed ‘seamless’ as Stan and his family were familiar with the nursing staff and some of the residents. This familiarity also allowed his family to ‘continue to be involved in his care once he moved to residential care, and they were ‘instrumental’ up to the end’. Eventually Stan required palliation and his family were still very much involved in his care, they were able to translate his care needs to nursing staff to ensure he received a more person-centred palliative approach.

**Volunteering opportunities**

Volunteering occurs in a number of settings and has a range of purposes, and outcomes. In some senses, this occurs naturally within the realms of family life, where the carer identifies specific roles and tasks for the person with dementia to contribute to the household. A number of people with dementia have initiated volunteering themselves, seeking opportunities to be ‘useful’ and ‘contribute’; for some, the absence of formal opportunities has spurred them to take the initiative and develop their own. Several examples were provided of men tending to the upkeep of their neighbours’ gardens. This gave them
personal satisfaction from their labours, kept them busy and also maintained their social relationships.

Examples of more formal volunteering were provided through local church groups or charitable organisations. Those who participated in such activities spoke of the opportunity this provided for them to ‘give something back’ and change their focus of attention onto others, rather than their own situation. A number of gardening-related activities were also cited. A young man with dementia spoke of his volunteering with a local gardening service; while the staff worked, he spent the time chatting with the clients and making tea and coffee for the workers. This not only gave him a sense of purpose, but also provided some company for the mostly elderly clients who lived alone, as well as ensured the workers were able to complete their work relatively uninterruptedly. A service provider has organised for people with younger onset dementia to help out in a local school garden. They suggested this model could be replicated, by collaborating with the relevant state Education Departments to develop a program whereby people with younger onset dementia work with schools to support activities in the garden.

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<tr>
<th>EXISTING PROGRAM EXAMPLE</th>
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<tr>
<td>Gardening on the Tram Tracks</td>
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<td>Partners: Norman House (Life Care), the City of Unley</td>
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A collaboration between Norman House and the local City Council, this is an eight week program in which men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens. As well as providing the men with a meaningful and rewarding activity it also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.

The Norman House webpage and contact details can be found at: [http://www.lifecare.org.au/comCare/norman.html](http://www.lifecare.org.au/comCare/norman.html)

The involvement of people with younger onset dementia in volunteering activities provides a good way of assisting them to keep in contact with their local community, increasing community awareness and helping reduce stigma associated with dementia. To be successful, volunteering needs to be approached in a structured manner. Key to the success of volunteer programs, however, is the tailoring of the activity to the particular talents, interests and abilities of the person with dementia. A number of service providers have developed relationships with a network of suitable local organisations that can be drawn upon and matched to clients wishing to volunteer. Once a suitable match has been identified, the service provider provides education and training for the staff of the relevant organisation and works alongside the person with dementia initially, until the parties are confident and comfortable working together. Regular follow-ups occur to ensure that things
are running smoothly, as well as monitoring the appropriateness of the activity to the capabilities of the individual.

Many of the focus group participants indicated that they would like to see more information about volunteering in their local area. They all felt that they had plenty of energy, could still be ‘high achievers’ and had ‘a lot to offer’.

**EXISTING PROGRAM EXAMPLE**

**Side by Side Project**

Partners: Life Care Australia, University of South Australia and Bunnings

This award winning service model involves a group of people with younger onset dementia working one day a week alongside a ‘buddy’ at the local Bunnings Hardware store. Their work tasks were negotiated at the beginning of each day in partnership with their buddy. An independent evaluation of this program found that all participants were able to adapt to the workplace environment; in addition, the experience was personally rewarding, having a positive impact on their self-esteem and overall satisfaction with life. Benefits were also identified for family members, who also reported a positive impact on self-esteem and life satisfaction as a result of the workplace experience; they refer to it a ‘guilt-free respite’. The evaluation of this initiative has exceeded all expectations and has demonstrated that it is possible to offer meaningful activities for people with mild dementia if an appropriate framework of support is provided.


**4.2.5 Social networks**

There was general agreement amongst all groups consulted of the importance of people with younger onset dementia to maintain their social networks as much as possible following diagnosis. This was not to discount the role of peer support, but rather the role that social networks play in maintaining the sense of ‘identity’ of the person with dementia. As discussed previously, the stigma associated with dementia, and lack of community awareness, mean that many people lose the things in life that help define who they are, such as their jobs, social interests as well as important relationships in their lives.

An important component of maintaining normal social networks is to continue doing what you would normally do prior to diagnosis. One service provider highlighted the importance
of the care worker to establish with the client what their preferred way of socialising is and then accommodate this. He stressed that:

*People with younger onset dementia do not need nurses, they need social support...they need assistance with living life as usual rather than becoming a client...there should be more focus on the needs of the individual*

The benefits of maintaining social networks also stem from the familiarity of routine that this provides, and reinforcement of skills learned. Indeed, a highly experienced policy and program officer suggested that people with younger onset dementia did not need access to support groups, rather they needed participation in ‘normal lifestyle activities’. This was echoed by comments of focus group participants. One example provided was that of walking, an important activity that people have always been involved in, in some form or other. A number spoke of the potential dangers in allowing the person with dementia to go walking, in case they ‘wander off’ or get lost. While a number of tracking devices have been developed in recent times, people were generally unsure of their utility, particularly if was not on their person when they set out. A small number were members of established walking groups, where fellow walkers understood that they had younger onset dementia and accommodated their ongoing participation in the group.

**INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY**

**Choir**

Alice attended a choir group in regional Australia prior to her younger onset dementia diagnosis. Post-diagnosis, she is still able to attend accompanied by her care worker who is introduced as a ‘friend’. Alice is therefore able to continue doing something she loves with a community group she has been associated with for a long time. Alice loves the fact that the focus in this group is on her singing and not on the fact that she has dementia.

A number of people with younger onset dementia highlighted the role that the internet and social media played in supporting their social connections; this was particularly important for people living in regional and remote areas where there is often a feeling of increased isolation. A number of younger participants, i.e. those in their forties, used Facebook to stay in touch with family and friends, as well as more generally to obtain information and for social interaction with people with similar interests. We were advised of a number of Facebook pages specifically targeted at people with younger onset dementia, where people regularly interact with these pages to share their thoughts and experiences.

Another notable model of providing people with younger onset dementia meaningful activities is through facilitated gym sessions. A number of people we spoke with were keen to ensure they maintained their physical health for as long as possible, and were regular gym attendees. While some continued to attend their local gym, others found this too difficult, and had to give this up. In one regional city, we met with a service that was operated in partnership with a local disability service, providing weekly gym sessions for both people
with younger onset dementia and their carers supervised by a personal trainer. After the gym session the participants all go for coffee together. Another example was a weekly gym program for clients with younger onset dementia, where the session is supervised by an occupational therapist, supported by volunteers, and health sciences students from the local university occasionally lend a hand as well. The gym fees are paid for by the families and supplemented by donations from the host organisation’s Staff Giving Fund. Anecdotal reports highlight that the men attending the regular gym sessions are able to operate the gym equipment independently, have relearned old gym skills and have improved their fitness.

**INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY**

**Men’s sheds**

Bill loved to keep busy, he enjoyed renovating things but was driving his wife mad being at home all day. A local service provider referred him to a men’s shed group that welcomed men with dementia. This shed used old fashioned tools (not power tools) thus minimizing the potential for danger. The men’s shed provided Bill with an opportunity to socialise with other men in similar circumstances to him. They got to help each other out with their projects and walk away at the end of the day in a positive frame of mind.

*If [men with younger onset dementia] can accept their diagnosis and comprehend it they realise that life is for living now...they meet others with an openness that they may not have demonstrated before and are much more open to talking about how they are feeling and other things*

In facilitating these types of social activities, we were reminded of the need to be aware that the symptoms for people with younger onset dementia fluctuate daily and therefore to be flexible to meet their needs according to their wellbeing. Similarly, underpinning any social activity designed for people with younger onset dementia was the need to include them in the planning, targeting and tailoring of the activity.

Of all the people we met with, it was clear that peer and social activities were especially important for those who lived alone. Their risk of social isolation and the attendant effects on the mental health and well-being are most acute, as is their risk of premature admission to residential care. Service providers and policy and program advisers highlighted the increased vulnerability within the context of a consumer directed care model and individualised funding approaches that are part of the recent aged care and disability reforms. A number pointed to the potential benefit that the Key Worker positions can play in terms of oversight and coordination of appropriate support and care services and networks; others however, argue that the presence of a carer who is able to advocate for their person’s needs, as well as their own, is more likely to be prioritised over those who are
effectively ‘voiceless’. In a similar vein, we found examples of people who lived alone being ‘left out of the communication loop’ regarding changes in service delivery. This has lead one person who lives alone to recommend the development of a Surrogate Carer pilot program, that focuses solely on clients who live on their own, and whose role would be:

_one of close monitoring, coordination and advocacy, ensuring appropriate access and oversight of the services and support required._

### 4.2.6 Impacts on services

People with younger onset dementia, their families and carers, are in clear need of a range of formal services to enable them to continue to remain living in the community, and accommodate them when this is no longer possible. In general, these services are delivered by a range of organisations including government (local and state/territory), hospitals and health services, community-based, church and charitable groups and privately run businesses. In the main, services for people with younger onset dementia are subsidised through Commonwealth aged care funding, or State/Territory disability and health funding, usually also involving some form of user-contribution.

The consultations highlighted the variability amongst services that have developed for people with younger onset dementia, their families and carers in terms of type, appropriateness, and accessibility. This is primarily due to the comparatively low numbers compared to other groups of services users, e.g. people with disabilities, cancer or diabetes, and the relative limited understanding about younger onset dementia amongst health professionals and service providers, as well as in the general community. The lack of ‘critical mass’ has significantly limited the ability of providers to develop specialist models of care that are sustainable, resulting in people having to ‘fit into’ the more traditional service models. A common sentiment amongst health professionals, service providers and policy and program officers who participated in the consultations was that people with younger onset dementia have ‘slipped through the gaps’ between health, aged care and disability sectors, in terms of funding as well as service provision.

Despite the current reality of a widespread lack of services, the consultations revealed a wealth of information regarding how existing services have been adapted and a number of new services developed at a national, state-wide, regional or local level. Often locally developed solutions have been implemented with little or no additional funding; they are the direct result of health professionals and service providers taking the initiative to identify strategies and models of care that address the unique and changing needs of this group of people. Most people involved in the consultations acknowledged that to address concerns regarding ‘lack of services’ and develop ‘ideal’ service models in all regions of Australia would be impossible due to high costs and the diverse features of a relatively small number of people with YOUNGER ONSET DEMENTIA who are scattered across the country. This section discusses the key issues for service provision that were identified in the consultations and provides examples of models that have the potential to be implemented more generally.
Diagnostic services

There are limited specialist diagnostic tools and services available nationally, resulting in people having to undergo multiple diagnostic processes often over an extensive period of time. As discussed in Sections 4.2.2 and 4.2.3, the long road to diagnosis has significant impacts on the well-being of the person, as well as their families and carers. Barriers to achieving a diagnosis are both structural as well as attitudinal. The complexity of the presentation of dementia means that a diagnosis is often arrived at through a process of elimination, involving various tests such as scans and blood tests, and attending a range of health appointments including general practice, psychiatry, psychology, neuropsychiatry, geriatrics to counselling and family therapy.

Attitudinal barriers also impact on people receiving an early and accurate diagnosis. This can be on the part of the person themselves taking time to accept they need assistance, as well as family and carers who may interpret the symptoms as being ‘all in their head’ or deliberate. In some cases the denial of dementia was on the part of the attending health care provider, with their disbelief of the possibility of a diagnosis in someone so young, or their difficulty in accepting the diagnosis and talking through the implications with their patient.

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Following a review of the diagnostic pathway for dementia in the Northern Territory, it was found that many people with younger onset dementia were either not receiving a formal assessment and diagnosis, or ‘dropped off the list’ and were not being followed up with appropriate services. A dementia pathway was developed whereby all people suspected of having impaired cognition or memory problems are now supposed to be automatically referred to the Memory Clinic, regardless of age, instead of referral to neurologists or other doctors. As the pathway has become established and known more widely, health and service providers believe that this has resulted in more people with suspected younger onset dementia being diagnosed earlier and more accurately, and increasing their likelihood of being linked in to support services.

While the capacity to diagnose younger onset dementia is improving nationally, due to greater awareness of its presenting symptoms and refinement of diagnostic processes, the majority of these are extensions of existing services for people with dementia and psychogeriatric conditions more generally. Not surprisingly, there is only a handful of specialist younger onset dementia health services nationally that provide a comprehensive assessment and diagnostic service; we were advised of only one that offered this through an inpatient facility and continued to oversight their health and care management over the longer term, the Neuropsychiatry Unit at the Royal Melbourne Hospital.
The Unit is staffed by three full-time consultants, three full-time registrars, and provides a mix of neuro-psychiatry, neurology, neuro-psychology, occupational therapy, nursing and social work (specialising in family therapy). Around 200 new clients are seen each year at the Unit and whilst there, they can access a range of assessment and diagnostic processes; families are invited to participate in the assessment process, in particular regarding post-discharge care and support requirements of the person as well as the family unit. Care plans are established, referrals made and services put in place where required and/or possible prior to discharge. A key component of the service involves information and education about what people can expect, and what services are available to them, as well as counselling and family therapy to support important relationships. Importantly, clients remain ‘on the books’ for life, in order to ensure continuity of care and also provide a reference point for any issues that may arise in the future.

**Service types**

The consultations revealed an array of services types that are available to support people with younger onset dementia to continue to live in the community. Some are targeted specifically to assist the person with dementia and others at families and carers to enable them to continue to support the person with dementia remain living at home for as long as possible. These include peer support activities, information and education, domestic assistance, meal services, transport, care coordination, counselling, respite care, and allied health, nursing and residential care. The majority are generic aged and community care, health or disability services funded under programs such as Home and Community Care (HACC), National Respite for Carers Program (NCRP), Commonwealth Home Care Packages as well as various health and disability programs run by State and Territory governments.

On the whole, the consultations revealed a limited range of services specifically targeted to address the needs of people with younger onset dementia. Most services used are additions to existing services, which are structured, timed or run slightly differently to the generic models of service. The spread of specialist services is variable across the nation; these have developed because of perceived need (e.g., sufficient quantum of people) as well as personal interest and commitment of a number of key providers and individuals.

A number of service providers spoke of the difficulty in establishing services that could appropriately meet the complex needs of people with younger onset dementia due to the lack of specific program funding. There was general consensus that the traditional aged care programs fell short of what was needed, due to inflexible guidelines and insufficient funding to ensure financial viability. Policy and program officers confirmed that, given the lack of clarity about overall numbers of people with younger onset dementia, there are no planning ratios or benchmarks for services as there are for other service types. The only jurisdictions that appear to have invested in the development of specialist services for younger onset dementia are the Commonwealth Government, through its Younger Onset Dementia Key Worker Program currently being delivered through Alzheimer’s Australia,\(^{13}\) and the NSW

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Government which is currently trialling individualised funding options through its Younger Onset Dementia Program.14

Information

Participants also noted the difficulty in finding contemporary information about possible service options, as there are no formal mechanisms to register services with appropriate models of care. While Alzheimer’s Australia offices have links with many of these services and can facilitate contact and referral, the details are not readily available to the general public. A number of agencies have developed resources for prospective clients that include lists of complementary services available in their immediate locality, however these are initiatives are generally unfunded, and therefore cannot be guaranteed to always be up to date or widely distributed. As a number of providers noted, the array of service types, each with their own entry protocols, funding contribution requirements, and operational models makes it difficult for them to always know what is available; ‘how then is the client supposed to know’?

Despite the ability of many to access information via the internet, the vast majority of people we spoke with usually found out about services through ‘word of mouth’; this was particularly important in assessing quality of care that provided by a service.

Information is important for people with dementia, their families and carers at the point of diagnosis as well as being available in an ongoing way to accommodate the changing needs of the situation. Some carers acknowledged that the information provided initially was overwhelming, having difficulty as they were with taking on board the immediate situation:

   I couldn't contemplate the latter part (of the dementia journey)

A number of service providers and health professionals have established strategies to enable them to support people with dementia, and carers in particular, through providing information in an ongoing and timely manner. This included ‘providing information only two steps ahead’ of the stage people were currently experiencing, ‘as this is all they can take in’ and keeping people ‘on the books for life’ so they feel free to seek further advice and information as the need arises.

A number of people spoke of the need to have information that is appropriately targeted to the needs of the particular audiences, both in terms of content and delivery. For example, a service provider supporting Aboriginal and Torres Strait Islander people in remote communities found that ‘being prepared to get down and sit with someone in the dirt helps building a rapport’ and from this, opportunities to provide information and education relevant to their needs. Others spoke of the role of resources produced in different languages for specific communities, and for them to offer clear messages and information, particularly given that in some communities ‘there is no word for dementia, or concept of

dementia occurring in younger people’. A service provider cautioned against the reliance on interpreters when discussing diagnosis and care planning with people from culturally and linguistically diverse communities, as these were ‘another CALD (sic) workforce group who need education about younger onset dementia. There was general consensus that information needs of culturally diverse groups were not well met.

**Focus on the individual**

One of the main limitations of the existing service system is that it offers generic models of care that are not suitable to accommodating the particular issues associated with younger onset dementia; that is, the different manifestations of dementia, variability in associated decline of cognition and function, and impact of the broader context in which people render the ‘one size fits all’ service models inappropriate and, indeed, potentially harmful and disabling.

The most widely supported aspect of service provision for people with younger onset dementia during the consultations was the need for an individualised approach to care. People with dementia spoke of their desire to ‘be treated like an adult’, with ‘respect’ and ‘dignity’, and being assisted to continue to ‘live life as usual’ rather than being considered as a passive recipient of services. As one person stated:

*People with younger onset dementia are humans too... we want people to collaborate with us ....it is essential that we have an input into the things that affect us.*

An individualised approach to service provision requires an understanding of the impact of dementia on the abilities of the person, and the identification of strategies to compensate or adjust accordingly. This extends beyond knowing the cognitive and functional changes arising from the dementia to include understanding how these things impact on their daily lives, and on the lives of those around them. They ‘need to find out people’s stories’, including their ‘preferred way of socialising’ to tailor intervention and activities that ‘link with the person’s past and build on their strengths’. Typically, this requires engagement with the relevant people in relationship with the person with dementia, such as their spouse, carer and family, to identify their needs in terms of adjustment to the diagnosis and what they may need to sustain them in their caring role over the longer term. Ideally, the engagement and assessment of need should be conducted within the person’s home, and over a period of time to ‘understand the family environment’.

The recent shift in the service sector towards Consumer Directed Care (CDC) was seen as a positive in regards to enabling individualised services to be provided. The principle was roundly supported by participants, although there was some variability in terms of understanding what this might mean for them in reality. Some health professionals and service providers expressed their reservations about the new model, as it was premised on the basis of people having a choice of options regarding their care which was not the situation for most people with younger onset dementia; specialist services for this group, on the whole, are very limited and ‘in reality, there is no choice’.
Tailoring services to meet the needs of the person with dementia is complemented in practice with having staff who know the person well, and understand the factors that are likely to impact on their well-being; this is particularly important for people who have associated behavioural changes that can easily escalate if left unchecked. Participants spoke of the importance of having workers specifically ‘matched’ with the person with dementia in terms of their knowledge about the person as well as their personal communication style and interests. Consistency amongst care staff was therefore seen as critical, helping workers to ‘form real partnerships’ and build trust with their clients, as well as carers and family members. One service provider stated in support of this approach that ‘people are more relaxed if they know their care worker knows them’:

*What is needed is a package of funding plus someone to ‘walk alongside’ the person and their family and help them organise their life and the supports they need. I.e., not necessarily case management, but someone who can assist them ‘navigate the maze’ of the system. This person needs to understand the client and family, in order to provide the right support/info/education to enable them to remain a unit as long as possible.*

**Integration strategies**

In addition to the difficulties many people experience in accessing information and appropriate services, is the intersection of matching their availability with the context in which the person with dementia lives. People often require services from a number of services, from various locations and across professional groups (e.g., clinicians, therapists, aged care providers). The disparate range of health and care services that may be required has been variously described as a ‘maze’ and ‘incomprehensible’ for services providers, ‘let alone people with dementia’. Consequently, the consultations suggested that there are many people experiencing undue burden and difficulties due to their inability to ‘navigate’ the services they need, for the time and purpose that they need. This is even more problematic for people who are from culturally diverse backgrounds, do not have a carer, live in rural and remote areas, or are homeless.

This fragmentation of services belies the concept of a singular ‘service system’ or a ‘one-stop shop’ that people may anticipate at the time of diagnosis. Indeed, the research team received follow-up correspondence from one concerned carer who noted that the relatively high profile of Alzheimer’s Australia is suggestive of its capacity to deliver comprehensive services and education for people with younger onset dementia; this carer was sorely disappointed to find that this was not the case.

A recurring theme of the consultations was the importance of individuals having access to a single point of service co-ordination, and there was great anticipation regarding the newly established Younger Onset Dementia Key Worker positions within Alzheimer’s Australia being able to take on this role. A number of health professionals and service providers had taken on this role of care co-ordination, including liaison with complementary service providers, to provide more coherent support to the people with dementia, their carers and families. This was alternatively described as having ‘continuity of services’, that were
'integrated’ and allowed for ‘seamless’ transitions from community care to residential services. For those providing ‘packaged care’, this was integral to their overall approach. Others, however, spoke of having to ‘cobble together’ a range of supports with funding from different programs to ensure a sense of coherence; this was particularly important for those approaching eligibility for packaged care, or where packages were not readily available.

