Flexible respite for carers of people living with dementia

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Abstract
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‘Flexible Respite for Carers of People Living with Dementia’

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Aims

• Caring, Dementia & Respite
• Factors associated with use and non-use of respite
• Review the evidence - what is ‘flexible’ respite for carers of people with dementia?
• Discussion - policy implications, ways forward
• 320,000 people living with dementia – projected to increase to >900,000 by 2050\(^1\)
• Living with dementia is associated with ageing and institutionalisation – those who live at home do so with the support of a carer\(^2\)
• Younger people also get dementia\(^3\)
• Caring for a family member with dementia can have many positive aspects\(^4-5\)
• However, can also be associated with physical and psychological stresses\(^6-7\) - particularly if the caregiver feels trapped\(^7\)
**Respite** - An alternative or supplementary care arrangement with the primary purpose of giving the carer:

- A short term break from their usual caring role;
- Assistance with performing the their caring role, on a short term basis (Dept, of Health, 2014)

**Respite & caregivers of people with dementia**

- Respite identified as a critical unmet need\(^8\)-\(^9\)
- Enables them to continue role for longer\(^10\)
- Delays institutionalisation (and associated risks)\(^11\)
- Reflects community and government preference for living in own home\(^12\)
Current Respite Program Structure - Aged

Figure 2.1: Current program structure for provision of respite

- **HACC**
  - ~100,000 clients
  - 75% centre based respite
  - 25% in-home / other respite
  - Rest of HACC ~600,000 clients

- **NRCP**
  - CRCC
    - Information Carer Support Emergency respite ~95,000 carers
  - Counselling ~5,500
  - Respite Services ~32,000 carers

- **Packages**
  - 75,000 clients
  - Respite within Packages not identified
  - Respite outside packages

- **Residential Respite**
  - ~50,000 Respite Users
  - ~2.5 beds / 70+ used
  - Rest of residential care program
Respite Use – carers of people living with dementia

- Carers of people with dementia are more likely than other carers to use respite
- However, despite high need, proportion of caregivers of people with dementia using available respite is low
- For out of home respite – 2 - 40% using RRC\textsuperscript{11-13} and 9-29% using a day centre\textsuperscript{14-15}
- Only 32% with an approval used residential respite (Australia)\textsuperscript{15}
- RRC - Phillipson et al (2013), NSW \textsuperscript{13}
  - 68/113 (60.2%) not using RRC
  - 66/68 indicated an unmet need
• Barriers to the use of respite services are specific to the respite service type
• Specific sub-groups of the carer population may be more prone than others to not utilising available care
• Strategies to support use need to address both attitudinal and practical barriers to the use of specific services rather than to ‘respite’ in general

Phillipson et al, 2013, Health & Social Care in the Community
Factors associated with non-use of Out of Home Respite Services

**Predisposing**
- Spousal caregiver; CALD care recipient
- Beliefs – Caregiving
- Expectations of negative outcomes
- Low perceived utility (CG & CR)

**Enabling/Impeding**
- Low knowledge of local facilities
- No assistance to navigate
- Service quality, availability, FLEXIBILITY – don’t meet needs

**Need**
- CR Behavioural Problems
- CG disturbance at CR functional problems

Phillipson et al, 2013, Health & Social Care in the Community\textsuperscript{13,16,17}
Flexible Respite Policy

• Flexible Respite Policy (ADHC, 2011) - families and unpaid carers of children, young people and adults with a disability
• No current policy regarding respite ‘flexibility’ for people living with dementia and their carers
• Difficulties due to the diverse funding sources and programs
• New proposed reforms - service amalgamation under a new single program - ‘Assistance with Care and Housing for the Aged’
• Incorporate HACC, CHSP & NRCP (Discussion paper, 2014)
• New service groups - (Social Participation) – Social support, centre based day care & (Care Relationships) - Flexible, cottage and emergency respite
• ‘Just in time’ - to define a policy on ‘flexible’ delivery under the new reforms
Evidence base - ‘flexibility’ in respite for dementia

