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Flexible respite for carers of people living with dementia

Abstract

Presentation from the National Respite and Community Care Conference, 23-24 October 2014, Sydney, Australia

Keywords

carers, flexible, dementia, respite, living, people

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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



Dementia & caregiving

- 320, 000 people living with dementia – projected to increase to >900,000 by 2050¹
- Living with dementia is associated with ageing and institutionalisation – those who live at home do so with the support of a carer²
- Younger people also get dementia³
- Caring for a family member with dementia can have many positive aspects⁴⁻⁵
- However, can also be associated with physical and psychological stresses⁶⁻⁷ - particularly if the caregiver feels trapped⁷



Respite

Respite - An alternative or supplementary care arrangement with the primary purpose of giving the carer:

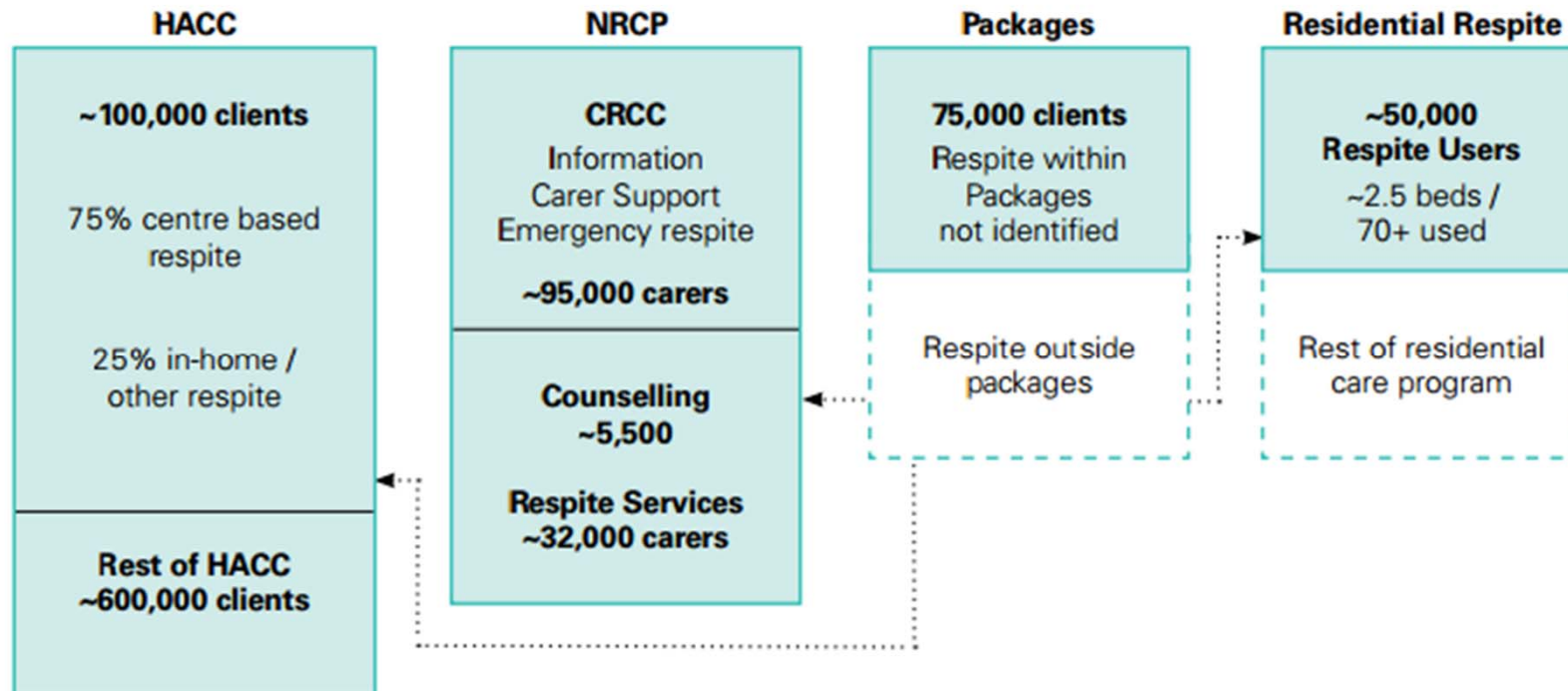
- A short term break from their usual caring role;
- Assistance with performing the their caring role, on a short term basis (Dept, of Health, 2014)