Service providers and health professionals spoke of the importance of referral and clinical pathways and protocols between services and sectors to facilitate a seamless approach to care and support. Service networking, ‘knowing who’s who in the zoo’ was considered especially important to maximise the impact of available funding. An example was given of two services working together to combine the four hours of respite they each had available (from different funding programs) to coordinate the total of eight hours respite to best meets the needs of the person with dementia and their carer. In another example, the care package provider collaborated with the local respite centre to deliver in-home respite for seven hours a day, five days a week to enable the carer to remain in full-time employment. Cross-agency collaboration is also important when trying to avert a care ‘crisis’, as providers or clinicians know who to call on, which services have vacancies, and which services are best placed to deal with the issues leading to the crisis. This can also assist people receiving support quickly, rather than being on the ‘wait list’ for a particular service, especially when there is an explicit organisational commitment or inter-agency protocol in place.

A person with dementia queried why it couldn’t be ‘someone’s job to build effective service networks’ to ensure people are supported in a more streamlined way:

*There is a need for inter-sectoral collaboration – so people can access different supports and services ... depending on need, not diagnosis.*

The consultations showed very clearly that the success of any interagency lies in the calibre of the people involved, and the level of trust and co-operation between the different parties:

*(L)ocally based networks of service providers who are ‘passionate’ about younger onset dementia are the key to developing flexible and appropriate service responses for younger onset dementia clients*

*There should be no competition between agencies – all should work together for the same cause.*

The complexity of issues facing people with younger onset dementia, and the differences in which it presents in any one person or context, highlights the need for services, professional groups and disciplines to work collaboratively and build capacity across care settings. As one policy and program officer noted:

*the service delivery system operates within silos....people with younger onset dementia can be provided with services by palliative care, aged care, disability services, acute care (with) little communication between each of the pillars.*
An example of a cross-discipline approach involves the memory clinic medical and nurse specialist working together with counsellors at a local branch of a national counselling service to support a person with younger onset dementia and their spouse through a difficult time in their relationship post diagnosis; this enabled the counselling service to better understand the issues associated with younger onset dementia, and to be better able to support similar clients in the future.

In all jurisdictions, the potential benefits of the newly established network of Key Workers was discussed, particularly in terms of working across services and sectors to breakdown existing barriers and build pathways and protocols.

*The key worker model is excellent and should be used more broadly. Partnerships (between service providers) should be encouraged. There should be no competition between agencies – all should work together for the same cause*

The role of Alzheimer’s Australia in developing collaborations across services and sectors more generally for people with dementia was also seen as a positive. In some jurisdictions, younger onset dementia interest groups have been established, including representatives of major clinical and service providers experienced in this field. These groups generally comprise representatives from health, aged care, disability and research sectors. Meetings are held quarterly and are used to share information about current service delivery issues, new initiatives and programs, as well as to problem-solve any cross-agency problems that emerge. While decisions made at the meetings may not necessarily be binding from an organisational perspective, participants are generally committed on the basis of the potential to improve outcomes for people with dementia and their carers.

The concept of collaboration appears to be quite well understood and practice amongst the community care services that participated in the consultations. This mindset, however, did not appear to be replicated within the medical sphere. The acute health and mental health sectors were also cited as potential recipients of interagency collaboration, for example when a person with younger onset dementia may need admission to an inpatient psychiatric ward for management of violent behaviour:

*The key to effective interagency responses for these clients is for the lead service (often the aged care service) to build up effective working relationships with the other key services (e.g. the local hospital and mental health service and psychiatrists and psychogeriatricians). This regular networking is critical to ensure that when a crisis occurs all key agencies are able to respond quickly and appropriately to ensure the best outcome for the person with younger onset dementia and their carer*
SERVICE DELIVERY MODEL

Multi-service approach

BANCPASS is a collaborative partnership across three service providers in Melbourne’s Northern Metropolitan region. It was established to help people with younger onset dementia and their families to navigate the health system and initiate service provision from the point of diagnosis of younger onset dementia through to community support and care.

If approved for a community support package BANCPASS will then allocate case management of the client to ensure that they are supported in their home and local community. In doing this the client commences down a service delivery pathway providing them and their families with a supported model of care. At the same time all relevant staff from each of the three service providers are provided with person specific clinical assessment outcomes and ongoing professional development, establishing a team of staff specialising in Young Onset Dementia.

The three services involved are Baptcare Northern, Northwest Aged Care Assessment Service (ACAS) and the Neuropsychiatry Unit (Royal Melbourne Hospital North West Adult Mental Health).

There appears to be recognition within the medical sector for health professionals to keep each other informed when they have a patient in common, however the service providers involved in the day to day care and support of these same people are often not automatically included in the ‘communication loop’. Furthermore, a number of health professionals and service providers noted that ‘some GPs don’t often know where to refer to’ when faced with a person with younger onset dementia:

There is no coordination of care between the GP, neurologist and (service name) – there is no care pathway.

A number of participants were unclear of the role of Medicare Locals in regards to support for people with younger onset dementia. Others, however, were quite clear of their potential to play a leading role, particularly in the development of referral protocols between General Practitioners and the relevant with local health and service providers:

A pathway model could be established... like with chronic disease

Flexible service options

The need for flexibility in service for people with younger onset dementia was a major theme in the consultations, particularly in regards to hours of operation. For many service providers, the ability to provide services to people when they needed them was core to
providing individualised care; consequently, many provided support and care outside usual business hours, such as evenings and on weekends, to accommodate the different needs of the person with younger onset dementia, their carers and families.

The main challenges associated with providing flexible services in this manner are workforce issues and additional costs associated with after-hours service provision, limited transport options, and inflexible funding guidelines. To support flexible service provision, a flexible workforce is required, including staff prepared to work evenings and weekends. When mixed with the ideal of having continuity of care, it can be difficult for staff to be able to accommodate changing work hours and days, particularly if they themselves have family and/or caring commitments. Delivering services in a flexible manner can also be more costly, due to penalty rates associated with weekend work and the additional costs associated with transport, neither of which can be recouped through higher fees and charges. One church-based provider described how it ‘wears’ these extra costs, without impacting on services provided to its other clients, through drawing on its extensive network of volunteers and using the ‘social capital’ of local connections and networks to link clients into a variety of local activities such as gardening, bowling, sailing and Men’s Sheds.

Transport services such as community transport are not generally available after usual business hours, and usually provided in ‘blocks’ of time. This makes participation in community or family activities outside business hours a costly exercise for the person with younger onset dementia, particularly if reliant on taxis. A number of service providers spoke of their negotiations with local community transport providers, some of which were successful and facilitated tailored services to the particular needs of the person with younger onset dementia. These were mainly in the form of breaking the ‘four-hour blocks’ of transport allocated into four separate one-hour blocks, or a mix of one-hour and half-hour blocks of transport. For one man, this allowed him to attend the local Men’s Shed several times a week, as the transport comprised half-hour blocks driving him to and from the Shed; another man who lived on his own was able to attend a mix of peer group activities per week, including a weekly swimming group and dementia café. Creativity was seen as the key for the use of the allocated transport time. Inflexibility of key components of service provision such as being unable to access transport services for activities on the weekend were seen as frustrating and unnecessary barriers to flexible service provision.

A number of service providers highlighted the importance of flexibility underpinning all service provision for people with younger onset dementia; the need to enable people to ‘come on/off programme as needed’ was critical in responding to the changing nature of the disease over time.
EXISTING PROGRAM EXAMPLE

Every Bloke Needs a Shed

Partners: Alzheimer’s Australia, the Hunter Valley Men’s Shed Cluster and the Australian Men’s Shed Association

This program encouraged and supported men with younger onset dementia, and their male carers, to access and participate in the activities available in their local men’s shed. Education about dementia, ageing and memory loss was an important part of the program. The shed provided the men with younger onset dementia a sense of belonging and they were able to demonstrate that they were useful contributors to a social group.


http://www.youtube.com/watch?v=80dHGWP-p_o&feature=youtu.be

Living with Risk

Related to the need for flexibility is the concept of risk. A number of people with younger onset dementia spoke of the feeling they were ‘wrapped up in cotton wool’ and not allowed to continue to participate in activities or take on new challenges that others thought involved too much risk. This was a cause of some frustration for those with insight into their dementia and wished to be able to make decisions about their daily activities. A number spoke of the ‘disabling’ effect this had on them, when it was clear that what many really wanted was an ‘enabling’ approach to support. A number of service providers supported this analysis, noting the risk aversion of many providers in the aged and community care sector who saw the risk associated with people with younger onset dementia as an ‘excuse’ or ‘barrier’ to accepting clients in the first place, let alone providing a flexible or individually focussed service:

The problem with service delivery is that organisations have become risk averse – looking for problems (what might go wrong) instead of solutions

There was general acknowledgement that there were indeed risks associated with providing support to people with younger onset dementia, particularly in relation to issues of safety. Some of these related to the relatively low levels of training that staff and volunteers (many of who were themselves elderly) had in understanding dementia and in particular managing behaviours that may arise in clients. In a similar vein, there were concerns about the risks associated with mixing frail elderly clients with those who were otherwise fit and strong.

To address these concerns, examples were provided about risk management processes that have been implemented. One service provider applied a very simple risk assessment criteria when assessing the inclusion of people with younger onset dementia in activities such as group outings; that is, there is no risk of aggression to staff or other clients, and only one
staff member is needed to assist at any time. Other providers use risk management plans which have been developed in conjunction with the person with dementia and, where appropriate, their carer and medical practitioner. There was some debate as to the extent to which medical practitioners could make a clinical decision about a person’s capacity to adequately assess their own risks.

However others reported that having a risk management plan has been useful in assisting care staff feel more comfortable about facilitating the involvement of the person with dementia in activities outlined, which would otherwise have been regarded as too risky:

*We need to acknowledge the need for risk assessments when thinking about activities... while (Jeff) can no longer go scuba diving, maybe he can still snorkel and photograph under the jetty.*

**Services that make sense**

The ideal model of service provision for people with younger onset dementia is one that ‘makes sense’ to the person and their immediate situation. One provider described the ‘service model coherency’ that underpins support to clients with younger onset dementia, by asking the question, does it make ‘sense’ in terms of the way service is provided and the activities that are conducted. Based on social role valorisation theory, the approach is not dissimilar to that which many argue should underpin all service models, irrespective of the age or cognitive status of clients. Elements of a service that makes sense were described as being ‘age appropriate’, with activities that are ‘vocational’ and meaningful for people.

**Age appropriate services**

A large number of people spoke of the need for ‘age appropriate’ services that are structured to take into account the different life stage of the person with dementia compared to older people, incorporating consideration of the needs of spouses and immediate families. In the words of one carer, the need for specific younger onset respite services was important:

*so people don’t have to listen to Vera Lynn all day*

A number of examples of innovative ways to provide more age appropriate services were provided. These were often developed because of the initiative of individual providers identifying a need, and seeking to construct a relevant response. Social media was seen as providing huge potential for networking and information; a number of Facebook pages have been established which attract a consistent and growing base of users. This is not the answer for all people, however, as one service provider found when the ‘blog’ it established was hardly used at all, despite promotion in newsletters and links from the host organisation website.

A number of providers noted that ‘the key’ to determining the environment and activities most suitable for people with younger onset was to understand ‘who that person is’, what their individual preferences are, and matching them to people with similar interests. For
group activities this can include ‘letting go of the planning’ and allowing participants to choose what they would like to do; examples include regular gym activities, walking groups, swimming, fishing and playing pool. In an example of thinking outside the ‘aged care square’, one provider facilitated a meeting of its clients with younger onset dementia and a number of people from the local brain injury group, who were of similar age and had similar interests; this group now meets regularly at a local pub as well as organising other social activities around interests in common.

When questioned further, proponents of ‘age appropriate’ services often acknowledged that the defining aspect of the activity or service was not so much about age, but of having shared interests. A number spoke of participating in art related activities, such as painting groups and gallery visits, which included people from a range of ages all of whom were interested in art. The quality of care and attitudes of staff were also described as factors that may take precedence over the ‘age’ of fellow clients, particularly when it came to residential aged care. Several carers acknowledged their initial hesitation about residential care was the age difference between their person with dementia and the much older residents but found that over time the distinction wasn’t really noticeable, ‘as long as I know (they are) looked after with love and care’ – the prevailing sentiment of carers in the consultations; and ‘they’re flexible in letting me still play a role in (my partner’s) life’ – this was raised by a number of participants who had same sex partners with dementia, and by families where children were still living at home. As one carer explained:

*when my wife went in to aged care it was clear as they entered the facility that she was being disconnected from people; however, now she is settled and happy where she is – so does age-appropriate always matter?*

The consultations revealed a small number of residential services had developed strategies to better provide ‘age appropriate’ facilities. These were usually based around the concept of ‘small cottages’, which are non-institutional in appearance and design i.e., staff don’t wear uniforms, décor is modern; and individuals are encouraged to participate in normal day to day activities as much as they are capable e.g.; cooking and gardening. A number also used technology as a way to encourage independence, as well as reduce overheads. These include use of tailored sensor pads in and beside beds that ‘trigger’ an alert if the person’s behaviours fall outside of established parameters.

Only one ‘purpose-built’ facility for people with younger onset dementia was identified nationally; however, we were advised that this service has recently needed to review its service model due to financial constraints. A purpose built facility for homeless people was visited during the consultations, and included a number of the environmental and service elements discussed above. While on the surface this service appeared to be more financially viable due to its ability to access funding from homeless as well as aged care programs, there were additional, un-funded costs associated with managing the often extreme behavioural issues that can arise with this client group. Several others are being explored for development, including one which is being underpinned by philanthropic funding, and another which is currently working through its financial modelling. A number of providers spoke of the complexity of ‘getting the numbers right’, and of additional costs associated with developing and running purpose-built facilities. This was particularly pressing for
established providers that wished to extend its services for younger onset dementia, many of whom were reported to be struggling financially and therefore not in a position to commission new facilities.  

**Meaningful activities**

A number of providers highlighted their approach to providing activities that enabled people with younger onset dementia to continue to feel that they are contributing to maintaining their independence, supporting their families, and participating in society more generally. This means providing opportunities for people to use the skills and abilities they have, for as long as possible. As one provider reasoned, by facilitating the involvement in meaningful activities, people ‘feel useful and valued’; this is particularly important given the experience of so many people with dementia who indicated their sense of identity and purpose had been removed once they were diagnosed with dementia (see Section 4.2.2).

The benefits of participating in such activities is not only personal for the person involved, it can also be beneficial for service providers. Examples were provided of people with younger onset dementia having ‘tasks’ or jobs to do, particularly in mixed aged group care environments, such as greeting visitors, assisting with morning tea, and providing social support to frail older clients. Some carers and providers expressed concern at the potential risks associated with having generally stronger and fitter people helping out, especially if they had significant cognitive impairment and/or behavioural issues. However, those experienced in facilitating this type of engagement found that a reduction in behaviours often resulted, as people experienced a sense of being purpose in attending, rather than just being passive recipients of care.

The social benefits of these activities were, on the whole, very important for the person involved. Similar to the experience of peer support groups, people experienced new friendships as well as a ‘safe’ place they could continue to contribute. The ability to realise these benefits, however, was very dependent on the capacity of others in the group to accept the supporting role they may need to take on for the person with dementia. We were informed of one Men’s Shed that had to ask the person with dementia to leave, as his behaviours were proving difficult for those around him.

Identifying what activities are meaningful to a person involves the service provider getting to know their clients, and developing a relationship to better understand what is likely to provide most sense of value to that person. This, in turn, requires time both at the outset as well as for the ongoing assessment of the person and their situation. Providers also generally need to provide some initial training and support to staff of the host organisation or group members, so they have an understanding of the particular attributes and constraints of the individual working amongst them. The level of engagement with these external groups can be quite intensive in the establishment phase, but once ongoing may require limited

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15 A provider referred us to the Stewart Brown Aged Care Financial Survey that showed profits had reduced by approximately one third for all providers over the previous year.  
investment of the service provider. The service providers we met who initiated these sorts of community engagement activities are all, without exception, committed and dedicated individuals who are willing to extend themselves and advocate on behalf of people with younger onset dementia. Some have had the backing of organisational management from the outset, while others have had to personally commit to establishing relationships and opportunities before their broader organisation ‘came on board with the concept’.

The potential for disability employment services to assist people with younger onset dementia to find meaningful engagement opportunities was discussed at a number of meetings, particularly amongst service providers and policy and program advisers. While a number were supportive of the concept in principle, most were cautious about entering this ‘space’ and none had done so to date. The primary concern raised about the involvement of disability services were the current difficulties between the disability and aged sectors that have become entrenched following the Commonwealth/State split agreed by COAG and the development of the National Disability Insurance Scheme. These issues are discussed further in Section 4.2.7; suffice to say, a number spoke of being ‘stung’ and ‘confused’ by the recent policy changes and preferred to wait until there was greater clarity and ‘things have settled down’ before attempting to explore this issue in a more systematic way.

**Staffing issues**

In the main, most participants spoke highly of individual staff members involved in their day to day support and care. However, people often arrived at this view following a number of negative experiences of service providers that had not provided staff with the requisite skills, training or attitude. This was particularly raised in relation to centre-based respite and residential care, where the organisational limitations were apparent – ‘staff are run off their feet’; it was also apparent in terms of in-home respite, where ‘matching’ the individual staff member to the person for whom they are caring is so important. Carers in particular found this confronting, as they relied heavily on being able to hand over the responsibilities and stresses that were part of their day to day existence into the hands of someone else. Comments such as ‘heart-wrenching’, ‘exasperating’, ‘exhausting’ were used to describe their experiences of trying to find appropriate services.

It was suggested by a number of participants that the reason it was difficult to get ‘good’ staff was that most were from aged care services that were typically task-focussed and ‘focussed on outcomes and numbers’ rather than the individual needs of the person for whom they are caring. Some felt that the reasons behind this difficulty to move to person-centred or individualised approaches to care planning and service delivery included the perception that it was more costly, as well as the concerns regarding risk and ‘duty of care’ that were particularly prominent amongst those with clinical backgrounds.

A number of service providers and health professionals spoke of the organisational culture that is needed to provide ‘good quality care’. This includes placing explicit value on the individual – clients, as well as staff – and having policies and programs that allow staff to be ‘creative’ and responsive to the needs of the individual with dementia, their carer and family. Importantly, this needs to be underpinned by a financial commitment, particularly in the exploratory phases of any new models being considered. These attributes were clearly evident amongst a number of service providers we visited, which had been identified as
‘progressive’ and ‘best practice’ by their peers; staff indicated that they were encouraged and respected by the broader organisational management to explore potential service models which could better cater for people with younger onset dementia.

### SERVICE DELIVERY MODEL

**Proposed multi-purpose model**

One highly experienced service provider shared her ideal service model, which is built on a greenfield site with an organic garden and chickens surrounded by separate small ‘pods’ or cabins, each of which look onto the garden. People with younger onset dementia would be able stay for periods and work in the garden. This would provide them with a meaningful activity which could also become a commercial venture.

Each cabin would have a view of the garden providing people with younger onset dementia an opportunity to either view or participate in a meaningful communal activity. The site could eventually include a café/restaurant utilising home-grown produce, or crops could be sold at local ‘farmer’s markets’.

The site would not be a permanent residence, rather she likened it to a ‘resting place’ where people could come, engage and work within the community for a period of time as well as access holistic care and support for the person and their family.

This model is based upon the Aldinga Arts EcoVillage in South Australia which is a sustainable housing development and intentional community based around the principles of permaculture, with a focus on arts and the environment. [http://www.aaev.net/about/index.html](http://www.aaev.net/about/index.html)

A basic principle of providing quality care is that the staff have the appropriate skills and attributes. Staff ‘need to understand the basics’ about younger onset dementia, and the ‘individual characteristics of the disease for each person’ including their carer and family environment. This is important for direct care staff and volunteers, as well as those groups and professions with whom people with dementia interact, such as health professionals (and students), particularly Aged Care Assessment Teams, ambulance personnel and General Practice staff:

*All levels of workers involved in service provision for people with younger onset dementia require appropriate training, including service provider managers*
INDIVIDUALISED SERVICE EXAMPLE – COMMUNITY

Care planning

Jason is an Aboriginal and Torres Strait Islander man who has alcohol related brain damage and is an untreated epileptic. Upon his arrest in the Northern Territory he was considered by the magistrate as ‘unfit to plead’ and as a result kept in prison. A local aged care, health and disability service provider collaborated with Jason and his family to put a proposal to the court to introduce a community based care plan for him. This proposal was accepted by the court and as a result Jason was released from prison. With this package of care from disability services, the service co-ordination, appropriate medication for epilepsy and abstinence from alcohol Jason is now able to live back in his community.

Other training needs identified included training for direct care workers regarding some of the more sensitive aspects of caring for a person with dementia such as relationships and sexuality.