• Alz Australia
  – Bruen and Howe 2009 – Discussion Paper
• Research with carers of people with dementia in Australia
  – Shanley, 2006; Phillipson et al 2009 -2014; Beattie et al 2012-2014; Stirling et al 2010-2014
• Iterative Coding by Respite Service type – Day care, Inhome care and Residential Care
• 5 domains of ‘flexibility’:
  – Location - Timing
  – Providers - Activities
  - Funding
<table>
<thead>
<tr>
<th><strong>Domains of Flexibility</strong></th>
<th><strong>Description</strong></th>
</tr>
</thead>
<tbody>
<tr>
<td>Service Activities</td>
<td>Tailored and person-centred to meet different needs e.g men, CALD, younger onset Social participation – variety of company, not just people with dementia Mental Stimulation – enjoyable, meaningful and stimulating Education - for people with dementia and carers</td>
</tr>
<tr>
<td>Service Timing</td>
<td>Variable e.g. Work hours, morning or afternoon, whole day, after care, before care, vacation care</td>
</tr>
<tr>
<td>Service Location/Facility</td>
<td>Flexible to meet needs of physical disability and behavioural problems BUT not institutional Local/Transport Able to provide care outings e.g. visits to parks, cinemas, gallery Able to provide occasional overnight care</td>
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<tr>
<td>Service Provider</td>
<td>Trained, Experienced, Creative, Varied</td>
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<tr>
<td>Service Funding</td>
<td>Flexible use of allocation - holidays, regular day care, all after care</td>
</tr>
<tr>
<td>Domains of Flexibility</td>
<td>Description</td>
</tr>
<tr>
<td>------------------------</td>
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</tbody>
</table>
| Service Location       | In the persons own home  
                          In the carers home  
                          In the home of another family member  
                          Ability to care for others e.g. grandchildren |
| Service Timing         | Daytime, night time, one-off, responsive, timely  
                          Emergency care  
                          Unmet need for night time and overnight care |
| Service Provider       | Regular, known to family and person with dementia |
| Service Activities     | Social, Domestic and personal care  
                          Education for the carer – insights from ‘in the home’ |
<p>| Service Funding        | Brokerage of services; consumer directed care; use of own family/friends |</p>
<table>
<thead>
<tr>
<th>Domains of Flexibility</th>
<th>Residential Care Services</th>
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<tbody>
<tr>
<td>Service Location</td>
<td>Residential care services</td>
</tr>
<tr>
<td></td>
<td>Community house or cottage</td>
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<tr>
<td></td>
<td>Destination e.g. holiday respite</td>
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<tr>
<td>Service Timing</td>
<td>Planned – break</td>
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<tr>
<td></td>
<td>Planned – stepping stone</td>
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<tr>
<td></td>
<td>Emergency e.g. carer illness – need for ‘rapid response pathways’</td>
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<td></td>
<td>Need for support to transition ‘in’ and ‘out’ of care</td>
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<tr>
<td>Service Providers</td>
<td>Residential Aged Care Providers</td>
</tr>
<tr>
<td></td>
<td>Cottage</td>
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<tr>
<td></td>
<td>Day care centres</td>
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<tr>
<td></td>
<td>Holiday</td>
</tr>
<tr>
<td>Service Activities</td>
<td>Person centred - comfort, purpose, social interaction, meaningful engagement</td>
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<td></td>
<td>Carer participation – ability to be involved/stay/assist (if they want to)</td>
</tr>
<tr>
<td>Service Funding</td>
<td>Current RACF allocations underutilised</td>
</tr>
<tr>
<td></td>
<td>Call for cashing out of allowance for RACFs for use in other settings</td>
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<td>Brokerage and trial of consumer directed care</td>
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<td>Financial subsidy for low income</td>
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Summary

• 5 domains – Location, Timing, Providers, Activities, Funding
• Aspects of ‘Flexibility’ varies between different respite service products
• Need for diverse responsive services - preferably with a knowledge of the carer and the person living with dementia
• Benefit of providers able to work across settings to meet the needs across product types to meet needs for flexibility
• Impact of new proposed reforms – separation of assessment and case management functions from service provision?
Discussion

• New system must be funded & structured to meet carers needs for ‘flexibility’
• However, multiple factors need to be addressed to achieving a mutually beneficial experience for carer and person living with dementia through respite
• Also need an integrated mix of strategies to address:
  – information needs & navigational support
  – attitudinal & practical barriers
  – quality of care - staff training, facilities, environment, staff to patient ratios
Discussion

• Alzheimer’s Australia (2013) – aim of any alternative respite program structure for people living with dementia and their carers:
  - reduce boundaries between types of respite
  - provide more choice in regards to type
  - provide more ‘flexibility’ in responding to needs
Thank you for your time and attention 😊

Any questions?

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