Respite & caregivers of people with dementia

- Respite identified as a critical unmet need⁸⁻⁹
- Enables them to continue role for longer¹⁰
- Delays institutionalisation (and associated risks)¹¹
- Reflects community and government preference for living in own home¹²

Current Respite Program Structure - Aged

Figure 2.1: Current program structure for provision of respite



Respite Use – carers of people living with dementia

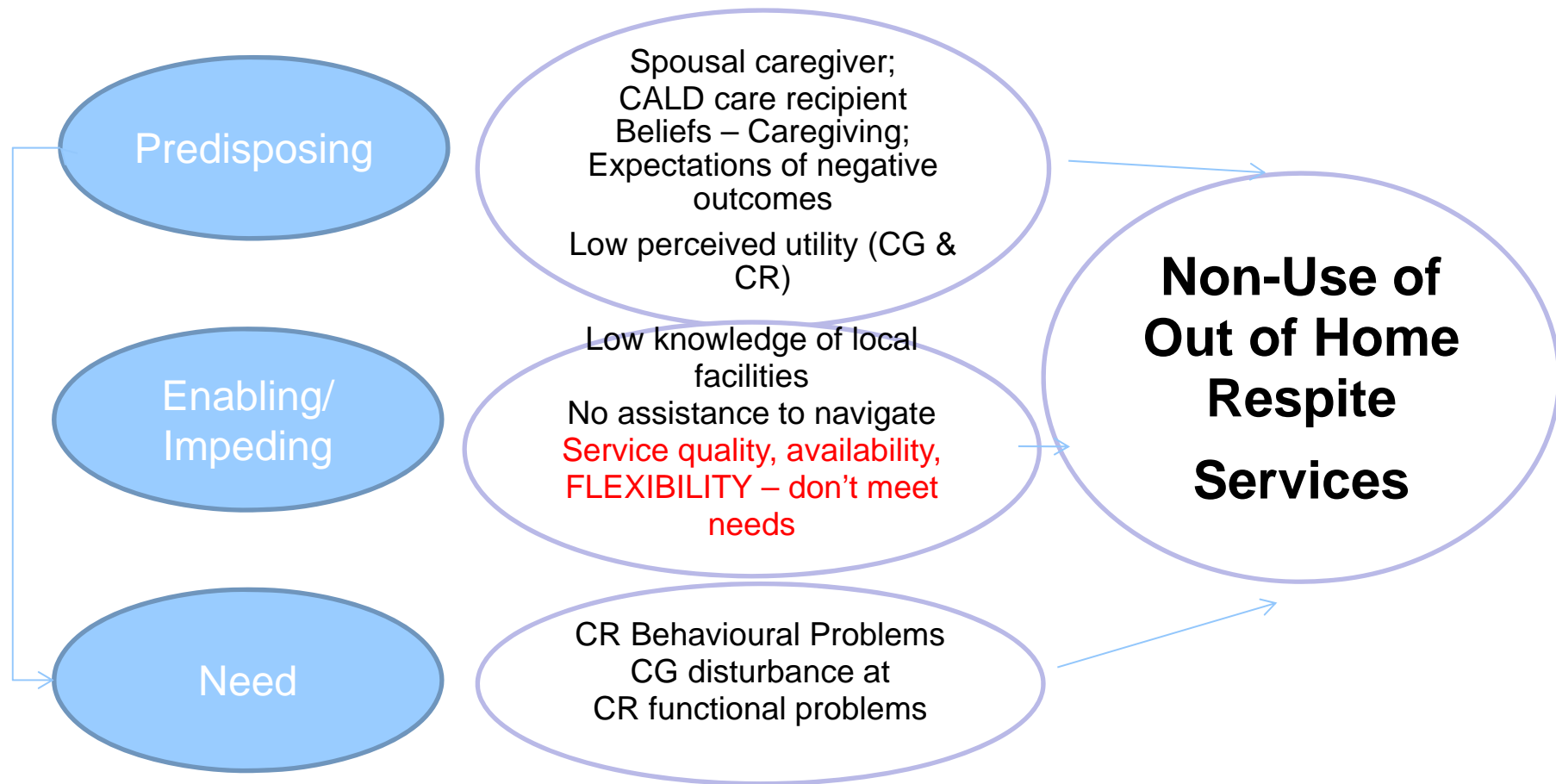
- Carers of people with dementia are more likely than other carers to use respite
- However, despite high need, proportion of caregivers of people with dementia using available respite is low
- For out of home respite – 2 - 40% using RRC¹¹⁻¹³ and 9-29% using a day centre¹⁴⁻¹⁵
- Only 32% with an approval used residential respite (Australia)¹⁵
- RRC - Phillipson et al (2013), NSW ¹³
 - 68/113 (60.2%) not using RRC
 - 66/68 indicated an unmet need