One health professional pointed to the requirements for registered health personnel to demonstrate continuing professional development, and posited that this is a positive step to ensuring ‘ongoing education is embedded into practice’. However, a number of participants also spoke of the barriers that staff face in accessing training, including staff shortages, no ‘time off’ to participate in training; this was particularly an issue for health professionals working supporting large geographic areas:

There is a high turnover of staff in remote communities ... it can be as frequent as 3 – 6 months due to demanding nature of work and regular, large amount of time away from home

The lack of appropriately skilled staff in remote areas often means that other professional groups require up-skilling to ensure the needs of people with younger onset dementia are met:

Our challenge is meeting needs of individuals in remote communities by up skilling other workers such as disability service staff. .... Our DBMAS (Dementia Behaviour Management Advisory Service) spends much of (its) time constantly training up new staff to ensure staff working with younger onset dementia clients are adequately skilled.

Skills transfer is hard. One service provider for disability services may develop skills in managing an individual client with dementia through working with DBMAS; however this knowledge will not translate across to other disability services such as State funded services due to very specific divisions within disability services.
A number of strategies have been developed to assist staff working in related sectors to receive training in dementia. One example was the invitation to staff working in the newly established Medicare Local to a ‘get to know you’ barbeque lunch by the local lead service provider, at which they also provided some initial information and training, and confirmed ongoing educational opportunities. Several service providers spoke of the need to embed training on younger onset dementia as compulsory subjects of the Certificate III and IV training undertaken by most care staff. However, as one seasoned service provider lamented, there is no real ‘quality control’ of training being provided by Registered Training Authorities, and so the educational base of staff in aged care can be quite variable.

One health professional noted that the recruitment and retention of staff to support people with younger onset dementia was hampered by some fundamental problems:

*There is a need for improved pay for pay care workers, chronic problems with recruitment of staff in remote areas, and the need for more male workers to work the high numbers of men with younger onset dementia*

### 4.2.7 Impacts on policy and legislation

The consultations identified a number of policy and legislative implications for the support of people with younger onset dementia and their carers. Overwhelmingly, and perhaps not surprisingly, participants spoke of the barriers to providing enabling, integrated and individually tailored supports and services. Some of these have been referred to in previous discussions (Sections 4.2.6 – 4.2.7). This section clarifies the issues in more detail, and identifies suggestions made from participants to enhance the policy and legislative framework that encompasses the ‘circles of younger onset dementia’.

**People with younger onset dementia**

People with younger onset dementia indicated the need for clarification and amendment of a number of policy and legislative domains to enable them to continue to live as independently as possible, for as long as they are able. The key to independence for many is to be able to continue to contribute financially and meaningfully to their immediate family and broader community, and to continue to live a life that is as normalised as possible; these options are automatically closed to most people immediately upon confirmation of a diagnosis of dementia. Suggestions included the need to address Work Health and Safety Legislation and Superannuation guidelines that currently preclude people from continuing in paid employment, albeit in reduced roles. The implications of automatic cancellation of a driving licence were raised by a number of people with dementia, increasing the risk of social isolation, depression and dependence on informal and formal services. There are clear opportunities for greater consideration to be given to the particular cognitive deficits that are more likely to impair driving ability, and for greater clarity and consistency in licencing regulations amongst jurisdictions.
Employment and financial considerations

Workplace related matters were seen as particularly relevant to people affected by younger onset dementia as many are still working at the time of diagnosis. The personal and financial impacts of ceasing work are discussed elsewhere in this report. In addition to those matters the issue of workplace response and relevant legislation was raised during consultations.
A number of factors were identified as contributing to the current practice of most people ceasing work when diagnosed with dementia. As noted in earlier sections of this report (Section 4.2.1 - 4.2.6), there is a general lack of understanding about younger onset dementia amongst families, the community, and members of the health profession.
Participants specifically cited current Work Health and Safety regulations, which currently enable the accommodation of people with a disability or medical condition to continue working but are not applied to people with younger onset dementia. As one person with younger onset dementia commented:

If you are a stroke patient you get rehabilitation and can return to work -what’s the difference?

Representatives of a peak body also discussed this point, stating that:

Workplace legislation has a focus on ‘reasonable adjustment’ to workplace, but this isn’t offered to people with younger onset dementia

In a similar vein, the rules regarding access to superannuation were also cited for attention. One woman with younger onset dementia who had retired when she was diagnosed stated that she still had the capacity to continue to do some work ‘at reduced levels…but was not allowed’; she had accessed her superannuation upon retirement following diagnosis, as she was classified as having a ‘permanent disability’. She and her carer believed that was the appropriate course of action at the time, and she indicated that since she had ‘gone down the path of accepting’ her superannuation payout, she is not legally able to return to the workforce.

A number of people spoke positively about their ability to access superannuation and insurance payments as a result of their diagnosis. Examples include self-employed men with income insurance, which provided ‘seventy five percent of a full-time wage for 2 years’;
Coupled with superannuation, several couples spoke of their ability to pay off the house, or significantly reduce their mortgage in order to adjust to the changed financial future.
There was general agreement within these discussions of the importance of:

Clear information is required from superannuation funds, for example about how/when super can be accessed and the impact this will have on the person and their family.

Additionally, a number of people spoke of the need for clearer information from Centrelink about benefits and entitlements.
Driving and dementia

Issues relevant to the impact of a diagnosis of dementia on driving and related legislative and policy matters, such as the timing of subsequent loss of licence, featured prominently within the consultations. Regulations regarding dementia and driving differ between jurisdictions, and some service providers and health professionals noted that there was often a degree of uncertainty about the relevant requirements. Some advised that there was no policy of automatic cancellation of licence upon diagnosis, but rather people were required to undergo regular testing as a condition of their licence; in these circumstances people either decided for themselves when to cease driving, or were compelled to upon failing this test. Other jurisdictions had very clear policies regarding mandatory reporting, with health professionals being required to notify the relevant driving authority upon a person’s diagnosis of dementia.

Accessing suitable driving assessment processes for people with younger onset dementia is a key issue. In some parts of the country there are simply no publicly funded specialist assessment services; in some cases, occupational therapists or neuropsychologists were available, but are unlikely to have access to the relevant equipment, such as a driver modified vehicle. Participants spoke of having to travel long distances, and even interstate, for assessment.

The alternative for many is to access a private assessment service, which can cost up to $1,200; this additional expense comes at a time when families are already facing financial impacts associated with dementia and therefore may be regarded as too prohibitive, given the uncertainty of the outcome. Several health professionals also spoke of the difficulty some couples and families had in coming to terms with the diagnosis of younger onset dementia:

They also don’t want to be told the person with younger onset dementia can’t drive anymore so this is another reason for not paying for the test.

Related to the issue of driver testing is the lack of objective basis on which to make decisions around whether a person could or should continue to drive. In many cases, the relevant medical practitioner is the person who suggests, or decides, that driving cease:

The issue of driving has become a medical value judgment.

A number of service providers spoke of the importance of having some discretion around when a licence was to be revoked, rather than having a blanket rule for all:

...need some grey area about driving after diagnosis – diagnosis takes away all power.

To provide guidance for those involved in making judgements about dementia and driving, one health professional suggested that jurisdictions work together to develop a national framework that ensured consistency and evidence based approach to assessment:
The policy could contain statements such as: ‘a person with younger onset dementia cannot continue to drive if they have had a car accident’ or another determined point when driving is no longer safe.

This suggestion was extended to include guidelines to support medical health professionals in providing advice and management concerning high-risk sporting and occupational activities.

Carers and families

The policy and legislative barriers for carers and families were mainly around issues of funding and delivery of appropriate support services, in particular respite and counselling. Most carers utilise services funded under the HACC program or National Respite for Carers program, or respite available as part of the Home Care Package being provided to the person for whom they are caring. Whilst there is clear appreciation of the services being available, the lack of coherence in delivery and consistency in terms of access and quality were cited as major concerns during the consultations (discussed in Section 4.2.2). The provision of counselling services was cited as being critical for carers and families but access to appropriately skilled personnel was limited, and costly.

Under Commonwealth funding arrangements, despite the COAG age related split, it appears that services funded by the Commonwealth as part of the Commonwealth National Respite for Carers Program, as they target the carer, do not currently have age restrictions on eligibility for funding.

Respite services

The chief concern for carers is the lack of appropriate respite services that can provide quality care and meaningful activities for the person with dementia, and delivered in a flexible format and of sufficient amount to fully meet the needs of carers and families. A number of carers spoke of having to ‘cobble together’ respite services, sometimes involving a mix of subsidised and privately secured services. It is clear that the current quantum of respite that is currently provided for in the main funding programs is not sufficient to meet the needs of those carers who wish to continue in paid employment and participate in social and family activities.

Accessing respite through different funding programs impacts on the coherence and consistency of service provided. Service providers spoke of ‘having to juggle’ and manoeuvre around program guidelines, particularly for carers requiring extended breaks such as hospital stays and attending family functions interstate, or when carers are facing the emotional upheaval that often results from transitioning of the person with dementia into residential care. Carers also spoke of the additional costs associated with the respite provided under different programs and through different providers:
The more respite I get, the more I have to pay. Don’t get me wrong, I’m really thankful for it being subsidised, but it’s the extra you have to pay, for every extra service …. that adds up, and sometimes I wonder how I’m going to afford it in the future, when he’ll (husband) needs more services.

Some carers expressed the fact that they were saving government lots of money by providing ongoing care in the home for people with younger onset dementia and wanted this to be acknowledged. This request was contrasted with other carers who stated that they were reluctant to use services such as respite as they felt guilty. But they recognised the need for balance in their life and suggested encouraging carers to access respite was an important ‘preventative approach’ to supporting carers.

Packages of care and support

The fragmented nature of the health and care services available to support carers of people with younger onset dementia can be difficult to navigate. Many participants spoke of the need for assistance in identifying, accessing and maintaining the support they need, from the time of diagnosis and onwards as the needs increase along the dementia ‘journey’. The Key Workers that have been employed by Alzheimer’s Australia were roundly considered a welcome addition to the suite of services available, particularly in regard to their ability to work across care and health groups, and coordinate service delivery. The role of the Key Worker is still in the establishment phase, and therefore relatively few individuals or carers that participated in the consultations had direct experience of the care coordination that is likely to be provided. Despite this, a number were quite concerned that the Key Worker Program is only funded for three years at this point in time, and strongly advocated for more certainty about their continuation.

Aligned with this, was the uncertainty amongst service providers about the possibility of the Key Worker Program to be transitioned into the National Disability Insurance Scheme NDIS). A number of concerns were raised, primarily due to the under-developed implementation of the NDIS and the national variability in its priorities and distribution, and the expertise within the NDIS around younger onset dementia that can provide a holistic assessment of care and support needs of the person with dementia, as well as their support network of carer and family.

Counselling and psychosocial support

A number of those consulted raised issues around funding for services provided to people with younger onset dementia and their families (see Sections 4.2.2 - 4.2.3). The major issue from a policy and legislative perspective is the funding mechanism that underpins these important services. While some counselling and support is currently available through the National Dementia Support Program run by Alzheimer’s Australia and the National Carer Counselling Program run by Carers Australia, this tends to be of a more basic nature. A number of participants raised the need for longer term and in-depth relationship and family counselling; this was particularly indicated amongst those people with dementia who had children with mental health concerns. These situations often require more sophisticated skills which are not always readily accessible in terms of location and cost. One health
professional spoke of utilising the outpatient services of the local hospital, which would mean services would be paid for through Medicare, but the waiting lists meant that these were not feasible for relationships in crisis. Furthermore, the complicating funding arrangements for allied health and outpatient services which were embedded into State-run hospitals compromised the delivery of service:

_In the past [we] used to bill Medicare, but the money went into the State Government coffers and never seemed to come back to the service._

**Service providers**

The policy and legislative issues that are currently impacting on service providers are predominantly around funding for programs, the implementation of major policy reforms in health, disability and ageing sectors and how this is being played out in inter-sectoral and inter-jurisdictional relationships.

**Program funding**

Under this broad topic, the main themes emerging were in relation to the issues relate to the amount of funding currently available, and the ways in which priorities are determined and funding is allocated. Not surprisingly, there was general consensus amongst all stakeholder groups of the need for additional funding for suitable services. However, each group had a slightly different emphasis in what it regarded as priorities for funding, and in terms of the way the funding is allocated.

Several health professionals and service providers spoke of the short-term nature of policy initiatives, which is driven by the electoral cycle. A number opined that ‘governments today’ are only interested in ‘short term dividends’ and don’t wish to engage with ‘long term projects which might straddle a change of government’. This, in turn, has implications for service planning, as well as the way jurisdictions work together.

The way in which funding is provided, and the rules that prescribe the nature of the service and the way it is delivered, were highlighted as factors that inhibit service development for people with younger onset dementia. As discussed throughout this report, the consistent themes regarding service provision include a more holistic and integrated approach to supporting the person with younger onset dementia, as well as their carer and immediate family, in order to maintain them within the community for as long as possible. A number of health professionals and service providers noted the ‘perverse disincentive’ that underpins aged care funding. For example in residential aged care the amount of funding provided for resident is determined by their level of deficit, and the greater the deficit, the greater the need and the greater funding; in contrast funding for restorative, enabling and well-ness programs is ‘miniscule’.

In addition, the programs that are available for people with younger onset dementia, carers and families have rigid guidelines that do not allow for flexibility that is often required in meeting the often complex needs of this unit:
The current approach to funding is focused on outputs, for example the number of hours per week respite. However, this group require a more comprehensive service that can spend time with them and their families identify what is needed and facilitate access .... block funding for this sort of thing, not iterative the way it is now.

Most acknowledged the important role that packaged care and care coordination services play in achieving this goal, however, these types of services continue to be constrained by the access criteria, limited availability across geographic and cultural communities, and the continued focus on outputs. A number of program and policy advisers spoke of the potential for funding agreements to reflect the need for flexibility to meet the needs of this target group; one added that these agreements:

should include essential action for service providers such as making dementia awareness training a core unit of training for both residential and community based service providers.

This flexibility was considered particularly important in areas of geographic isolation or amongst groups of cultural and linguistic diversity, where there may not be a ‘critical mass’ to make a younger onset dementia service viable. This would facilitate partnerships between services, as well as with community resources such as local clubs and facilities. An example of where this appears to be working well is an indigenous art centre in a rural community where a person with younger onset dementia participates in painting activities, similar to ‘art therapy’ that is a feature of many mainstream day centres. This allows the person to be involved in culturally appropriate and meaningful activity, and the community benefits from the income that results from the sale of the art. According to the service provider who made us aware of this scenario, if the art centre was eligible to receive funding through a disability or health activity program it could extend its reach and provide training to staff and volunteers, which in turn could result in greater respite opportunities for the person’s family. Fundamentally, the service model is one of community capacity building, as opposed to the traditional ‘medical’ or ‘top down’ approach to ‘providing services to’ people.

Using community capacity as the paradigm for supporting people with younger onset dementia resonates with many of our stakeholder groups, particularly because of the result can be a very ‘low cost’ and very effective solution to maintaining the dignity and productivity of people with younger onset dementia, while at the same time providing valuable respite for their carer. The ability to develop these types of initiatives is limited by inflexible program guidelines as well as the time-limited nature that usually accompanies funding for ‘innovative’ service models. A number of service providers expressed their keen interest in community capacity building activities, but were reluctant to pursue these concepts based on their experience of running pilot programs previously; they spoke of the difficulties in attracting suitably qualified staff when ongoing funding could not be guaranteed; the reporting requirements for such initiatives were generally more onerous than for routine programs; and build-up in client expectations about ongoing service provision that could not be realised. The current uncertainties about service provision arising
from the NDIS and the aged care/disability split under the National Health Agreement (discussed below), reported to be further compounding the reticence to develop innovative service models.

The Younger Onset Dementia Key Worker Program, while generally seen as a welcome addition to the suite of services, was highlighted as an example of a program that may create expectations that can’t be guaranteed to be fulfilled:

*People need assurance that Alzheimer’s Australia funding continues – sustainability of programs is crucial. We need commitment from the Government.*

There was general uncertainty amongst key stakeholder groups regarding the future of the Program once the initial three-year funding period was over; possibilities ranged from the program being ‘moved’ under the realm of the NDIS, to its continuation under Alzheimer’s Australia or open to competitive tender across the sector more generally. Concerns were also raised about how the program is currently structured, in terms of the location of key workers within Alzheimer’s Australia which means they are ‘separated’ from the existing service system, rather than being ‘embedded’ into the existing care services, ‘so it will be difficult to work together’. Other issues raised included the potential duplication with existing services such as Community Options and the NSW Dementia Advisory Service pilot sites, as well as the risk that Key Workers may put ‘pressure on services to take on or increase provision for people with younger onset dementia, which may not be fair for other client of that service’. As one experienced service provider cautioned:

*pilots like this ... are new and full of energy and enthusiasm .... (while this is) a good thing .... can often tread on other people’s toes .... (It) takes time to build relationships and trust between services.*

**Aged care / disability split**

The division of responsibilities for aged care and disability services under the National Health Agreement has caused a number of difficulties for service providers involved in supporting people with younger onset dementia. The changes have introduced an artificial barrier of age 65 years (or 50 for Aboriginal and Torres Strait Islander) for people accessing aged care services and effectively limits the ability of services providers to deliver integrated and continuity of care and for people to access appropriate services in a timely manner. Concerns were also raised about the skills and capacity of the different sectors to support people with younger onset dementia, particularly in light of the roll-out of the NDIS, with only one jurisdiction appearing to have actively planned for the changes ahead. Furthermore, the changes appear to have limited the opportunities for innovative models of care and support to emerge, with the ‘dividing line’ already straining some inter-jurisdictional relationships.

A number of stakeholder groups spoke of the difficulties encountered following the National Health Agreement, with the age of 65 years being used as a defining point at which ‘responsibility’ for a person with younger onset dementia shifts from State and Territory Government responsibility to Commonwealth. In some jurisdictions, the age threshold is
being strictly interpreted and people are regarded as being either ‘in’ one sector or the other, but ‘you can’t be receiving services from both’:

*Living Longer Living Better reforms (mean that) clients cannot access ACAT and disability services at the same time…Disability sector is ‘actively ignoring referrals’ – can take up to 12 months for a referral to be considered and ‘rejected’ by Disability Services; only after this ‘rejection’ can they apply for ACAT assessment. Aged care system does not help either – you can access home care (low level, HACC type services) but not packaged care, which is what is really needed for this client group this requires ACAT assessment...*

A number of policy and program advisers and service providers raised concerns about the perceived age threshold of 50 years for Aboriginal and Torres Strait Islanders in relation to access to aged care services. Despite being advised that the age threshold was initially designed for service planning (not access) purposes and the absence of any age threshold within the National Health Reform Agreement, this misperception underpinned much of the commentary received about access to dementia services funded under aged care programs. There was general agreement that the higher incidence of dementia within Aboriginal communities demands that these misperceptions be addressed, so no person is denied access to dementia services on the basis of age. The concern is evidenced in the following quote from a state-based health bureaucrat:

*If the Commonwealth aged care services consider 50 to be the age of access for Aboriginal and Torres Strait Islander people then that implies that disability services will not accept an Aboriginal and Torres Strait Islander person over 50 years.*

The tension between the sectors is particularly evident in regard to accessing ACAT services, where the inflexibility and inconsistency of the application of policy guidelines is most acute. Service providers in a number of jurisdictions expressed frustration and exasperation with the current ACAT policies and processes, ranging from ‘there are problems’ and ‘ACAT was reluctant to assess him due to his age’ to more strident comments that ‘the ACAT assessment system is horrible’ and ‘it is not possible to get people with younger onset dementia into [Commonwealth funded] residential aged care facilities’. When prompted further, the vast majority of participants were unaware that the legislation covering the ACAT and aged care services more generally do not include an explicit age ‘cut off’ point.

**Expertise**

The availability of appropriately skilled staff was identified as a core issue for service providers, as well as care recipients. It was acknowledged that the disability sector was more likely to have a more ‘enabling’ approach to support for people with acquired disabilities who were at similar life stages as people with younger onset dementia; however it did not have the specialist expertise that has been developed within the aged care sector.
A number spoke of the different ‘operating paradigms’ between the different sectors, noting that the preventative health services within the health sector is another skill set or ‘culture’ that needs to be part of service provision for people with dementia. Concerns were raised about the continued involvement of health services in providing hospital based day centres and specialist advice and expertise to aged care services. We were advised of one Health Department that had recently ceased its training programs (Aboriginal Primary Health care, and Aboriginal HACC):

*(the) focus ... is now about providing direct health services, not community development or health promotion things they used to do with Aboriginal and Torres Strait Islander communities*

Similarly, concerns were raised about the absence of evidence based approaches to care and support and health systems pathways, and the limited access to clinical services that may be required to support a person with dementia. With jurisdictional borderlines being drawn increasingly hard and firm, a number of participants were very concerned about the opportunities for the ageing and disability sectors to share resources and learn from each other for the benefit of people with younger onset dementia:

*now there is a cut-off point of 65 years for where funding and responsibility lies between Commonwealth and State funded aged care and disability services, it is even more critical that the national policy context for younger onset dementia enables effective interagency service responses*

**National Disability Insurance Scheme (NDIS)**

Throughout the consultations, there were mixed messages about the potential impact of the NDIS for people with younger onset dementia. A number of carers and people with dementia were positive about the concept in principle, as they anticipated it would allow them to have greater access to coordinated care and support. However, when prompted, most admitted their opinion was generally made on the basis of limited information they had read about the scheme. Other stakeholder groups were more wary, given its infancy and variability of implementation (in terms of locations and priority groups targeted) to date, and the number of ‘unknowns’ about how it will work in the future.