Respite non-use

- 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

Factors associated with non-use Out of Home Respite



Phillipson et al, 2013, Health & Social Care in the Community^{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
 - Respite Review – Policy Paper 33 – Howe 2013
 - 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
 - Providers
 - Funding
 - Timing
 - Activities





Flexibility – Day Care

Domains of Flexibility	Description
Service Activities	<p>Tailored and person-centred to meet different needs e.g men, CALD, younger onset</p> <p>Social participation – variety of company, not just people with dementia</p> <p>Mental Stimulation – enjoyable, meaningful and stimulating</p> <p>Education - for people with dementia and carers</p>
Service Timing	<p>Variable e.g. Work hours, morning or afternoon, whole day, after care, before care, vacation care</p>
Service Location/Facility	<p>Flexible to meet needs of physical disability and behavioural problems BUT not institutional</p> <p>Local/Transport</p> <p>Able to provide care outings e.g. visits to parks, cinemas, gallery</p> <p>Able to provide occasional overnight care</p>
Service Provider	<p>Trained, Experienced, Creative, Varied</p>
Service Funding	<p>Flexible use of allocation - holidays, regular day care, all after care</p>



Flexibility – In-home care

Domains of Flexibility	Description
Service Location	<p>In the persons own home</p> <p>In the carers home</p> <p>In the home of another family member</p> <p>Ability to care for others e.g. grandchildren</p>
Service Timing	<p>Daytime, night time, one-off, responsive, timely</p> <p>Emergency care</p> <p>Unmet need for night time and overnight care</p>
Service Provider	<p>Regular, known to family and person with dementia</p>
Service Activities	<p>Social, Domestic and personal care</p> <p>Education for the carer – insights from ‘in the home’</p>
Service Funding	<p>Brokerage of services; consumer directed care; use of own family/friends</p>



Residential Care

Domains of Flexibility	
Service Location	Residential care services Community house or cottage Destination e.g. holiday respite
Service Timing	Planned – break Planned – stepping stone Emergency e.g. carer illness – need for ‘rapid response pathways’ Need for support to transition ‘in’ and ‘out’ of care
Service Providers	Residential Aged Care Providers Cottage Day care centres Holiday
Service Activities	Person centred - comfort, purpose, social interaction, meaningful engagement Carer participation – ability to be involved/stay/assist (if they want to)
Service Funding	Current RACF allocations underutilised Call for cashing out of allowance for RACFs for use in other settings Brokerage and trial of consumer directed care Financial subsidy for low income



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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