Concerns primarily related to the expertise of the assessors and disability service co-ordinators that will be assisting people in their care planning. The familiar refrain ‘they don’t know what they don’t know’ was used, particularly in regard to the clinical care needs and co-morbidities that may be associated with dementia. There was uncertainty amongst providers as to whether people with younger onset dementia was a ‘priority group’ under the NDIS as it would operate in the future, with one jurisdiction pointing out that its priority group was children and therefore it could take some time before people with dementia would be able to access the NDIS. Others noted the progressive degenerative nature of dementia, and the impact of being forced to ‘wait in line’ to access services under NDIS when they need the services ‘now’. This was compared to a person with a diagnosis of terminal cancer who the service provider understood was able to receive assistance without waiting.
A number of concerns were raised about the funding arrangements under NDIS. As funding is ‘attached’ to the assessed needs of the disability client, it is unclear how carers and families will fit into this mix, in terms of assessors understanding of their pivotal role in supporting the person to continue living in the community and the funding for their own support needs. The NDIS fees policy was raised by a number of service providers, particularly in terms of its implications for service provision; i.e., whether the total cost of service will be covered or clients will need to pay contribution; and, whether there is an expectation that NDIS recipients will be prioritised over other clients seeking to access their services.

**Jurisdictional program boundaries**

A number of challenges have arisen for cross-jurisdictional relationships as a result of the major disability, health and aged care policy reforms of recent times. As noted above, the rigidity of the application of the age threshold defining access to disability and aged care services has posed a number of problems, delays and frustrations for program and policy advisers, service providers, people with younger onset dementia as well as carers. There appears to be a reluctance to engage in interagency collaboration that can be so vital to ensuring a coherent and comprehensive service is provided to support the person with dementia within the community. The concern expressed by a range of those participating in consultations was that less than optimal care may result from a lack of co-ordination and integration between government agencies:

*Government agencies cannot work hand in hand – they can share data, but they do not know what is happening (on the ground)*

The impacts are most keenly felt by those people who are at risk, such as those with complex co-morbidities, are homeless or in crisis. Examples were provided of aged care staff attending the hospital with a person experiencing a psychotic episode with the view of working alongside the hospital staff regarding behaviour management options. Others spoke of palliative care, allied and rehabilitation services that may be available within the health system, but not readily provided to aged care clients in the community who are placed on the waiting list as per usual practice; while some aged care services have developed specialists in these fields within their residential services, their capacity to deliver that support in the community can be hampered by concerns about risk and liability.

People who are homeless and have younger onset dementia were highlighted as an example of client group that is desperate for cross-agency collaboration, but due to financial and regulatory constraints are not able to receive appropriate support. These individuals often are reluctant to use ‘formal’ services such as hospitals, and may require a mix of primary care and mental health as well as aged care services; the ideal service attributes include bringing the service to them, at a convenient location and staffed by personnel with the requisite skills, knowledge and, importantly, attitude. The providers we spoke with that aimed to assist homeless people with dementia spoke of the numerous barriers that were placed before them in implementing this coordinated and integrated service model.
Similarly, service providers identified other groups of people with dual diagnoses of dementia and disability or mental illness as being at high risk of ‘falling through the gaps’. Access to mental health crisis teams is problematic, due to people with a diagnosis being deemed ‘ineligible’ for support under state mental health funding guidelines. As one seasoned health professional noted:

these people face the prospect of an ED, RACF, or mental health unit revolving door

Specific jurisdictional responses

Despite the difficulties described above, a number of jurisdictions are actively pursuing strategies to better meet the needs of people with younger onset dementia.

The NSW Government has invested in a major research projects, consultations and provided $1,000,000 for a three year pilot program that provides care coordination for people with younger onset dementia; importantly, carers are eligible for funding in their own right under this program.\(^1\)

In South Australia, we were advised of a pilot project that is expected to be delivered through a state-wide autism service. The rationale for its association with autism services is the high incidence of autism amongst indigenous children that appears to be related to foetal alcohol syndrome, which in turn is usually indicative of alcohol abuse amongst adults within that family and/or community; it is expected that the autism networks will provide the dementia worker with better access to those extended family members of the child with autism who may be experiencing symptoms associated with dementia.

Additional policy issues

- Centrelink

Concerns and frustrations were expressed with difficulties accessing income support payments through Centrelink. Variation across the country in responses of Centrelink staff to people with younger onset dementia and their carers was significant. A number of service providers identified the Centrelink Social Work services as a possible ‘accessible entry point’ into the Centrelink system for people with younger onset dementia; there were others within the consultations who had never heard that such a role exists within Centrelink. The issue of assessment of financial hardship was raised by a number of service providers, and the importance for Centrelink staff to understand that this may be the experience of people with younger onset dementia and their carers, due to their unique circumstances, despite what may appear to be a healthy financial situation ‘on paper’. Suggestions from service providers included the need for a cross-portfolio policy response, including delivery of training for Centrelink staff regarding how to identify and work effectively with people with younger onset dementia.

\(^1\) https://www.adhc.nsw.gov.au/__data/assets/file/0005/263264/Younger_onset_dementia_program_-_program_guidelines.pdf
- Police checks
  Aged care providers are required to conduct police checks on all staff or applicants, and cannot employ people with a police record as service workers. This was a source of some tension in remote communities, where a past community dispute may have resulted in a person having a criminal record, was roundly supported but problems were identified for services in remote communities. It was suggested that some leniency be applied to such circumstances, as the nature of the offence did not necessarily relate to their potential to provide care for people with dementia.

- Guardianship
  A number of service providers spoke of the difficulties associated with obtaining a Guardianship Order for a person with younger onset dementia. The process was regarded as too complex and often required health or support workers to spend many (unfunded) hours to support a person through the process.
4.3 ONLINE SURVEY

4.3.1 METHODS

Overview

The survey was administered both online and in the more traditional paper format. We recognised that many consumers may not have had access to a Key Worker or a community care provider and would not have the opportunity to participate in a focus group. Therefore, we also used the Key Workers to email a link to the on-line survey to be completed by their clients. Where a client did not have access to the internet the Key Worker posted out the survey to their client to be completed. A pre-paid reply envelope was included for return postage to CHSD. Again, to capture information from rural and remote areas we also used selected community care providers to email or post the survey.

Methods

The survey was originally designed using SurveyMonkey® and then adapted to hard copy for the paper surveys. The survey was piloted with key individuals to gain feedback on the design and useability of the survey. The initial survey was sent to a project officer with a research speciality in younger onset dementia and a statistician. Extensive feedback was gained from these sources and significant changes were made to the survey. After these changes were made the survey was then sent to an Aged Care Assessment Team (ACAT) representative in Cairns for further feedback on the reworked survey. The survey took approximately 15-20 minutes to complete. Appendix 4 includes a copy of the survey for people with younger onset dementia and a survey for carers of people with younger onset dementia.

Feedback from members of the AA Dementia Advisory Committee suggested that for many people with younger onset dementia, social media plays an important source of information and networking. Therefore, the survey was also hosted by a well-known Australian Younger Onset Dementia Facebook® site that supports people with younger onset dementia:

https://www.facebook.com/YoungOnsetDementiaSupportGroup?fref=ts

Paper surveys were also handed out during site visits or were posted out as requested. During the consultation process research team members left paper surveys with Key Workers to distribute to their clients or were handed to those requesting a paper copy of the survey at focus groups. In addition surveys were posted to relevant aged care organisations, community care providers and people with younger onset dementia and their carers who requested paper copies of the survey during the consultation process. A total of 64 paper surveys were distributed to participants who were not able to access the online survey. Written consent was obtained from respondents to the paper survey and consent was indicated by choosing the consent option at the beginning of the on-line survey.

Surveys were distributed via hard copy and collected on-line from 11 November 2013 to 10 January 2014. SurveyMonkey® was used to collect and store survey responses during the survey period. Paper copy surveys returned to the CHSD were manually entered into
SurveyMonkey®. At the completion of the survey period all surveys were downloaded into Microsoft Excel for analysis. Data analysis involved the use of descriptive statistics such as frequencies and qualitative analysis of open-ended responses.

4.3.2 RESULTS

This section summarises the results of the survey for both people with younger onset dementia and their carer/family members. Detailed results can be found in Appendix 6.

Results

Responses to the survey were lower than expected. Of the 97 survey responses only six people with younger onset dementia and 23 carers completed the survey in full. Response numbers may have been higher, however it appeared that a number of respondents who started the survey did not progress past the first page and were excluded. It is not clear if this was because they were not able to adequately navigate the on-line questionnaire or whether, due to the nature of their disease, they were not able to complete the questionnaire. Brown et al (2012) also found that questionnaire respondents with younger onset dementia had difficulty in completing a questionnaire and unfortunately had to be excluded.

Findings

People with younger onset dementia were asked 3 questions relating to their experiences of living with younger onset dementia.

What do you think can be done to assist you to remain living and participating in your own home and/or community?

Of the five responses to this question, four respondents indicated that their carer needed respite. Two respondents also noted the need for better transport options. Day time activities were also noted, including age appropriate activities, awareness raising and education, for carers and service providers, including Centrelink. Other assistance mentioned included social interaction, timely access to a geriatrician, assisted employment and volunteering options, dementia friendly communities and higher disability and carer’s pensions.

What would you like to continue to do if you were provided with the right opportunity and/or support?

Six people with younger onset dementia responded to this question and individuals provided a range of activities that they would like to be involved in with the right support. All respondents identified either working in paid employment or volunteering as important to them. Being involved in social and family activities was also considered important.

What could assist you to become more involved in the activities identified in the previous question (e.g. working, volunteering, family activities, social activities, etc.)?

Four of the six respondents identified personal assistance as important in helping them participate in the activities mentioned in the previous question. Tips to support daily functioning, legislation and counselling were also identified by half of the respondents to this question. Information about dementia was considered least important by people with younger onset dementia.

Five questions relating to service delivery were asked of both people with younger onset dementia and their carer/family members.

What services are received by your carer / family member OR What services does the person with younger onset dementia currently receive?

It appears that the service most received by both carer/family members and people with younger onset dementia was support or educational groups. Carer/family members also indicated that people with younger onset dementia mostly received leisure and activity/therapy based services, respite and information about services.

If you are currently receiving any of the following services please indicate whether or not they are ‘getting it right’ for you.

Both people with younger onset dementia and their carer/family members were asked to select from a list, services that were ‘getting it right’ for them. People with younger onset dementia mostly identified that the services they received were not getting it right. The services that most attracted a negative response by people with younger onset dementia were information about services, one to one social support, residential respite and leisure and activity/therapy based services. The service with the fewest negative and the most positive reviews combined was home modification and equipment.

Overall, carer/family members were more positive about the services that they received than the people with younger onset dementia, however they were still slightly more likely to indicate that services were not getting it right for them. Information about services, support or educational groups and case management and assistance with planning were those options that carers indicated most as getting it right. Those services most indicated as not getting it right were personal care or domestic assistance and one to one respite.

Of the services that are ‘getting it right’, what do you like about these services?

People with younger onset dementia identified that services offering emotional support, a stimulating and inclusive environment and friendship/companionship were more likely to get it ‘right’.

Carer/family members indicated that they liked the activities provided to people with younger onset dementia as this provided them with some much needed respite. They also
recognised the support offered from local carer groups. They particularly enjoyed the opportunity to debrief and talk with people in a similar situation as themselves.

Some carer/family members noted that the service support staff they had come into contact with often had genuine concern and went out of their way to help people, to be friendly and approachable and provide individual help such as guiding people to the services they needed.

**What are the main ways you have been linked to services?**

People with younger onset dementia were most likely to have found out about services by themselves. They were also linked to services via a referral from a health/diagnostic practitioner or by Alzheimer’s Australia. Carer/family members were most likely to be referred to services by Alzheimer’s Australia, although many found out about services by themselves.

**What sort of assistance would you like to receive in the future?**

Only four people with younger onset dementia indicated what sort of assistance they would like in the future. All of them wanted care services in the future. They also indicated that financial and legal services and family/carer involvement were also important services for the future. Two respondents indicated there were other types of services they wanted in the future including support and companionship during respite and social interaction.

An overwhelming majority of carers also wanted care services in the future. Over half of them also wanted financial and legal and family/carer involvement in the future. Other services carers would like to receive in the future included more physiotherapy in nursing homes, activity based social interaction with other people with younger onset dementia, a case worker to help with paperwork, banking and Centrelink, psychological support for carers and respite in an appropriate setting (not residential aged care).

Finally, both people with younger onset dementia and carer/family members were asked:

**Do you have anything else to add?**

Only two people with younger onset dementia took the opportunity to provide an additional response. One responded stated that people with younger onset dementia and their carers were not getting the help that they needed. After being told about what they could receive the respondent felt that it was ‘unfair’ that they had in fact received little help at all. There was also a stoic sense that they would ‘soldier on’ regardless.

The other person commented on their specific needs, particularly relating to the future and the lack of support/facilities available for people with younger onset dementia.

Seven carers/family members provided additional information. Overall, they expressed a range of needs for themselves and the person they care for as well as problems associated
with a number of gaps in the system. It was important for them to have individual assistance in navigating the ‘system’, including help with finding services, budgeting and financial help. Carers also noted that the provision of age appropriate and disease specific services were lacking. Other needs expressed by carers included the need for training of staff that work with or provide services for people with younger onset dementia and their carers.

**Discussion**

Due to the small numbers of respondents to this survey caution should be used when making comparisons or drawing conclusions about the service needs for people with younger onset dementia and their carer/family members. There are some interesting comparisons between carers and people with younger onset dementia within the survey. For example, this group of carer/family members mostly felt that information about services was ‘getting it right’ but people with younger onset dementia did not. On the other hand carer/family members and people with younger onset dementia and carers both had a positive view of personal care services or domestic assistance and one to one respite.

A number of recurring themes were identified throughout the survey. Respondents often identified a lack of services for people with younger onset dementia. Both people with younger onset dementia and their carer/family members related instances where services were inappropriate as they were aimed at older people with dementia or that services were simply not available for people of a younger age.

There was a need expressed by a number of carer/family members and people with younger onset dementia for a person to help with navigating the service system. Some respondents indicated that while there was information out there it was inadequate as it did not help them identify what they needed, what was available or how to get it.

The impact of financial adjustments was also noted by a number of respondents. Adjusting from two incomes to one often placed a strain on spouses and family members. Help with both immediate budgeting and longer term financial aspects were noted.

Respite was also a common theme for both carer/family members and people with younger onset dementia. Respite specifically aimed at people with younger onset dementia was stressed throughout. Respite was seen as a necessary way of relieving the burden for carers but if respite was not age appropriate or disease specific then carers may be reluctant to use it.

While a number of respondents indicated that most service providers they dealt with were friendly and caring and did their best to help there was still some need for improvement relating to staff training. It was noted that some staff did not necessarily have an understanding of dementia or how to work with people who have younger onset dementia.
5 FEASIBILITY ASSESSMENT

The majority of services used by people with younger onset dementia are those that have emerged from within an aged care context, with a smaller number being delivered by the disability and health sectors. These services are generally in the nature of respite and peer support, home support, transport, meals and shopping. The majority of well-targeted and responsive models of care are those that use a combination of disability and aged care program funding, applied in a flexible manner. For example, some organisations pool respite funding with transport services to create flexible peer group activities that included outings as well as centre-based activities. Some Alzheimer’s Australia organisations supplement respite and peer group funding with Dementia Support program funding to deliver ‘dementia cafés’; these not only provide an opportunity for people with younger onset dementia and carers to socialise, but education and support can be incorporated into the suite of options for that service model. It is clear that the concept of flexibility is needed within program management as well as the service delivery model being implemented.

Given this need for flexibility and creativity in terms of accessing and utilising program funding, it is not surprising that the majority of providers involved in delivering these innovative services were generally larger organisations from the church and charitable sector. These providers often have a greater capacity to explore new models of service delivery, both in terms of resources (staff as well as dollars) and a missional culture that strives to develop meaningful responses to the needs of its vulnerable client groups.

The feasibility analysis detailed in this chapter uses the Younger Onset Dementia Key Service Attributes as a guide to identify service delivery models that meet, or have the potential to meet, the needs of people with younger onset dementia and their carers. The analysis did not include established dementia services but rather focused on those services which were known to include elements that differentiate them from the ‘mainstream’, and which have the capacity to be replicated more broadly within the community care sector. Some of the examples are drawn from the consultation process; these are predominantly funded under generic aged care, disability and/or health programs using pooled funding described above. Despite our broad search strategy, both in terms of the literature and the consultation process, the overall number of models in practice are quite small. Consequently, we sought to identify possible service delivery models that, with some modifications, have the potential to meet the Key Service Attributes. Many of the potential models are found within the disability sector, which has a longer history of providing supports that are tailored to the needs of the individual, and offered within an enabling framework. Overall, the service types include modifications of respite and peer support groups, health and fitness initiatives, employment and vocational options, inter-sectoral partnerships, diagnostic and health pathways, accommodation and residential aged care models. These include social activities and employment services.
### Figure 4 Younger Onset Dementia Key Service Attributes

#### Younger Onset Dementia Key Service Attributes

**Individualised model of service**
- Listen to people with younger onset dementia and their carers
- Individualised service planning / person centred approach
- Whole of family approaches
- Ongoing needs assessment
- Meaningful engagement and vocational activities
- Recognise and respond to the different diagnostic groups and their needs

**Staff attributes**
- Appropriate skills and attitude
- Holistic approach to care and support
- Enabling and consumer centred approach
- Care co-ordination / case management skills
- Effective communication and interpersonal skills
- Flexibility
- Capacity building

**Organisational attributes**
- Integrated specialist diagnostic and ongoing symptom management services
- Organisational change capabilities
- Regionally based, integrated and coordinated interagency partnerships and pathways
- Timely service provision
- Dementia friendly environments
- Cost effective and flexible fees policy
- Cultural Safety
- Cater for needs of people in rural and remote communities
- Individualised service planning / person centred approach / continuity
- Respect and consideration for staff and clients
- Manage risk effectively
- Effective exit policies: re suspension and withdrawal of services.
5.1 Respite and peer group activities

5.1.1 Vocational activities
Evidence is emerging of the importance of vocational activities for people with younger onset dementia as a means to maintain their skills and abilities, as well as build self-esteem and enable them to continue to contribute to family and community life.

Family man Ted: Ted was supported at home for 8 years after being diagnosed with younger onset dementia. He was able to remain living with his family primarily through the provision of respite services which was activity based, and included vocational elements such as assistance to undertake the family’s grocery shopping as well as recreational activities such as outings, photography etc. The respite service use was attuned to Ted’s individual needs and interests and remained at low to modest level of provision over the eight year timeframe.

Single but not alone: Andrew enjoys attending his weekly peer-support group ‘meetings’. The group is activity based which usually consists of various outings to the local botanic gardens, aviation museum, winery, art gallery and even dolphin cruises. The group has been meeting for a while and in Andrew’s words is ‘tight knit’. He felt he was starting to ‘fall into a hole’ and attending the social group was good for his ‘psyche’ and he loved the fact that everyone in the group was positive. Over time, a real sense of camaraderie developed between the members as they began to have a better understanding of each other. He knew he had something good planned for the week and looked forward to his group outings, ‘Regular and meaningful activities in a supportive group is what is needed’.

Additional examples of ‘vocational’ respite:

• Joan attends a day respite centre twice a week and helps out with the mobility of the older clients and coordinates mealtime activities.
• Fred, a former ‘jack of all trades’, attends his local respite centre with his toolkit and, under supervision, does maintenance jobs around the centre.
• John is the ‘gardener’ at his local respite centre.
• Dave lives alone and attends his local respite centre two days a week, returning on the other three days to ‘help out’.

5.1.2 Meaningful activities
Similarly, there are clear benefits that arise from enabling the person with younger onset dementia participate in activities that are meaningful to them. Below are examples of respite services that have been applied flexibly to facilitate meaningful engagement:

Singing as respite: Alice attended a choir group in regional Australia prior to her younger onset dementia diagnosis. Post-diagnosis, she is still able to attend accompanied by her care worker who is introduced as a ‘friend’. Alice is therefore able to continue doing something she loves with a community group she has been associated with for a long time. Alice loves the fact that the focus in this group is on her singing and not on the fact that she has dementia.
Photography as respite: Attendance at a Living with Memory Loss program linked up a group of men with a shared interest in photography. Two local service providers collaborated to provide tailored respite to this group of men. At the photography respite sessions the men would plan their ‘shoots’ including the subject as well as location. They all soon learned to use a digital camera and then they learnt how to use Photoshop. Within no time the men were producing calendars for their friends and families.

Handyman Vernon: Vernon is a big man with younger onset dementia who lives with his daughter at home. Unfortunately for Vernon, he experienced a progressive decline with his behaviour and had to be placed in a residential aged care facility. However, the staff at the facility were unable to handle his behavioural issues due to Vernon’s size and strength and he lasted only a few days before being discharged. Consequently he had to return home to live with his daughter again. It looked like Vernon’s daughter would have to give up her part-time work as he could not be left alone at home all day. After further discussion, the aged care facility agreed to take Vernon in for respite during her work days. The facility became more proactive with Vernon and got him involved in cleaning and gardening activities. He has now been attending regularly for six weeks and they have not experienced any problems with his behaviour. As Vernon’s daughter said:

Residential care is predominantly set up for frailty for those who ‘can’t do’, younger people like Vernon are fit and strong and ‘can do’ and very much ‘want to do’.

Gardening on the Tram Tracks: Norman House (Life Care), the City of Unley
http://www.lifecare.org.au/comCare/norman.html: A collaboration between Norman House and the local City Council, this is an eight week program in which men with younger onset dementia are supported and supervised by a council worker and a volunteer to beautify the nearby Black Forest Tram Stop gardens. As well as providing the men with a meaningful and rewarding activity it also provides an opportunity for them to speak to commuters about the issues relating to younger onset dementia.

Driving Miss Daisy: Several women from a peer support group, some of whom lived alone, had formed a ‘cinema club’ which involved regular outings to the local cinema, with members transported by one of their own who still had her licence. This activity was not part of any formal service but organised amongst the women themselves, allowing them to continue to have a sense of independence and autonomy as well as much needed social company and stimulation.

5.2 Health and fitness
The importance of maintaining fitness for people with younger onset dementia is increasingly recognised for the benefits it has to overall health and well-being, sleep patterns, behaviours and, importantly, cognition. Whether explicitly for these reasons, or simply because it is an enjoyable pastime, numerous examples were provided during the consultations of gym attendance and walking being integral to the peer support activities and respite services. A number of people with younger onset dementia we spoke with had been regular gym attendees prior to their diagnosis, and while some continued to attend,
others found the experience too difficult; concerns were also raised about the safety of the gym environment for people with cognitive impairments. Below are some examples of services and initiatives that actively support fitness activities for groups and individuals of people with younger onset dementia.

**Walking as respite:** Brian used to be a fit man with younger onset dementia, but since his diagnosis has spent most of his days sitting at home watching television. Following a change of carer providing in-house respite, Brian was asked about his likes and dislikes and after some time, he spoke of his love for the ocean. His ‘in-home’ respite is now provided ‘out-of-doors’ as a walk along the local paths overlooking the ocean, enabling Brian to keep fit as well as tiring him out and thereby assisting with his sleeping patterns; all while ‘stimulating his senses’. In the words of his carer: ‘He would really enjoy the experience and ‘milk it for everything’

**Safe2Walk** [safe2walk@alzheimers.asn.au](mailto:safe2walk@alzheimers.asn.au) The Safe2Walk system was developed to support people with dementia being able to choose the timing and duration of their walking activities, as opposed to a traditional service delivery which dictates to the person depending on the availability of the worker and the resources available to pay for that service. In addition to potentially reducing the risk associated with walking (i.e., getting lost), it was expected that the device would allow people to be more independent and engage in meaningful activities, such as shopping, going to a café or cinema.

The program uses a small mobile phone like device with a Global Positioning System (GPS) function that can locate a person to within 10 metres. It has one large button which, when pressed, calls and connects with one of three pre-programmed numbers; it also acts as an SOS as when pressed the location data is sent to the carer’s mobile phone via SMS, enabling carers to log on to a secure website to locate the person.

Pilot projects were undertaken by AA WA and AA Vic and independently evaluated. The outcomes were positive for a number of people with dementia, giving them greater confidence to leave their house independently; however, were not so successful with people who were unfamiliar with using mobile phones or unused to carrying one on their person. Carers, likewise, experienced mixed results in terms of stress levels associated with their person using the device. It is possible that people with younger onset dementia may be more likely to benefit from this type of assistive technology, given the increased likelihood of their familiarity with using mobile phones, GPS technology and computer-based programs.

**Community care and disability partnership:** A regional Community Options service formed a partnership with a local disability service that had an arrangement with a local gymnasium. It introduced a program of weekly gym sessions for people with younger onset dementia and their carers; these are supervised by a personal trainer. After the gym session the participants all go for coffee together.

**Aged care and university partnership:** A weekly gym program for people with younger onset dementia was developed by an Occupational Therapist (OT) employed in an aged care service. The sessions were run by the OT, supported by volunteers. Health sciences students from the local university also participated as part of their clinical placements. The gym fees
are paid for by the families and supplemented by donations from the host organisation’s Staff Giving Fund. The participants who attended the gym sessions on a regular basis were able to operate the gym equipment independently, have relearned ‘old gym skills’ and have improved their fitness.

5.3 Employment
For the majority of people, a diagnosis of younger onset dementia is usually accompanied by a recommendation that they cease paid employment, without any real consideration of workplace adjustments that could be made to enable their continued employment. In addition to the financial impact that this has on the individual and their immediate family, there are significant impacts on their mental health and well-being, and that of their families. A recurring theme during the consultations was the different requirements of employers in regard to facilitating employment of people with dementia compared to people with a disability or who had a work-related injury.

It is clear that few people are aware that early onset dementia is classified as a disability within the context of the Australian Government’s JobAccess website www.jobaccess.gov.au. The site includes a comprehensive range of information and resources to support people with a disability participate in the workforce. It is underpinned by the following principles:

- People with disability should have equal access to employment.
- Australian Commonwealth, state, territory and local governments have an important role in promoting the employment of people with disability.
- Employers and recruitment agencies must make their recruitment and employment practices accessible to people with disability

One of the resources on the site is the Workplace Adjustment Tool that provides information about early onset dementia and suggestions for workplace adjustments and modifications http://www.jobaccess.gov.au/content/early-onset-pre-senile-dementia.

While some parts of the disability services sector have developed services to better meet the needs of people with younger onset dementia, this does not appear to be the case in terms of employment services. The Disability Employment Services funded by the Australian, State and Territory Governments include two types of services: Disability Management Service that ‘provides assistance to people with disability, injury or health condition who need the assistance of Disability Employment Services and who might need irregular or occasional support to keep a job’; and, Disability Employment Services that provide regular, ongoing support to people with a permanent disability. It is clear that there remains much potential within the Disability Employment Services sector to better support people with younger onset dementia in the workplace.

5.3.1 Continuing employment experiences
During the consultations a small number of examples were provided of workplaces or vocational spaces where adjustments had been made to enable people to continue in either paid employment or vocational pursuits:
Keeping on Trucking: John, a truck driver working for a regional trucking company felt that he was not ready to finish work after his diagnosis. He communicated these feelings to the company who, after much discussion, assigned John to a job with lesser demands that were more suitable for him. Over time as John’s cognitive abilities deteriorated, he was reassigned to other jobs. This went on for 6 years allowing him to maintain a job and colleagues, and receive an income.

Side by Side Project: Life Care Australia, University of South Australia, Bunnings www.lifecare.org.au This service model involves a group of people with younger onset dementia working one day a week alongside a ‘buddy’ at the local Bunnings Hardware store. Their work tasks were negotiated at the beginning of each day in partnership with their buddy. An independent evaluation of this program found that all participants were able to adapt to the workplace environment; in addition, the experience was personally rewarding, having a positive impact on their self-esteem and overall satisfaction with life. Benefits were also identified for family members, who also reported a positive impact on self-esteem and life satisfaction as a result of the workplace experience; they refer to it a ‘guilt-free respite’. The evaluation of this initiative has exceeded all expectations and has demonstrated that it is possible to offer meaningful activities for people with mild dementia if an appropriate framework of support is provided. For more information, see http://dem.sagepub.com/content/12/5/666.full.pdf+html.

Landscape reshape: Anne is married to James who has younger onset dementia and she uses respite care to allow her to continue to run her landscape business part-time. When a pre-booked respite session was cancelled at the last minute, James came along with her to work for the day. Anne initially gave him small, simple tasks, thinking that was all he was capable of; these were all readily completed, albeit at a slow pace. Anne was pleasantly surprised by James’ contribution and, over time, they soon developed a method of working collaboratively whereby he undertook basic tasks and she completed the more complex ones. While it ‘probably didn’t go as quickly as usual’, it was still a positive experience for both of them. Anne commented that: ‘the more loving, patient, supportive and positive I am, the more he progresses his skills’.

Accounting adjustment: Michael is an experienced accountant and business owner. When he could no longer deal with full-time work, he sold the business but continued to work in a less demanding and complex field as an auditor for a number of years. When this became too difficult, he took on the task of bush regeneration near his place of residence.

Teaching as therapy: Catherine is a senior physiotherapist who resigned once she received her diagnosis. With her desire to continue to ‘do something meaningful’ and ‘use my skills’, she taught ‘movement’ classes with a local community education group for approximately 18 months post diagnosis.

Neuroplasticity explored: Patricia was halfway through her university studies when she was diagnosed with dementia. She not only finished that degree, but has recently commenced an on-line master’s degree in Dementia which she calls her ‘own experiment in neuroplasticity’. She is an active advocate for younger onset dementia including writing, public speaking and regular interstate travel.
Butchering re-visited: Dave is a former butcher who had to sell his business upon diagnosis. He continues to work on a casual basis at his former business, making sausages or other products that don’t require the use of sharp implements or machinery.

Men’s Sheds
Every Bloke Needs a Shed: Alzheimer’s Australia NSW, Hunter Valley Men’s Shed Cluster and the Australian Men’s Shed Association [http://www.fightdementia.org.au/services/nsw---every-bloke-needs-a-shed.aspx](http://www.fightdementia.org.au/services/nsw---every-bloke-needs-a-shed.aspx). This program encourages and supports men with younger onset dementia, and their male carers, to access and participate in the activities available in their local Men’s Shed. Education about dementia, ageing and memory loss is an important part of the program. The shed provided the men with younger onset dementia a sense of belonging and they were able to demonstrate that they were useful contributors to a social group. See [http://www.youtube.com/watch?v=80dHGWP-p_o&feature=youtu.be](http://www.youtube.com/watch?v=80dHGWP-p_o&feature=youtu.be).

Renovation man: Bill loved to keep busy, he enjoyed renovating things but was driving his wife mad being at home all day. A local service provider referred him to a Men’s Shed group that welcomed men with dementia. This shed used old fashioned tools (not power tools) thus minimizing the potential for danger. The Men’s Shed provided Bill with an opportunity to socialise with other men in similar circumstances to him. They got to help each other out with their projects and walk away at the end of the day in a positive frame of mind.

If [men with younger onset dementia] can accept their diagnosis and comprehend it they realise that life is for living now...they meet others with an openness that they may not have demonstrated before and are much more open to talking about how they are feeling and other things.

5.4 Inter-sectoral partnerships
There is clear evidence of people with younger onset dementia ‘falling through the gaps’ between the disability, aged care and health sectors. Many of the difficulties have been attributed to the fragmented service system and bureaucratic boundaries (in particular post-implementation of the National Health reforms). However, there are examples where efforts have been made to improve coherence in terms of service development and delivery, resulting in positive outcomes for people with younger onset dementia and their carers, as well as the staff and organisations involved in implementing the support services.

Disability, Health and Aged Care: Jason is an Aboriginal and Torres Strait Islander man who has alcohol related brain damage and is an untreated epileptic. Upon his arrest in the Northern Territory he was considered by the magistrate as ‘unfit to plead’ and as a result kept in prison. A local aged care, health and disability service provider collaborated with Jason and his family to put a proposal to the court to introduce a community based care plan for him. This proposal was accepted by the court and as a result Jason was released from prison. With this package of care from disability services, the service co-ordination, appropriate medication for epilepsy and abstinence from alcohol Jason is now able to live back in his community.
Partnerships with intent: Circles of Support. This is an informal support network currently being implemented primarily within the disability sector, but has potential with other vulnerable and/or isolated groups. Originally developed by Planned Lifetime Advocacy Network (PLAN) www.plan.ca, this model aims to bring together a group of people where members provide support to a person and their family, work alongside the formal service provider and agree to ‘make time to look out’ for the person. Currently operating in Western Australia by Planned Individual Networks (PIN) www.pin.org.au, in Victoria by UnitingCare Community Options www.ucco.org.au and in NSW by Down Syndrome NSW in partnership with UnitingCare Disability Services www.ilsi.net.au.

Staying connected: TYZE www.tyze.com: The Tyze personal network is a secure web-based social network that aims to support people with disabilities. Developed by Canadian organisation PLAN, it is designed to enable people to communicate privately with family, friends and helpers about an individual, schedule events and appointments and share files, photos etc. It is unclear if any Australian groups use this service at the time of reporting.

5.5 Diagnostic and health pathways

The difficulties in obtaining an accurate diagnosis of younger onset dementia have been well documented, as is the paucity of health and care pathways that enable people to be referred to appropriate services in a timely manner. Only a handful of specialist diagnostic and assessment services are available nationally, located in major capital cities, and access to follow-up support services at the local level remains problematic for the vast majority of people diagnosed and their families.

Neuropsychiatry Unit at the Royal Melbourne Hospital: This Unit was the only example of an integrated diagnostic and assessment service that was seen during the consultation phase of the project. The Unit is staffed by three full-time consultants, three full-time registrars, and provides a mix of neuro-psychiatry, neurology, neuro-psychology, occupational therapy, nursing and social work (specialising in family therapy). Around 200 new clients are seen each year at the Unit and whilst there access a range of assessment and diagnostic processes; families are invited to participate in the assessment process, in particular regarding post-discharge care and support requirements of the person as well as the family unit. Care plans are established, referrals made and services put in place where required and/or possible prior to discharge. A key component of the service involves information and education about what people can expect, and what services are available to them, as well as counselling and family therapy to support important relationships. Importantly, clients remain ‘on the books’ for life, in order to ensure continuity of care and also provide a reference point for any issues that may arise in the future.

Northern Territory pathway: Following a review of the diagnostic pathway for dementia in the Northern Territory, it was found that many people with younger onset dementia were either not receiving a formal assessment and diagnosis, or ‘dropped off the list’ and were not being followed up with appropriate services. A dementia pathway was developed whereby all people suspected of having impaired cognition or memory problems are now supposed to be automatically referred to the Memory Clinic, regardless of age, instead of referral to neurologists or other doctors. As the pathway has become established and known more widely, health and service providers believe that this has resulted in more people with
suspected younger onset dementia being diagnosed earlier and more accurately, and increasing their likelihood of being linked in to support services.

**Integrated service pathway: BANCPASS:** Collaboration between Baptcare Northern, Northwest Aged Care Assessment Service (ACAS) and the Neuropsychiatry Unit (Royal Melbourne Hospital North West Adult Mental Health). BANCPASS was established to help people with younger onset dementia and their families to navigate the health system and initiate service provision from the point of diagnosis of younger onset dementia through to community support and care. If a person is approved for a community support package BANCPASS will then allocate case management of the client to ensure that they are supported in their home and local community. In doing this the client commences down a service delivery pathway providing them and their families with a supported model of care. At the same time all relevant staff from each of the three service providers are provided with person specific clinical assessment outcomes and ongoing professional development, establishing a team of staff specialising in Young Onset Dementia.

### 5.6 Accommodation options

Accommodation options will need to be considered if the person with younger onset dementia can no longer remain living in the same place of residence. Currently, the only options that appear to be available are those offered by aged care services. However, in recent years a number of accommodation options have been developed, primarily driven by people with disability and their advocates/carers, and may offer a more appropriate model than the traditional aged care residential service.

**Intentional communities: HOME.** The Home Occupiers Mutual Enterprise (HOME) is a proposed intentional community in the Sydney’s Inner West region [www.homecommunity.com.au](http://www.homecommunity.com.au). Intentional communities are those whereby ‘people with a disability and people without a disability live in a collaborative and supportive way’. The HOME model has completed a feasibility study and is currently sourcing funding to develop the concept more fully. The model includes a purpose built apartment block of approximately 40 dwellings, of which 15% would be allocated for people with disabilities who have significant support needs which would be met by a partner provider (in this case, UnitingCare Supported Living).

**Freedom Housing** [www.freedomhousing.com.au](http://www.freedomhousing.com.au) This is a purpose built private housing model that is based in Victoria. Comprising four houses which are linked through a care facility, the houses can be privately owned by owner-occupiers or leased by tenants from investor landlords. It is managed by the Freedom Key Management Committee, with the optional assistance of a professional facilitator acting as coach. Assessment of need and provision of packaged care is undertaken as per usual Program guidelines; the delivery of the care package is determined by the individual in need, or the approved agent or agency acting on their behalf.

**Independent Living Supported Initiative** [www.ilsi.net.au](http://www.ilsi.net.au): This initiative is designed to assist people with a disability who have ageing carers live more independently in the community.
by developing stable long-term accommodation arrangements. It provides a key worker/facilitator who works with the person to identify their goals and aspirations, and works with them to achieve this; it also helps develop an informal support network – a ‘circle of support’ – who can support the person realise their goals. Fundamentally, the objectives are to provide person centred intensive training and formal support services, and helps families develop their own support networks. This initiative is funded by Ageing, Disability and Home Care, Department of Family and Community Services NSW, and has been designed in collaboration and consultation with Down Syndrome NSW, UnitingCare Disability and House With No Steps (Hunter Region).

National Rental Affordability Scheme (NRAS) [http://www.dss.gov.au/our-responsibilities/housing-support/programs-services/national-rental-affordability-scheme/about-the-national-rental-affordability-scheme-nras](http://www.dss.gov.au/our-responsibilities/housing-support/programs-services/national-rental-affordability-scheme/about-the-national-rental-affordability-scheme-nras) Under NRAS, financial incentives have been provided to a range of organisations to increase the availability of affordable rental housing and reduce the rental costs for low to moderate income households. Housing under NRAS is national, managed by a mix of community housing groups, aged care services, universities as well as private investors and other organisations. A list of providers can be obtained from the NRAS website, included within the NRAS Monthly Performance Reports.

5.7 Aged care residential services

As noted through-out this report, there are very few aged care residential options for people with younger onset dementia. A number of organisations have sought to develop options within existing facilities (e.g., dedicated ‘wings’), and a small number have new purpose-built facilities that appear to align with the Younger Onset Dementia Key Service Attributes. Of this latter group, two facilities stand out for comment:

**Streeton Lodge, Hammondcare** - [http://www.hammond.com.au/services/younger-onset-dementia](http://www.hammond.com.au/services/younger-onset-dementia) This is a purpose built cottage that is designed to assist people with younger onset dementia remain as independent and autonomous as possible. Part of a complex of six cottages, residents are encouraged to remain connected to the wider community and participate in activity and routines that are meaningful to them.

**Eunice Seddon Home, Wintringham Specialist Aged Care** [http://www.wintringham.org.au/ResidentialServices/EuniceSeddonHome.aspx](http://www.wintringham.org.au/ResidentialServices/EuniceSeddonHome.aspx) This purpose built facility was developed with its clientele in mind (predominantly homeless people or those at risk of homelessness), in terms of the layout, facility structure, furnishings and service delivery model. This 60 bed facility is co-located with a supported accommodation service for people. Services are tailored to the needs of each person, and independence with everyday activities is facilitated. Importantly for this client group, ‘rules are kept to an absolute minimum and we respect the rights of residents to drink alcohol and smoke, provided they do not disturb other residents.’
6 DISCUSSION

The project brings together a comprehensive review of the international literature on the needs of and services for people with younger onset dementia, and a national consultation process that included face to face meetings, an online survey and email and telephone discussions, and included people with younger onset dementia, carers, service providers, researchers, policy and program advisers. In summary:

- we reviewed over 300 journal articles, reports, presentations and websites out of 425 identified from the search strategy;
- interviewed 215 people, including 33 people with dementia and carers, 54 from special interest groups; 77 service providers; 19 peak body representatives; 11 researchers and 21 policy and program advisers (state and territory government representatives); and
- received 29 completed survey responses, out of a total 97 received.

6.1 Methodological issues

In recognition of the relatively low level of younger onset specific services that currently exist, the project sought to identify models from other sectors that may be transferable to meet the needs of people at this life stage. Our approach from the outset was to assign a broad definition of ‘younger onset dementia’ to ensure we captured the more well-known diagnostic groups e.g., Alzheimer’s Disease, fronto-temporal dementia, as well as those who may have developed a dementia as a secondary condition associated with another primary diagnosis e.g., HIV/AIDS, Parkinson’s disease, alcohol or drug abuse, Huntington’s chorea, Down syndrome and Multiple Sclerosis. We also considered the different contextual factors associated with dementia, such as living arrangements, and the social, economic and environmental factors that enable and support people with younger onset dementia.

The consultations were designed to canvass as many representative groups as possible, and therefore destinations were chosen to maximise efficiency of the consultations rather than jurisdictional representation. The survey was designed to supplement face to face consultations, and was widely advertised through the main communication channels targeting people with younger onset dementia.

Disappointingly, despite a comprehensive literature search and consultation strategy, we were unable to find many examples from those other sectors that could have ready application for this client group. There are a number of possible reasons for this, including the limited overall time-frame for the project, the timing of the consultations (close to the end of the year), competing priorities (e.g., Care Leavers network was occupied with Royal Commission into Institutional Responses to Child Sexual Abuse that had just commenced) and perceived irrelevance of our enquiry (we often needed to go back to an organisation several times to clarify our objective, and identify the appropriate person to speak with).
6.2 **Five stages of dementia**
Building on existing models, we have conceptualised the trajectory of dementia according to five stages.

**Figure 5 Five stages of younger onset dementia support**

<table>
<thead>
<tr>
<th>Stage 1</th>
<th>Stage 2</th>
<th>Stage 3</th>
<th>Stage 4</th>
<th>Stage 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Risk Reduction, Awareness &amp; Recognition</td>
<td>Assessment, Diagnosis &amp; Post Diagnostic Support</td>
<td>Adjustment, Enablement &amp; Engagement</td>
<td>Management Care, Support &amp; Review</td>
<td>Later stages of dementia</td>
</tr>
</tbody>
</table>

Most policy documents that seek to diagrammatically represent the dementia journey have been developed from a medical and/or care related perspective, reflecting the existing service framework that supports people with dementia in general. Not surprisingly, this was also reflected in much of the literature that had been undertaken to date, and the paradigm within which the majority of services operate.

An early finding of this project was that a point of difference for people with younger onset dementia was their life stage, and their desire to continue to participate in its associated activities. The conceptualisation of this middle stage, which we’ve called ‘Adjustment, Enablement and Engagement’, seeks to focus on the aspects of ‘living with dementia’, rather than being a passive recipient of services, or the ‘prescribed disengagement’ that occurs upon diagnosis.18 This focus on maintaining an active role in their families, workplaces, relationships and broader community was very clearly articulated by those present at the inaugural meeting of the Dementia Advisory Group in Canberra in September 2013, and subsequently reinforced, albeit perhaps less stridently, during our consultations.

6.3 **Circles of impact**
The recurring message from people with dementia was, effectively, ‘I’m still here’; that is, they are still people who have capacity, abilities, interests, desires and hopes, as well as fears, for the future. Consequently, any services they may require need to be framed with this in mind, and underpinned by an ‘enabling’ approach to care and support. This is being borne out in the latest literature, including recent international studies (Bakker, 2013; Tolhurst et al 2012)19,20 and findings from consumer ‘roundtables’.

Using a systems approach, we sought to clarify the context within which people with younger onset dementia lived, and to identify potential opportunities for improvement to enable them to maximise their sense of identity, as well as independence, for as long as

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18 Kate Swaffer, op cit
possible. This served to clarify the groups that are influenced by, and have influence on, people with younger onset dementia; this conceptual model then informed the stakeholder consultations and subsequent analysis of findings. These groups are depicted graphically in the ‘circles of impact’ of younger onset dementia in Figure 6.

**Figure 6  Circles of impact of younger onset dementia**

![Circles of impact](image)

### 6.4 Lessons for service delivery

There was strong alignment of the major issues and practices raised in both elements of the project. In one sense this was a very positive outcome – there seems to be a number of service models that are exhibiting the good practices identified in the literature, including some ‘cutting edge’ examples; however, the systemic deficits identified in the literature appear to be equally evident in the Australian context.

In general, the key issues raised by people with younger onset dementia and about their support needs were not new; that is, there is resonance with the issues that other groups with complex chronic and debilitating conditions experience. What makes this group different, however, is the unique mix of factors that mean there is no ‘one-size-fits-all’ service delivery model. Primarily, this is the inter-relationship between the person with dementia, the underlying cause and presentation of the dementia, their life stage and environment. The aspects of daily life that usually consume a person at this stage of life, such as relationships, family responsibilities, paying off a mortgage, participating in employment and planning for the future, will be different for each person, and therefore a diagnosis of dementia will likewise impact differently on these aspects of daily life. Consequently, the ability for a person with younger onset to remain living within the community will depend on how well these different elements are functioning, and can be sustained over the longer term.

The service delivery models that offer the strongest evidence for good practice are those that address all elements of the ‘circles of impact’, starting with a focus on the person with younger onset dementia and working outwards to facilitate the enablers within the surrounding spheres of influence. This requires different emphases of effort across the five stages of dementia support. The attributes of service delivery that show the strongest
evidence of facilitating a coherent, meaningful and valued life for those living with younger onset dementia are discussed below.

**Focus on the individual**

As noted above, there is increasing recognition that people with younger onset dementia have a desire and capacity to continue to participate in activities that are meaningful for them. The barriers to this occurring include lack of community and provider awareness; social stigma regarding dementia; traditional ‘care’ paradigms of service that encourage dependence and passivity rather than enablement and wellness, are risk averse and process oriented; and absence of informal supports.

Good practice models are those that have a sound understanding of who the person is, including their personal attributes, goals and interests; includes the person in service planning; provides holistic and ongoing assessment of need; is flexible in terms of service delivery; is accessible and affordable; and, works alongside the person in a respectful and considerate manner.

**Timely and accurate diagnosis**

A recurring theme in both the literature and consultations was the extended period of time between the onset of symptoms and receiving a formal and accurate diagnosis. For many, this process can take several years. Barriers identified include the lack of awareness that dementia can affect younger people; the multifactorial nature of presentations, and the need to discount other, potentially treatable causes of symptoms; limited specialist services comprising multidisciplinary teams and assessment tools; and, attitudinal factors such as denial on the part of the person themselves, carers and health professionals.

Good practice models include a broad community education and awareness activities; targeted information for primary health care professionals; access to multidisciplinary teams that can provide holistic assessment, treatment and management options.

**Appropriate services**

Services need to be put in place that build on the strengths of the person and their immediate care and support network (spouse, partner, family, social group), in order to compensate for the deficits that have arisen as a result of dementia; this includes addressing the physical and cognitive effects, as well as financial, social and familial engagement impacts. Barriers identified include the general lack of age-appropriate support services and activities; inflexible work practices and business rules; access to services in terms of transport, timing and cost; and, staff education, skills and attitudes.

Good practice models include services which are individually tailored to the needs and interests of the person with dementia, their carer and family; are underpinned with an enabling and well-being approach to service provision; provide ongoing assessment to monitor changes and adapt services accordingly; are accessible in terms of location, transport and cost; are flexible and able to deal with change; have appropriately skilled staff
who are supported by a sound business framework that includes ongoing education and risk management policies; and, are culturally appropriate and accommodating of special needs groups.

**Integrated care**

There are often complex array of factors that need to be taken into account to support a person with younger onset dementia in the community. Providing individually tailored care requires knowledge of and coordination across the potential personal, social and community resources, as well as formal services that may be needed. Barriers include lack of knowledge of potential resources or how to access them; limited care coordination services; separate guidelines and funding rules for formal services; and, program policies that enforce an age threshold of 65 years.

Good practice models are those that are based on an understanding of the individual’s capacities and preferences and the needs of their immediate support network; have a capacity building approach that draws on personal, social and community networks as well as formal services; are flexible regarding their service provision according to changing needs of the client; have the appropriate skills, education and attitude; and are networked into specialist services and able to draw on expertise as needed.

**Continuity of care**

Continuity of care is a fundamental part of providing individually tailored care and support, and deserves particular mention because of the likelihood that people with younger onset dementia will require a range of formal services over time, which are likely to increase in intensity as their cognitive and functional abilities decline. The importance of understanding the person with dementia well has been discussed previously, to ensure their abilities are maximised and to offset any premature need for services, including those related to behaviour management. Barriers currently include a fragmented service system that can involve a number of different services and staff involved in providing care and support; limited opportunities for staff to get to know the person fully and target services to maximise their independence; and different levels of understanding amongst service types and staff about the nature of younger onset dementia and appropriate management and support practices.

Good practice models are those that have an identified ‘case manager’ or ‘care coordinator’ who fully understands the needs and aspirations of the person with dementia and those of their immediate care support network; can work across different services and sectors to build capacity within support and care services, as well as the person’s social and community networks; and, facilitates the involvement of carers and families across the continuum of the dementia journey, including palliative care and death, for as long as is desired.

**Service specific issues – respite care**

A recurring theme has been the inability of carers to access appropriate and timely respite services; this is particularly for those carers who are working and/or have family commitments. Concerns were raised about the person entering respite, and whether their
individual care needs and interests would be catered for, whether staff had the right skills, and the impact of having generally strong and fit clients mixing with frail older people. The amount of time available under current program guidelines is often insufficient for people in paid employment, or not offered with sufficient flexibility to accommodate working and family commitments.

Good practice models are those that, in addition to the attributes identified above, take into account the specific needs of both the person with dementia as well as the carer; provide meaningful activities that cater for the interests of the person with dementia; and are offered in ‘blocks’ of sufficient time to enable carers to engage in their desired activities.

**Service specific issues – peer support**

Peer support services are important mechanisms to provide much-needed social engagement for people with younger onset dementia and carers. Barriers currently include the inflexibility of some services in terms of their timing and the activities undertaken; transport to and from activities; capacity to manage changing dynamics of the group that may arise from different age ranges or behaviours; and age thresholds for different programs.

Good practice models are those that are designed around the needs of carers as well as people with dementia, in terms of timing, and the nature of activities; are self-directed as much as possible by group members; are accessible in terms of transport and cost; offer opportunities for meaningful engagement amongst one another, and with their local community; and do not enforce arbitrary age thresholds of programs which disadvantage clients.

**Policy and program issues**

People with younger onset dementia currently ‘fall between’ policies and programs that have arbitrary thresholds regarding eligibility, resulting in premature dependence, social isolation and incoherent access to appropriate care and support. In the early stages of younger onset dementia, this is primarily a result of the lack of understanding of the differential presentations of younger onset dementia, and of validated and accessible assessment tools and processes. As their need for formal services increases, the determinant for access is age, with 65 years (50 for people from Aboriginal and Torres Strait Islander backgrounds) being increasingly applied as the ‘cut-off’ point between the disability and aged care sectors. This is particularly problematic for those whose age and needs straddle the lines drawn between the different sectors.

Good policy design is that which does not arbitrarily require people with a diagnosis of dementia to cease particular activities; includes provision for targeted assessment of attributes and capacity pertaining to the relevant activities, e.g., driving, paid employment; acknowledges the interdependence of people with dementia and their carers when considering program eligibility and funding; and facilitates cross-sector and inter-jurisdictional approaches to supporting people with dual diagnoses and complex health, care and accommodation needs.
7 CONCLUSION and RECOMMENDATIONS

The findings of this project reinforce the issues that have been raised previously about the difficulties associated with access to and provision of appropriate care and support options for people with younger onset dementia. The capacity of government to develop responsive policies and service planning is hindered by a lack of evidence regarding prevalence, presentation and appropriate management strategies. Consequently, the default service option has been those within the aged care system which has dependency and frailty as its operating paradigms. The life stage at which dementia emerges for this group is quite different, and therefore the presentation, context and impact of living with dementia is more complex.

Evidence is emerging regarding the implications for service planning and delivery, with the number of research papers in the last five years alone suggesting that needs are being recognised and new models of support are being developed. While there is significant variability in the methodology and strength of evidence, there are a number of consistent themes to indicate the elements of a good practice service model. The needs and feasibility assessment undertaken as part of this project sought to clarify the elements identified in the literature through a series of consultations, interviews and surveys. The findings supported the core lessons arising from the literature, and confirmed the attributes that appear to provide the best elements of service design and delivery for people with younger onset dementia.

The literature review is the most comprehensive undertaken internationally for its time. The research field, however, is extremely dynamic, with several new studies having been published in the few months since the literature search was completed. The consultations similarly were designed to be as broad and inclusive as possible within the constraints of the project timeframe and budget. It included representatives from the major stakeholder groups, across a number of related sectors and from different special needs groups. This has provided us with indicative perspectives only, and we have identified the subject areas that would benefit from more targeted research in the future. In particular, but perhaps not surprisingly, the most pressing issues are those involving people from special needs groups and people who live alone.

There are clear examples of good practice that is occurring nationally, and samples of these are provided in the report. However, these tend to be one-off and initiated at the individual level by highly committed and motivated personnel within a service, and embraced on a larger scale by a small number of like-minded service providers. The major barriers to implementing good practice services arise from a mix of personal, cultural, organisational and attitudinal factors; addressing this requires collaboration across and between individuals, services, sectors and jurisdictions. The Key Worker program is a positive step towards progressing this at the local level; there are real opportunities for government to provide leadership and the policy context for this to be realised more systemically.


Recommendations

1. Increase community awareness of younger onset dementia to encourage greater awareness of the continuing contribution that people can make, e.g., the ‘Don’t Dis my ABILITY campaign’.

2. Develop an inter-jurisdictional working group to address the issues identified in the report, in particular: development of integrated assessment, diagnostic and care pathways; improved employment options; and removal of local policies currently being employed that restrict access to appropriate services in a timely manner.

3. Convene a panel of cross-sector representatives to further develop service delivery models identified in the Feasibility Assessment.

4. Work with relevant health and medical colleges to identify opportunities to increase awareness and improve access to specialist assessment, diagnostic and ongoing management of younger onset dementia.

5. Enhance the opportunity for people with younger onset dementia to be involved in the design, development and delivery of services and policies that affect them through the development of appropriate resources and/or financial incentives.

6. Make this Final Report and the Literature Review on Younger Onset Dementia publicly available to encourage the continued development of research, service and policy initiatives that will benefit people with younger onset dementia.
Appendix 1 Focus Group Participant Information Sheet, Consent Form and Questions

CENTRE FOR HEALTH SERVICE DEVELOPMENT
Level 1, Enterprise 1
Innovation Campus
UNIVERSITY OF WOLLONGONG
WOLLONGONG NSW 2522
Ph: (02) 4221 4411
Fax: (02) 4221 4679

Research and consultations to support people with younger onset dementia

The Centre for Health Service Development (CHSD) at the University of Wollongong has been commissioned by the Department of Health and Ageing to conduct a series of consultations to clarify the needs of people with younger onset dementia and the services and supports available to them.

You are invited to participate in a focus group to share your views and experiences. We are particularly keen to hear your ideas about how you can continue to live at home, in your own community, as well as services that have worked well for you and where you think improvements can be made. These discussions will take place at a location near you, and will take between an hour and an hour and a half of your time.

Some of the questions we will be asking in the discussion group include:
What have you found helpful in your day to day living since your diagnosis?
Do you have examples of services that are ‘getting it right’ for you and/or your family?
At the beginning of the focus group you will be asked to confirm that you have read this information sheet and you will have the opportunity to ask any questions, and sign a consent form. We will also be collecting some basic demographic information at this time.

It is possible that you may find some questions personal or upsetting during the course of the interview. If this happens, please let us know and we can stop the discussion if you wish, or prefer not to continue. We will have a list of useful contacts that will be available to you should you feel the need to talk to someone following the interview, and services available in your local area.

Your participation is voluntary and you are free to withdraw your consent at any time. Your decision whether to participate in the focus group or not will in no way affect your relationship with Alzheimer’s Australia or your usual service provider.

To ensure that there is an accurate record of what you say we would like to record the discussion on a digital recorder. However, if you prefer, we can take notes of the key points you make.
Your identity at all times will be anonymous. All recordings and notes will be given a code number known only to the evaluation team. As required by University policy, all records of the discussions will be securely stored for five years and then destroyed.

The final report of this project will be provided to the Department of Health and Ageing. We anticipate that the findings will be made available to key groups such as Alzheimer’s Australia and may be used for conference presentations and journal articles. No individuals will be identified in these reports, presentations or articles.

If you would like further information, or have any questions about the project, please contact the project lead, Anita Westera, on 02 4221 4411 or email westera@uow.edu.au. If you have any concerns or complaints about the way the project is being conducted, you may wish to contact the Ethics Officer at the University of Wollongong on 02 4221 4457 and quote reference number HE13/363.

Thank you
Research and consultations to support people with younger onset dementia

Consent Form

I have been given information about the Services for people with Younger Onset Dementia Project being conducted by the Centre for Health Service Development, University of Wollongong. I understand that the aim of the project is to identify possible service needs and models that will assist people with younger onset dementia continue to live in their own communities for as long as possible.

☐ I have had the opportunity to discuss any questions or concerns about the project with a member of the project team.

☐ I have been advised that I can have my carer or support person to assist me if needed, and that the discussion group will take around 60-90 minutes.

I understand that my participation in this project is entirely voluntary, that I am free to refuse to participate and that I am free to withdraw from the discussion group at any time. I understand that if I decline to participate or withdraw my consent, this will not adversely affect my relationship with Alzheimer’s Australia or my service provider or the University of Wollongong. I also understand that no identifying information will be included in any reports, publications or presentations developed from the interview, and that all materials generated as part of the interview will be securely stored and destroyed in accordance with relevant University guidelines.

I understand that if I have any questions or concerns about the project and my participation I can contact the Centre for Health Service Development (Project Manager, Anita Westera on 02 4221 4411). If I have any concerns or complaints regarding the way the project is or has been conducted, I can contact the Ethics Officer at the University of Wollongong on (02) 4221 4457 or rso-ethics@uow.edu.au and quote the reference number HE13/363. (See the Participant Information Sheet for further information.)

By signing below I am indicating my consent to participate in an audio-recorded focus group discussion as part of the Services for Younger people with Dementia project.

Signed  ........................................................................................................................................................................................................

Date   ....../....../......

Name (please print)  ........................................................................................................................................................................
Research and consultations to support people with younger onset dementia

About you:

1. What is your age?

☐ 18-24 years old
☐ 25-34 years old
☐ 35-44 years old
☐ 45-54 years old
☐ 55-65 years old
☐ Over 65

2. What is your gender?

☐ Male
☐ Female
☐ Other

3. Do you identify as being from one of the following groups? (Tick all that are applicable)

☐ A person from Aboriginal and/or Torres Strait Islander community
☐ A person from a non-English speaking background
☐ A person from who lives in a rural and remote area
☐ A person who is financially or socially disadvantaged
☐ A veteran
☐ A person who is homeless or at risk of becoming homeless
☐ A person who is a care leavers (a person who was raised in a care home)
☐ A person who is Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI)
Research and consultations to support people with younger onset dementia
Proposed questions

1: What assistance do you or your family and carers currently receive?

- Social activities (e.g. outings; art; walking groups)
- Information, Support or educational services e.g. Living with Memory Loss groups;
- Assistance with planning services to meet your needs e.g. Case management
- Counselling services - marriage, grief and loss, child and adolescent mental health etc.
- Transport services
- Personal or household assistance
- Other

2: What have you found helpful in your day to day living since your diagnosis?

3: What supports and services are 'getting it right' for you and/or your family?

3a: What is it about them that works so well?
   e.g. flexibility; tailored to my interests; similar age group; similar living circumstances;
   keeps me active; makes me feel like I'm contributing.

4: What would you have liked to continue to do?

- Working (in paid employment)
- Volunteering
- Family activities
- Social activities

5: What would help you to continue to do these things?
Appendix 2 Extract from Hope Newsletter

RESEARCH PROJECTS, NEWS AND BREAKTHROUGHS

*** ADVANCE NOTICE ***

CONSULTATIONS REGARDING SERVICES FOR PEOPLE WITH YOUNGER ONSET DEMENTIA

The Centre for Health Service Development (CHSD) at the University of Wollongong has contacted Alzheimer’s Australia to invite people with younger onset dementia and their carers to participate in a project being funded by the Australian Government. The project will aim to identify the services that are most likely to assist people with younger onset dementia remain living and participating in their own communities.

Consultations with consumers will form a significant part of the project. The focus of the consultations will be to identify local groups, services and workplaces that enable people to continue to live and stay actively involved in their own communities. We will also be conducting a review of the international literature and websites for examples of good practice and service models.

We are currently finalising details of our consumer consultations, which will then be provided to the University of Wollongong’s Human Research Ethics Committee for approval. At this stage, we are aiming to convene meetings in most capital cities as well as a number of regional and rural towns during October and November this year. For those who can’t make it to a meeting, there will also be the opportunity to participate by phone or email.

Where possible, we will seek to work closely with Alzheimer’s Australia in conducting the consultations. Please let your local Alzheimer’s Australia Younger Onset Dementia Key Worker or Alzheimer’s Australia office know if you would like to participate. You will then be contacted by a representative of CHSD.

You can contact your local Key Worker or Alzheimer’s Australia office on 1800 100 500.

Kind regards,

Anita Westera
Research Fellow, CHSD
westera@uow.edu.au
Appendix 3  Alzheimer’s Australia Tip Sheets

DEVELOP STRATEGIES TO IMPROVE COMPREHENSION

- Be patient and don’t assume what you have said has been understood.
- Use simple and clear language, and allow thinking time.
- Keep sentences brief. Only provide a small amount of information at once.
- Ask the person the question in a format that allows an easy answer such as ‘yes’ or ‘no’ or a choice between two things.
- Don’t ask two questions at once – let the person answer the first question before asking the second.
- Ask the person to repeat the information in their own words, to ensure they have correctly understood it.
- Use visual cues – gesture, facial expression, pointing, demonstrations, pictures.

SEEK WAYS TO ENCOURAGE COMMUNICATION AND EXPRESSION

- Encourage the person to demonstrate, describe or use other visual cues.
- The use of drawings and writing may be helpful where communication is becoming difficult. Encourage the use of a notepad.
- Try to help with gentle suggestions as to the word or idea they might be trying to generate – but let them try first. If it is a word that won’t come, sometimes just suggesting a letter it might start with is helpful in letting them come up with the word themselves.
- Allow extra time to search for the right words and ideas to get to the point.
- Stay focussed on the person with dementia when they are talking to you so they know that you are listening.
- Prompt with specific questions or ‘who’, ‘what’, ‘where’.
- Complete a topic before moving to the next. Try not to shift back and forth between ideas in a conversation.
- Explain to key people (employers, teachers, friends, co-workers) the nature of the language difficulty and how they can help with communication.
Appendix 4 Younger Onset Dementia Online Survey

University of Wollongong Younger Onset Dementia Survey

PARTICIPANT INFORMATION SHEET

The Centre for Health Service Development (CHSD) at the University of Wollongong has been commissioned by the Department of Social Services to conduct research to clarify the needs of people with younger onset dementia and the services and supports available to them.

You are invited to participate in this process by completing this survey. We would very much welcome your views and comments, and anticipate that the survey will take about 10 minutes to complete.

Some of the questions in the survey include:
- What do you think can be done to assist you to remain living and participating in your own home and/or community?
- Are you currently receiving services that are ‘getting it right’ for you and/or your family?
- What sort of assistance would you like to receive in the future?

Your participation is entirely voluntary and you are free to discontinue the survey at any time. Confidentiality of this survey will be maintained at all times.

The final report of this project will be provided to the Department of Social Services. We anticipate that the findings will be made available to key groups such as Alzheimer’s Australia and may be used for conference presentations and journal articles. No individuals will be identified in these reports, presentations or articles.

If you would like further information, or have any questions about the project, please contact the project lead, Anita Westera, on 02 4221 4411 or email westera@uow.edu.au. If you have any concerns or complaints about the way the project is being conducted, you may wish to contact the Ethics Officer at the University of Wollongong on 02 4221 4457 or email rso-ethics@uow.edu.au and quote reference number HE13/363.
University of Wollongong Younger Onset Dementia Survey

CONSENT FORM

I have been given information about the University of Wollongong Younger Onset Dementia Survey, being conducted by the Centre for Health Service Development, University of Wollongong. I understand that the aim of the research is to assess clarify the needs of people with younger onset dementia and the services and supports available to them. I have had the opportunity to discuss any questions or concerns about the research with a member of the evaluation team.

I have been advised of the risks associated with this research and the conditions of participation, which consists of participating in a survey that will take approximately 10 minutes to complete.

I understand that my participation in this survey is entirely voluntary and that I am free to refuse to participate. I understand that if I decline to participate or withdraw my consent, this will not adversely affect my relationship with the University of Wollongong. I also understand that no identifying information will be included in any reports, publications or presentations developed from the survey, and that all materials generated as part of the survey will be securely stored and destroyed in accordance with relevant University guidelines.

I understand that if I have any questions or concerns about the research and my participation, I can contact the Centre for Health Service Development (project lead, Anita Westera, on 02 4221 4411 or email westera@uow.edu.au). If I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Complaints Officer, Human Research Ethics Committee, at the University of Wollongong on 02 4221 4457 or rso-ethics@uow.edu.au and quote the reference number HE13/363.

By signing below I am indicating my consent to participate in this survey.

Signed..............................................................................................................................

Date ....../....../......

Name (please print)..........................................................................................................

A completed consent form must be returned with the survey. Please return both the completed consent form and survey in the postage-paid self-addressed envelope provided.

Thank you.
University of Wollongong Younger Onset Dementia Survey

Person with younger onset dementia

Do you reside in Australia?

☐ Yes
☐ No

What is the Australian postcode of where you live? .................

If residing outside Australia what country do you live in? .................

What is your age? .................

What is your gender?

☐ Male
☐ Female

Are you:

from an Aboriginal and/or Torres Strait Islander community ☐ Yes ☐ No
from a non-English speaking background ☐ Yes ☐ No
living in a rural or remote area ☐ Yes ☐ No
financially or socially disadvantaged ☐ Yes ☐ No
a veteran ☐ Yes ☐ No
homeless or at risk of becoming homeless ☐ Yes ☐ No
a person who was raised in a care home (a care leaver) ☐ Yes ☐ No
lesbian, gay, bisexual, transgender or intersex (LGBTI) ☐ Yes ☐ No

What do you think can be done to assist you to remain living and participating in your own home and/or community?

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................................................................................................................................................................
................................................................................................................................................................

What would you like to continue to do if you were provided with the right opportunity and/or support? (Select all that are applicable)

☐ Working (in paid employment)
Final Report: Services for People with Younger Onset Dementia

☐ Volunteering
☐ Family activities
☐ Social activities
☐ Other

If 'Other', please describe:

………………………………………………………………………………………………………………………………

What could assist you to become more involved in the activities identified in the previous question (e.g. working, volunteering, family activities, social activities, etc.)? (Select all that are applicable)

☐ Information about dementia
☐ Tips to support daily functioning
☐ Legislation (e.g. anti-discrimination)
☐ Financial support (e.g. Centrelink or other government benefits)
☐ Work placement assistance
☐ Legal advice
☐ Counselling services (e.g. marriage, grief and loss, child and adolescent mental health)
☐ Personal assistance (e.g. day to day management, care related needs)
☐ Other

If 'Other', please describe:

………………………………………………………………………………………………………………………………

If you are currently receiving any of the following services please indicate whether or not they are 'getting it right' for you.

<table>
<thead>
<tr>
<th>Service</th>
<th>Getting it right</th>
<th>Not getting it right</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to one social support</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>One to one respite</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Personal care or domestic assistance</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Residential respite</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Permanent residential care</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Leisure and activity/therapy based services</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Support or educational groups</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Case management and assistance with planning</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Home modification and equipment</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Information about services</td>
<td>☐</td>
<td>☐</td>
</tr>
<tr>
<td>Other</td>
<td>☐</td>
<td>☐</td>
</tr>
</tbody>
</table>

If 'Other', please describe:

………………………………………………………………………………………………………………………………

………………………………………………………………………………………………………………………………

Of the services that are 'getting it right', what do you like about these services?
What services are received by your carer / family member? (Select all that are applicable)

☐ One to one social support  
☐ One to one respite  
☐ Personal care or domestic assistance  
☐ Leisure and activity/therapy based services  
☐ Support or educational groups  
☐ Case management and assistance with planning  
☐ Home modification and equipment  
☐ Information about services  
☐ Other

If 'Other', please describe:

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What are the main ways you have been linked to services? (Select all that are applicable)

☐ Referred by health/diagnostic practitioner  
☐ Referred by local dementia advisor  
☐ Referred by Alzheimer’s Australia  
☐ Found out from someone else with dementia/their family  
☐ Found out by ourselves  
☐ Currently not linked to services  
☐ Other

If 'Other', please describe:

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What sort of assistance would you like to receive in the future? (Select all that are applicable)
☐ Financial and legal  
☐ Care services  
☐ Family/carer involvement  
☐ Other

If 'Other', please describe:

................................................................................................................................................................
................................................................................................................................................................

Do you have anything else to add?

................................................................................................................................................................
................................................................................................................................................................
................................................................................................................................................................
................................................................................................................................................................
University of Wollongong Younger Onset Dementia Survey

PARTICIPANT INFORMATION SHEET

The Centre for Health Service Development (CHSD) at the University of Wollongong has been commissioned by the Department of Social Services to conduct research to clarify the needs of people with younger onset dementia and the services and supports available to them.

You are invited to participate in this process by completing this survey. We would very much welcome your views and comments, and anticipate that the survey will take about 10 minutes to complete.

Some of the questions in the survey include:
- What do you think can be done to assist you to remain living and participating in your own home and/or community?
- Are you currently receiving services that are ‘getting it right’ for you and/or your family?
- What sort of assistance would you like to receive in the future?

Your participation is entirely voluntary and you are free to discontinue the survey at any time. Confidentiality of this survey will be maintained at all times.

The final report of this project will be provided to the Department of Social Services. We anticipate that the findings will be made available to key groups such as Alzheimer’s Australia and may be used for conference presentations and journal articles. No individuals will be identified in these reports, presentations or articles.

If you would like further information, or have any questions about the project, please contact the project lead, Anita Westera, on 02 4221 4411 or email westera@uow.edu.au. If you have any concerns or complaints about the way the project is being conducted, you may wish to contact the Ethics Officer at the University of Wollongong on 02 4221 4457 or email rso‐ethics@uow.edu.au and quote reference number HE13/363.
University of Wollongong Younger Onset Dementia Survey

CONSENT FORM

I have been given information about the University of Wollongong Younger Onset Dementia Survey, being conducted by the Centre for Health Service Development, University of Wollongong. I understand that the aim of the research is to assess clarify the needs of people with younger onset dementia and the services and supports available to them. I have had the opportunity to discuss any questions or concerns about the research with a member of the evaluation team.

I have been advised of the risks associated with this research and the conditions of participation, which consists of participating in a survey that will take approximately 10 minutes to complete.

I understand that my participation in this survey is entirely voluntary and that I am free to refuse to participate. I understand that if I decline to participate or withdraw my consent, this will not adversely affect my relationship with the University of Wollongong. I also understand that no identifying information will be included in any reports, publications or presentations developed from the survey, and that all materials generated as part of the survey will be securely stored and destroyed in accordance with relevant University guidelines.

I understand that if I have any questions or concerns about the research and my participation, I can contact the Centre for Health Service Development (project lead, Anita Westera, on 02 4221 4411 or email westera@uow.edu.au). If I have any concerns or complaints regarding the way the research is or has been conducted, I can contact the Complaints Officer, Human Research Ethics Committee, at the University of Wollongong on 02 4221 4457 or rso-ethics@uow.edu.au and quote the reference number HE13/363.

By signing below I am indicating my consent to participate in this survey.

Signed..............................................................................................................................

Date ....../....../......

Name (please print)..........................................................................................................

A completed consent form must be returned with the survey. Please return both the completed consent form and survey in the postage-paid self-addressed envelope provided.

Thank you.
University of Wollongong Younger Onset Dementia Survey
Carer / family member

Do you reside in Australia?
☐ Yes
☐ No

What is the Australian postcode of where you live? .................

If residing outside Australia what country do you live in? .................

What is your age? .................

What is your gender?
☐ Male
☐ Female

Are you:
from an Aboriginal and/or Torres Strait Islander community ☐ Yes ☐ No
from a non-English speaking background ☐ Yes ☐ No
living in a rural or remote area ☐ Yes ☐ No
financially or socially disadvantaged ☐ Yes ☐ No
a veteran ☐ Yes ☐ No
homeless or at risk of becoming homeless ☐ Yes ☐ No
a person who was raised in a care home (a care leaver) ☐ Yes ☐ No
lesbian, gay, bisexual, transgender or intersex (LGBTI) ☐ Yes ☐ No

If you are currently receiving any of the following services please indicate whether or not they are 'getting it right' for you.

One to one social support ☐ Getting it right ☐ Not getting it right
One to one respite ☐ □
Personal care or domestic assistance ☐ □
Leisure and activity/therapy based services ☐ □
Support or educational groups ☐ □
Case management and assistance with planning ☐ □
Home modification and equipment ☐ □
Information about services ☐ □
Other ☐ □

If 'Other', please describe:
Of the services that are 'getting it right', what do you like about these services?

What services does the person with younger onset dementia currently receive? (Select all that are applicable)

☐ One to one social support
☐ One to one respite
☐ Personal care or domestic assistance
☐ Residential respite
☐ Permanent residential care
☐ Leisure and activity/therapy based services
☐ Support or educational groups
☐ Case management and assistance with planning
☐ Home modification and assistance with planning
☐ Information about services
☐ Other

If 'Other', please describe:

………………………………………………………………………………………………………………………………
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………………………………………………………………………………………………………………………………
What are the main ways you have been linked to services? (Select all that are applicable)

☐ Referred by health/diagnostic practitioner
☐ Referred by local dementia advisor
☐ Referred by Alzheimer’s Australia
☐ Found out from someone else with dementia/their family
☐ Found out by ourselves
☐ Currently not linked to services
☐ Other

If 'Other', please describe:

What sort of assistance would you like to receive in the future? (Select all that are applicable)

☐ Financial and legal
☐ Care services
☐ Family/carer involvement
☐ Other

If 'Other', please describe:

Do you have anything else to add?
### Appendix 5 Number of times issues raised in the consultations

<table>
<thead>
<tr>
<th>People with younger onset dementia</th>
<th>n</th>
</tr>
</thead>
<tbody>
<tr>
<td>Access to disease specific information/e.g. living with memory loss/access to service provision information</td>
<td>7</td>
</tr>
<tr>
<td>Case management</td>
<td>15</td>
</tr>
<tr>
<td>Community awareness/stigma</td>
<td>9</td>
</tr>
<tr>
<td>Diagnosis – timely/access</td>
<td>16</td>
</tr>
<tr>
<td>Driving and transport</td>
<td>12</td>
</tr>
<tr>
<td>Finances/legal</td>
<td>14</td>
</tr>
<tr>
<td>Many people unfit to plea</td>
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<tr>
<td>Meaningful participation/employment</td>
<td>20</td>
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<tr>
<td>Peer-support groups</td>
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</tr>
<tr>
<td>Relationships/grief, bereavement and loss</td>
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</tr>
<tr>
<td>Self-determination/control/normalisation/ Change of role</td>
<td>11</td>
</tr>
<tr>
<td><strong>Family/carers</strong></td>
<td></td>
</tr>
<tr>
<td>Behavioural management issues</td>
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</tr>
<tr>
<td>Case management</td>
<td>7</td>
</tr>
<tr>
<td>Education and support for children (loss of childhood)</td>
<td>8</td>
</tr>
<tr>
<td>Financial and legal</td>
<td>15</td>
</tr>
<tr>
<td>Information re diagnosis and management/ timely information and communication</td>
<td>8</td>
</tr>
<tr>
<td>Peer-support groups</td>
<td>13</td>
</tr>
<tr>
<td>Psycho-social support/counselling/denial and lack of insight (marriage and family, incl. children) and education</td>
<td>13</td>
</tr>
<tr>
<td>Respite/carer support</td>
<td>25</td>
</tr>
<tr>
<td>Self-determination/normalisation/working</td>
<td>5</td>
</tr>
<tr>
<td>Transport</td>
<td>4</td>
</tr>
<tr>
<td><strong>Social networks</strong></td>
<td></td>
</tr>
<tr>
<td>Community awareness/stigma</td>
<td>19</td>
</tr>
<tr>
<td>Community organisations and businesses/capacity building (dementia-friendly cities)</td>
<td>13</td>
</tr>
<tr>
<td>Meaningful participation/employment/volunteering</td>
<td>13</td>
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<tr>
<td>Normal social networks</td>
<td>13</td>
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<tr>
<td><strong>Formal Services</strong></td>
<td></td>
</tr>
<tr>
<td>Accommodation options – age appropriate</td>
<td>19</td>
</tr>
<tr>
<td>Age appropriate, e.g. fitter stronger clients</td>
<td>17</td>
</tr>
<tr>
<td>Cross cultural issues</td>
<td>3</td>
</tr>
<tr>
<td>Cultural issues (paternalistic) relating to health service delivery – reverse ageism, bed-side manner</td>
<td>4</td>
</tr>
<tr>
<td>Dementia low priority</td>
<td>2</td>
</tr>
<tr>
<td>Flexibility and after-hours</td>
<td>19</td>
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<tr>
<td>Inter-agency communication – pathways and protocols</td>
<td>15</td>
</tr>
<tr>
<td>Lack of formal and financially viable services</td>
<td>15</td>
</tr>
<tr>
<td>Lack of information about what services are ‘out there’</td>
<td>5</td>
</tr>
<tr>
<td>-----------------------------------------------------</td>
<td>---</td>
</tr>
<tr>
<td>More options for formal younger onset dementia specific respite</td>
<td>5</td>
</tr>
<tr>
<td>Package managers take easier cases</td>
<td>1</td>
</tr>
<tr>
<td>Person-centred/care planning and care coordination</td>
<td>25</td>
</tr>
<tr>
<td>Staff training and awareness/staffing issues – numbers, retention, salary</td>
<td>17</td>
</tr>
<tr>
<td>Transport (lack of it)</td>
<td>3</td>
</tr>
</tbody>
</table>

### Policy and legislation

<table>
<thead>
<tr>
<th>Access to services (ACAT)</th>
<th>11</th>
</tr>
</thead>
<tbody>
<tr>
<td>COAG re ageing and disability split</td>
<td>11</td>
</tr>
<tr>
<td>Dementia Awareness compulsory training module</td>
<td>1</td>
</tr>
<tr>
<td>Driving legislation and dementia</td>
<td>2</td>
</tr>
<tr>
<td>Commonwealth stronger compliance</td>
<td>1</td>
</tr>
<tr>
<td>Guardianship – power of attorney – advance care directives</td>
<td>1</td>
</tr>
<tr>
<td>MBS item counselling/support family members needed</td>
<td>1</td>
</tr>
<tr>
<td>NDIS – mystery? National Disability Strategy</td>
<td>10</td>
</tr>
<tr>
<td>Need for police check</td>
<td>1</td>
</tr>
<tr>
<td>Non-traditional service types</td>
<td>2</td>
</tr>
<tr>
<td>Output-based funding models</td>
<td>1</td>
</tr>
<tr>
<td>Superannuation legislation – accessing funds</td>
<td>1</td>
</tr>
<tr>
<td>Work Health and Safety Legislation</td>
<td>1</td>
</tr>
</tbody>
</table>
Appendix 6  Results: Online Survey

This appendix reports on the results and overall findings of the survey for both people with younger onset dementia and carers for people with younger onset dementia.

There were a total of 97 responses to the survey, of which 90 were received via the online survey and the remaining seven were from paper surveys received via post, a response rate of just under 11%. One respondent who started an online survey indicated that they did not give their consent and exited the survey. A further nine respondents did not answer any more questions after providing consent and were excluded from the survey. Another 38 respondents indicated they were neither a person with younger onset dementia nor a carer of someone with younger onset dementia and also exited the survey.

A total of 14 respondents indicated that they were a person with younger onset dementia themselves but only six of these respondents completed the survey. There were 35 carers who responded to the survey. Of these 11 did not complete the survey and one was excluded after their responses indicated that they were not a carer. This left a total of 23 carers who completed the survey.

11.1  People with Younger Onset Dementia

11.1.1  Demographic questions
Respondents were asked several demographic questions including their country of residence, their postcode if residing in Australia, their age, gender and whether they fell into any special interest groups.

Nine (64%) respondents with younger onset dementia indicated that they resided in Australia. The remainder did not answer this question. A further six participants provided a postcode including two from South Australia, Two from Queensland, one from New South Wales and one from Western Australia.

Ten respondents provided their age or indicated an age group. Ages ranged from 40 years to 62 years.
Table 3 below provides a summary of the number of respondents by age group.

Table 3  People with younger onset dementia by age group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44</td>
<td>3 (21)</td>
</tr>
<tr>
<td>45-54</td>
<td>1 (7)</td>
</tr>
<tr>
<td>55-65</td>
<td>5 (36)</td>
</tr>
<tr>
<td>Not stated</td>
<td>4 (29)</td>
</tr>
</tbody>
</table>

Ten respondents also provided their gender. There was an even split between male and female respondents for those who answered this question.
Table 4 People with younger onset dementia by gender

<table>
<thead>
<tr>
<th>Gender</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Male</td>
<td>5 (36)</td>
</tr>
<tr>
<td>Female</td>
<td>5 (36)</td>
</tr>
<tr>
<td>Not stated</td>
<td>4 (29)</td>
</tr>
</tbody>
</table>

Participants were asked about their background, including whether they identified as being in one of the following special interest groups.

- Aboriginal or Torres Strait Islander
- from a non-English speaking background
- living in a rural or remote area
- financially or socially disadvantaged
- a veteran
- homeless or at risk of becoming homeless
- a person who was raised in a care home (a care leaver)
- lesbian, gay, bisexual, transgender or intersex (LGBTI)

The majority of participants who answered this question indicated that they did not fall into any of these groups. One respondent was a veteran. Another respondent was from a rural/remote area as well as a socially and financially disadvantaged area.

11.1.2 Survey Questions

The remainder of the survey asked for responses specific to the experience of younger onset dementia. Only six respondents with younger onset dementia went on to complete the survey from this point. Results are collated according to question number.

1. What do you think can be done to assist you to remain living and participating in your own home and/or community?

This question allowed respondents to provide a free text answer. There were five responses to this question. Of these four respondents indicated that their carer needed respite. Two respondents also noted the need for better transport options. Day time activities were also noted, including age appropriate activities, awareness raising and education, for carers and service providers, including Centrelink. Other assistance mentioned included social interaction, timely access to a geriatrician, assisted employment and volunteering options, dementia friendly communities and higher disability and carer’s pensions.

One participant indicated in particular the difficulties faced by those living with younger onset dementia and how these difficulties have impacted the lives of themselves and their carer.

*I think we need more help for my carer. My carer is my husband and he still works full time as we are paying our house off still and I cannot work anymore so I can’t help financially. Our house is so neglected and we have asked for help and get told ok but nothing happens. My husband is a wonderful man but his stress level*
is so high. I’m so worried it will end up too much for him. I am on a disability pension but most of the time I get no funds from that because my husband works. We have worked hard all our lives and now we really need help but I feel like we are just not important anymore.

2. What would you like to continue to do if you were provided with the right opportunity and/or support?

Six respondents indicated a range of activities they would like to be involved in with the right support. Two participants indicated they would like to be involved in up to four different activities. Working in paid employment and social activities were those most popular. Table 5 below provides a summary of responses to this question. One participant indicated another activity they would like to be involved in was memory courses.

**Table 5 Supported activities for people with younger onset dementia**

<table>
<thead>
<tr>
<th>Activity</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Working (in paid employment)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Volunteering</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Family activities</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Social activities</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (17)</td>
</tr>
</tbody>
</table>

3. What could assist you to become more involved in the activities identified in the previous question (e.g. working, volunteering, family activities, social activities, etc.)?

Of those who answered this question (n=6), personal assistance was the most popular response (67%). Tips to support daily functioning, legislation and counselling were also chosen by half of the respondents to this question. Information about dementia was least chosen by respondents (17%). One participant indicated that ‘other’ assistance was needed for them to be involved, namely support for the carer as this would allow the respondent to be involved in family and social functions. Table 6 below provides a summary of the range of responses to this question.

**Table 6 What would assist involvement in identified activities?**

<table>
<thead>
<tr>
<th>Assistance</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Information about dementia</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Tips to support daily functioning</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Legislation</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Financial support</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Work placement assistance</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Legal advice</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Counselling services</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Personal assistance</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (17)</td>
</tr>
</tbody>
</table>
Given that respondents expressed a desire to be involved in paid employment and social activities in the previous question, it is interesting that they felt that personal assistance and tips to support daily functioning would help with these activities, each of which would help reduce carer burden. Only two respondents thought they needed work placement assistance. Respondents also indicated that legislation and counselling would also help assist them in participating in the activities they would like to be involved in. More information on the type of legislation may also be an interesting line of enquiry.

4. **If you are currently receiving any of the following services please indicate whether or not they are 'getting it right' for you.**

Respondents (n=6) were more likely to indicate that specific services were not getting it right. Those services that most attracted a negative review by respondents were information about services, one to one social support, residential respite and leisure and activity/therapy based services. Those services for which no respondents indicated they were getting it right but were in fact ‘not getting it right’ were information about services, one to one respite, personal care or domestic assistance and permanent residential care. The service with the fewest negative and the most positive reviews combined was home modification and equipment. Table 7 below provides a summary of responses.

<table>
<thead>
<tr>
<th>Service</th>
<th>Getting it right: n (%)</th>
<th>Not getting it right: n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to one social support</td>
<td>1 (17)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>One to one respite</td>
<td>0</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Personal care or domestic assistance</td>
<td>0</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Residential respite</td>
<td>1 (17)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Permanent residential care</td>
<td>0</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Leisure and activity/therapy based services</td>
<td>1 (17)</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Support or educational groups</td>
<td>1 (17)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Case management and assistance with planning</td>
<td>1 (17)</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Home modification and equipment</td>
<td>1 (17)</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Information about services</td>
<td>0</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
<td>2 (33)</td>
</tr>
</tbody>
</table>

Two respondents also indicated that there were other ways services were ‘not getting it right’. One respondent indicated they were having difficulty obtaining home modification equipment due to financial restraints while another respondent discussed the difficulties and impact related to diagnosis.

*After a diagnosis of dementia you are virtually left in a black hole and have to find information out yourself while dealing with the loss of income, emotional distress and no help in the public health system. At 44 I can’t get an ACAT assessment done as I’m under 65. There are no real services for people with younger onset dementia.*

5. **Of the services that are 'getting it right', what do you like about these services?**
This was an open-ended question that allowed respondents to provide their own answers. Their responses have been summarised. Respondents (n=5) were positive about services that provided emotional support and care, a stimulating and inclusive environment and friendship/companionship. Services noted as getting it right were leisure and activity/therapy based services, support or educational groups and case management and assistance with planning.

One participant indicated that person centred care was what they liked but that it depended on who the specific worker was. They also indicated that residential respite was the service getting it right.

Another participant indicated that they had recently accessed the Key Worker program and were waiting to see how it would go for them. This respondent did not indicate that any of the service options given were getting it right.

Not all respondents entered a positive response. One respondent commented on the inadequacy of services for people with younger onset dementia and the personal impact of this.

*I see my Specialist and have been told that I am too young for anymore services, that they have gone as far as I can with them. What a load of rubbish my Dementia is not going to go away just because they say I’m too young.*

This respondent indicated that only home modification and equipment was the only service getting it right.

### 6. What services are received by your carer / family member?

A total of six respondents provided answers for this question. Respondents were most likely to say that their carer received support or educational groups (67%). According to respondents, carers also received one to one social support and respite, case management and assistance with planning and information about services. One respondent also indicated that their carer received ‘other’ services but did not say what they were. Table 8 below gives a summary of services received by respondent’s carers.

<table>
<thead>
<tr>
<th>Service</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to one social support</td>
<td>1 (17)</td>
</tr>
<tr>
<td>One to one respite</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Personal care or domestic assistance</td>
<td>0</td>
</tr>
<tr>
<td>Leisure and activity/therapy based services</td>
<td>0</td>
</tr>
<tr>
<td>Support or educational groups</td>
<td>4 (67)</td>
</tr>
<tr>
<td>Case management and assistance with planning</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Home modification and equipment</td>
<td>0</td>
</tr>
<tr>
<td>Information about services</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (17)</td>
</tr>
</tbody>
</table>
7. What are the main ways you have been linked to services?

Almost all respondents who answered this question (83%) indicated that they often found out about services themselves. Respondents were also linked to services via a referral from a health/diagnostic practitioner or by Alzheimer’s Australia. No participants were referred by a local dementia advisor. It is not clear if this was because of a lack of local dementia advisory services or another reason. It was noted that of the two respondents who were not currently linked to services also indicated that they also found out about services themselves, although one of the two also indicated they had been referred by a health/diagnostic practitioner at some point as well. Table 9 below gives a summary of responses.

Table 9 How were people with younger onset dementia linked to services

<table>
<thead>
<tr>
<th>Link</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred by health/diagnostic practitioner</td>
<td>3 (50)</td>
</tr>
<tr>
<td>Referred by local dementia advisor</td>
<td>0</td>
</tr>
<tr>
<td>Referred by Alzheimer’s Australia</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Found out from someone else with dementia/their family</td>
<td>1 (17)</td>
</tr>
<tr>
<td>Found out by ourselves</td>
<td>5 (83)</td>
</tr>
<tr>
<td>Currently not linked to services</td>
<td>2 (33)</td>
</tr>
<tr>
<td>Other</td>
<td>0</td>
</tr>
</tbody>
</table>

8. What sort of assistance would you like to receive in the future?

Only four respondents indicated what sort of assistance they would like in the future. All of those who responded wanted care services in the future (see Table 10 below). Respondents also indicated that financial and legal services and family/carer involvement were also important services for the future. Two respondents indicated there were other types of services they wanted in the future including support and companionship during respite and social interaction.

Table 10 What future assistance people with younger onset dementia would like.

<table>
<thead>
<tr>
<th>Assistance</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial and legal</td>
<td>3 (75)</td>
</tr>
<tr>
<td>Care services</td>
<td>4 (100)</td>
</tr>
<tr>
<td>Family/carer involvement</td>
<td>3 (75)</td>
</tr>
<tr>
<td>Other</td>
<td>2 (50)</td>
</tr>
</tbody>
</table>

9. Do you have anything else to add?

Two respondents took the opportunity to provide an additional response of their own concerns. One responded stated that people with younger onset dementia and their carers were not getting the help that they needed. After being told about what they could receive the respondent felt that it was ‘unfair’ that they had in fact received little help at all. There was also a stoic sense that they would ‘soldier on’ regardless.

Another participant commented on their specific needs, particularly relating to the future and the lack of support/facilities available for people with younger onset dementia. It is
interesting to note that needs relating to modern technology are also clearly stated by this respondent.

There are currently NO facilities for younger people with dementia. If I needed to go into full time care I would have to go into an aged care home with much older people than me. I want to access the Internet and various TV shows that I'm interested in. I want access to different forms of technology. E.g.: PC’s, tablets, mobile phones, pay TV. These are all things I use now but wouldn’t have in an aged care dementia wing. I want to use Facebook to stay connected to family and friends. I want to program the TV to record shows I like. I collect stamps and need access to a PC and an up to date library to research my stamp collection. The Public Health system basically said you have dementia and discharged me from hospital. There was no support. We had to find help and support ourselves.

11.2 Carers of People with Younger Onset Dementia

11.2.1 Demographic questions
Results for demographic questions relate to the 34 carers who started the survey. All carers indicated that they resided in Australia. Table 11 below gives an outline of which states carers resided in.

Table 11 Number of carers by state

<table>
<thead>
<tr>
<th>State</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>New South Wales</td>
<td>7 (21)</td>
</tr>
<tr>
<td>Victoria</td>
<td>4 (12)</td>
</tr>
<tr>
<td>South Australia</td>
<td>3 (9)</td>
</tr>
<tr>
<td>Queensland</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Northern Territory</td>
<td>2 (6)</td>
</tr>
<tr>
<td>Tasmania</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Australian Capital Territory</td>
<td>1 (3)</td>
</tr>
<tr>
<td>Western Australia</td>
<td>0</td>
</tr>
<tr>
<td>Not stated</td>
<td>14 (41)</td>
</tr>
</tbody>
</table>

Carers indicated a much broader age range compared to respondents with younger onset dementia. Carer’s ages ranged from 38 -70 years of age. Table 12 below gives an overview of the number of carers in each age group.

Table 12 Carers by age group

<table>
<thead>
<tr>
<th>Age Group</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>35-44yrs</td>
<td>2 (6)</td>
</tr>
<tr>
<td>45-54yrs</td>
<td>7 (21)</td>
</tr>
<tr>
<td>55-64yrs</td>
<td>10 (29)</td>
</tr>
<tr>
<td>65+yrs</td>
<td>3 (9)</td>
</tr>
<tr>
<td>NA*</td>
<td>12 (35)</td>
</tr>
</tbody>
</table>

*Did not answer this question
In our sample carers were more than three times as likely to be female than male. Of those carers who provided their gender for the survey, 78% (n=18) of carers were female while only 22% (n=5) were male.

There was also a broader range of backgrounds indicated by carers compared to people with younger onset dementia from our survey. In particular there were four carers who indicated they were from a financially or socially disadvantaged area. Other carers indicated they were from a NESB background (1), a rural/remote area (1) or were LGBTI (1).

11.2.2 Survey Questions
The remainder of the survey asked for responses specific to the experience of younger onset dementia. Only six respondents with younger onset dementia went on to complete the survey from this point. Results are collated according to question number.

1. If you are currently receiving any of the following services please indicate whether or not they are 'getting it right' for you.

Eighteen carers responded to this question, providing answers for some or all of the options available. Carers were slightly more likely to indicate services that were not getting it right than services that were getting it right. Information about services, support or educational groups and case management and assistance with planning were those options that carers indicated most as getting it right. Those services most indicated as not getting it right were personal care or domestic assistance and one to one respite.

Comparison of carer responses with responses from people with younger onset dementia for this survey should be viewed with caution due to the small number of respondents with younger onset dementia. Given that, this group of carers was very different in their view of information about services compared to the view of people with younger onset dementia who responded to this survey. There appeared to be some similarities in carers view of personal care or domestic assistance and one to one respite and that of people with younger onset dementia, however, as numbers are small no conclusions can be drawn.

**Table 13 Carer services getting it right**

<table>
<thead>
<tr>
<th>Service</th>
<th>Getting it right: n (%)</th>
<th>Not getting it right: n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to one social support</td>
<td>4 (22)</td>
<td>7 (39)</td>
</tr>
<tr>
<td>One to one respite</td>
<td>3 (17)</td>
<td>8 (44)</td>
</tr>
<tr>
<td>Personal care or domestic assistance</td>
<td>1 (6)</td>
<td>9 (50)</td>
</tr>
<tr>
<td>Leisure and activity/therapy based services</td>
<td>6 (33)</td>
<td>6 (33)</td>
</tr>
<tr>
<td>Support or educational groups</td>
<td>9 (50)</td>
<td>4 (22)</td>
</tr>
<tr>
<td>Case management and assistance with planning</td>
<td>8 (44)</td>
<td>5 (28)</td>
</tr>
<tr>
<td>Home modification and equipment</td>
<td>2 (11)</td>
<td>6 (33)</td>
</tr>
<tr>
<td>Information about services</td>
<td>10 (56)</td>
<td>5 (28)</td>
</tr>
<tr>
<td>Other</td>
<td>1 (6)</td>
<td>9 (50)</td>
</tr>
</tbody>
</table>

Of those participants who noted ‘other’ services, one participant indicated that the local monthly meeting for carers of people with younger onset dementia was getting it right. The four carers who indicated ‘other’ services that were not getting it right indicated a range of services including: lack of help when needed, resulting in spouse being placed in nursing
home; carer was not receiving any of the above services mentioned; a lack of financial support, appropriate and meaningful social support, respite and leisure and activity services for ‘Younger Onset Dementia families’; and a lack of permanent placements for short and long term residential respite.

2. Of the services that are ‘getting it right’, what do you like about these services?

There were eleven carers who provided a response to what they liked about services that were getting it right. A number of carers discussed the ongoing support provided by local organisations such as Alzheimer’s Australia, ACH (SA aged care organisation) and Life Care. Carers indicated that they liked the activities provided to for people with younger onset dementia, some much needed respite as well as the ongoing support from local carer groups. This included the opportunity to debrief and talk with people in a similar situation as themselves. One carer also noted that respite removed some of their burden and allowed them to feel like they had a normal and productive life.

Some carers noted the staff or organisation representatives they had contact with were what they liked most. Workers often had genuine concern and went out of their way to help people, to be friendly and approachable and provide individual help such as guiding people to the services they needed. One participant noted that while they liked how staff tried to make things work for them there was still some room for improvement:

* I like the fact that they try their best to make it work. They are very available and friendly to talk to but the theory and the planning, is not as complex as the reality of the situation. I'm grateful that such services exist but there is a need for specified preparation for the worker with people with younger onset dementia.

3. What services does the person with younger onset dementia currently receive?

There were 18 carers who indicated the services that the person with younger onset dementia currently receives. Leisure activity/therapy based services were the most common services mentioned by carers (50%). Home modification and equipment services (11%) and permanent residential care (11%) were least mentioned by carers. Table below provides an overview of services received. Other services noted by carers included supported volunteer work and neurology and neuropsychology services. One carer noted that they had been referred to Vision Australia due to vision problems. They also noted that they had been referred to Dementia Advisory Services but had not used this service yet. Overnight and daily respite involving other people with younger onset dementia were also noted by one carer.
Table 14  Services the person with younger onset dementia receives

<table>
<thead>
<tr>
<th>Service</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>One to one social support</td>
<td>5 (28)</td>
</tr>
<tr>
<td>One to one respite</td>
<td>7 (39)</td>
</tr>
<tr>
<td>Personal care or domestic assistance</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Residential respite</td>
<td>3 (17)</td>
</tr>
<tr>
<td>Permanent residential care</td>
<td>2 (11)</td>
</tr>
<tr>
<td>Leisure and activity/therapy based services</td>
<td>9 (50)</td>
</tr>
<tr>
<td>Support or educational groups</td>
<td>8 (44)</td>
</tr>
<tr>
<td>Case management and assistance with planning</td>
<td>5 (28)</td>
</tr>
<tr>
<td>Home modification and equipment</td>
<td>2 (11)</td>
</tr>
<tr>
<td>Information about services</td>
<td>7 (39)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (17)</td>
</tr>
</tbody>
</table>

When asked what services their carer received, respondents to the survey for people with younger onset dementia were most likely to say support or educational groups. Almost half of carers who responded to this survey also noted that the person they cared for also received support and educational groups.

4.  What are the main ways you have been linked to services?

Of the 21 carers who answered this question over a half (57%) were referred to services by Alzheimer’s Australia. Almost a half (48%) found out about services by themselves. There were very few (5%) who were currently not linked to services. Table 15 below gives an overview of the way carers were linked to services. Of both groups of respondents to this survey, carers and people with younger onset dementia, there were a number who indicated that they found out about services by themselves.

Table 15  Ways that carers were linked to services

<table>
<thead>
<tr>
<th>Link</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Referred by health/diagnostic practitioner</td>
<td>6 (29)</td>
</tr>
<tr>
<td>Referred by local dementia advisor</td>
<td>5 (24)</td>
</tr>
<tr>
<td>Referred by Alzheimer’s Australia</td>
<td>12 (57)</td>
</tr>
<tr>
<td>Found out from someone else with dementia/their family</td>
<td>4 (19)</td>
</tr>
<tr>
<td>Found out by ourselves</td>
<td>10 (48)</td>
</tr>
<tr>
<td>Currently not linked to services</td>
<td>1 (5)</td>
</tr>
<tr>
<td>Other</td>
<td>3 (14)</td>
</tr>
</tbody>
</table>

Other ways that carers indicated they were linked to services included printed information provided by dementia organisations and carer organisations, as well as linking through ACAT and an ‘ethnic organisation’. Regarding literature one carer noted it was not always helpful as it was often not aimed at younger onset dementia. The help provided by Centrelink was also often not available for people with younger onset dementia. The carer also noted that:

*There is a LOT of literature but really what you need in the middle of this is someone to help you ferret through it and basically hold your hand!*

5.  What sort of assistance would you like to receive in the future?
A total of 21 carers provided responses for this question. Responses are summarised in Table 16 below. An overwhelming majority (81%) of carers wanted care services in the future. Over half of carers (52%) also wanted financial and legal and family/carer involvement in the future. People with younger onset dementia who responded to this survey were similar to carers regarding the assistance they would like to receive in the future, with care services most wanted by both groups.

**Table 16  Future assistance that carers would like to receive**

<table>
<thead>
<tr>
<th>Assistance</th>
<th>n (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Financial and legal</td>
<td>11 (52)</td>
</tr>
<tr>
<td>Care services</td>
<td>17 (81)</td>
</tr>
<tr>
<td>Family/carer involvement</td>
<td>11 (52)</td>
</tr>
<tr>
<td>Other</td>
<td>6 (29)</td>
</tr>
</tbody>
</table>

Other services carers would like to receive in the future included more physiotherapy in nursing homes, activity based social interaction with other people with younger onset dementia, a case worker to help with paperwork, banking and Centrelink, psychological support for carers and respite in an appropriate setting (not residential aged care). One carer was unsure what they might need in the future as they did not know how they or their spouse would cope with the deterioration.

Help with Centrelink was specifically noted by two carers. The burden of sorting out forms/paperwork and payments (getting it right) was seen as stressful and adding burden to the impact of the diagnosis itself. A worker who could help carers and people with younger onset dementia with Centrelink was seen by carers as the best way to provide assistance for them.

6. **Do you have anything else to add?**

Carers were asked if there was anything else they would like to add to give them a chance to bring up issues that may have been missed in the survey. Seven carers provided an additional response.

Carers expressed a range of needs for themselves and the person they care for as well as problems associated with a number of gaps in the system. Carers expressed a need for individual help with navigating the system, including help with finding services and budgeting and financial help. The impact of a spouse developing younger onset dementia often placed a great deal of burden and complexity on the carer, in particular financial burden, as noted by one carer.

*Like most people in my age our age bracket, our finances are geared to a double income in order to prepare for our retirement. Now that my husband has had to give up work and is too young for a pension and I earn just a little too much for financial support, our out goings are more than our incoming so a huge adjustment has to be made. This is hard for someone with FTD who is very set in routine. I have to work to make ends meet and deal with my grief and care for my*
husband and I have to take time off work to deal with paperwork and make appointments to deal with paperwork. It’s all too much. I am running myself ragged. The thing is, this has to be done by me. Carers allowance paperwork could surely be given to carers and gone through, filled in etc. by Carers NT or Alzheimer’s Aust. Much nicer with someone you are forming a relationship with than Centrelink. Also helpful would be free budget advice and planning and maybe even creating a budget. Financial advice costs money and is desperately needed at a time when you can least afford it.

Several needs can be identified from the carer’s statement above, in particular the need for individual assistance with financial and budgetary matters, making appointments, filling out paperwork and dealing with Centrelink. While the carer must still care for her husband and deal with her grief she must also take on the job of earning money. The need for financial advice was strongly stated by this carer, particularly in the face of difficult readjustments to a smaller income.

Another carer noted the difficulties in finding and obtaining needed services. In particular the carer noted that information about services was often inadequate.

There are lots of phone numbers e.g. in Alzheimer’s Australia’s Younger Onset Dementia Newsletter. Don’t know who to contact and what to ask for from whom. Have scant information from medical practitioners who just provide more names and phone numbers without specifying the assistance that can be obtained. This survey again raises suggestions as to what services might be available but nothing about how to obtain them. There appears to be lots of ‘caring’ people forming groups and advocating support but no-one actually telling carers nor those with dementia as to what they can actually provide and how to get it.

Both of the carer statements above provide a clear indication of the need for individual assistance, such as a key worker. This key worker could not only provide support but also help with navigating the system, gaining financial assistance and dealing with the impact of younger onset dementia, such as readjustments to lifestyle and financial status.

Other needs expressed by carers included the need for training of staff that work with or provide services for people with younger onset dementia and their carers. Services and their staff need to understand issues relating to dementia. A lack of understanding can lead to difficulties for the person with younger onset dementia and their carer. One carer noted that it was pointless to make alternative arrangements for services with the person with younger onset dementia rather than their carer.

Carers also noted gaps in the system relating to services for people with younger onset dementia. Services that were both age and disease appropriate were noted as lacking by carers. One carer noted that now that her husband was 65 he was considered to be under ‘aged care’ but as he was fit and healthy, activities provided by aged care were not age appropriate. Another carer also noted the difficulty in finding activities for a spouse who was intellectually aware but whose dementia had stopped them from participating physically.
One carer noted that there was not enough appropriate support, activities, respite, groups or other support available for people with younger onset dementia. In particular this carer noted that they felt discriminated against due to the age of the person with younger onset dementia.

Another care noted that there was a gap in residential respite facilities for people with younger onset dementia. Aged care facilities were not appropriate for younger people leaving carers reluctant to use these services for respite and thus increasing the caregiving burden on the carer.