

Rethinking respite care

Lyn Phillipson reports on an innovative project to support carers and people living with dementia to use respite services and also address the low uptake for such services

Caring for a family member with dementia can be a positive experience (Carbonneau & Desrosiers 2010). However, caring for someone with dementia has also been associated with stress and physical disability, particularly if the carer feels trapped (Bertrand *et al* 2006). As a result, respite is consistently identified by carers of people with dementia as one of their critical unmet care needs. However, the overall proportion who use available respite and other support programs tends to be low (Brodaty *et al* 2005; Phillipson *et al* 2013).

In Australia, the low uptake for respite services is likely to be the result of many complex and interacting factors.

Firstly, the dementia services care environment is complex and fragmented with carers and people living with dementia experiencing delays in diagnosis and poor communication and referrals to support services (Boustani *et al* 2008).

Use of respite services can also be influenced by perceptions of poor service quality, lack of availability, cost, a lack of flexibility in service arrangements and expectations that negative outcomes will occur as a result of using respite (Fielding *et al* 2012; Phillipson *et al* 2013; Neville *et al* 2014; Phillipson *et al* 2014).

Finally, some carers of people with dementia associate the use of respite and support services with guilt and failure or not fulfilling family responsibilities, which can create additional barriers to service use (Fielding *et al* 2012; Phillipson *et al* 2013; Neville *et al* 2014; Phillipson *et al* 2014).

All of these factors highlight the critical need for action to address and improve the



Dr Lyn Phillipson (project leader, right) and Associate Professor Helen Hasan (co-investigator, left) explore the 'Rethink Respite' website with Illawarra carer support group leader Val Fell

quality, access and use of respite services by people with dementia and their carers.

The University of Wollongong (UOW) in NSW recently launched an innovative project supporting carers and people living with dementia to 'Rethink Respite'. This multifaceted project aims to improve knowledge about, attitudes toward, and uptake of, respite services for people living with dementia and their carers, in the Illawarra-Shoalhaven region. It also aims to improve the capacity of the service system to promote and provide flexible respite services.

ReThink Respite

'ReThink Respite' is a community-based intervention in the Illawarra Shoalhaven region of NSW which has engaged with carers, people living with dementia and local service providers in its

planning and implementation.

The project aims to assist people living with dementia and their carers to:

- improve their knowledge of local respite services
- increase positive attitudes towards the benefit of respite services
- increase their capacity and

efficacy to navigate the service system to find appropriate respite services

- increase use of respite services by those with a perceived and measured need.

The project is also targeting providers and referrers of

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respite services in the Illawarra and Shoalhaven to:

- improve the quality of information available about respite
- increase respite service providers' knowledge of factors that support use of respite services
- motivate respite services to set goals and take action to enhance their service to better meet service needs
- increase promotion of, and referral to, respite services by service providers and practice nurses.

A carer reference group, including current and previous carers of people living with dementia, was instrumental in the development and testing of ReThink Respite project materials, coaching service and information resources, as well as user testing of the website. A service provider reference group helped to develop workshops for service providers. Partnership with local networks (including the Illawarra and Shoalhaven Dementia Services Networks, Aged Care Assessment Team and carer support groups) and other agencies (including Commonwealth Respite and Carelink Centre, Aged Care Assessment Teams and Alzheimer's Australia NSW) supported the development and/or promotion of the project.

Project activities

The community intervention was launched in February this year. Resources, information and activities available for people living with dementia and their carers include:

- A free ReThink Respite coaching service where health professionals use motivational theories and psychological approaches to work with carers and people with dementia to identify strengths, needs and values to encourage positive attitudes about and use of respite services/strategies.
- Information sessions at carers' groups and dementia education events.

- Stalls at community events such as the Illawarra Memory Walk.
- A tailored local website (www.rethinkrespite.com) which includes:
 - Text which repositions respite as a normal part of positive caregiving and guides use across a care pathway.
 - A decision-making guide.
 - Printable checklists to help when choosing a respite service.
 - Videos of local carers and people living with dementia's respite experiences.
 - A moderated discussion forum for carers to share their respite experiences.
 - A local calendar of dementia education and events.
 - Links to an online service directory with guides on 'how to search' including key search words.
 - Printable lists of local respite services and carer support groups.
 - A news blog.
- ReThink Respite kits (an adapted printed version of website information).
- ReThink Respite newsletter.
- A multimedia communications campaign promoting the coaching service, website and resources.
- Promotional materials include a brochure about the project, a flyer promoting local websites, a bookmark and a fridge magnet.

Components of the ReThink Respite service intervention include:

- Respite service provider training to improve the quality of local information available about respite for carers of people with dementia.
- Service provider awareness and motivational change sessions to develop services to better meet carer needs, and improve information accessibility and utility.
- Information sessions for primary health care nurses, Aged Care Assessment

Teams, Regional Assessment Services and other respite service provider groups.

- A service providers page on the 'ReThink Respite' website which includes:
 - Printable lists of local services and support groups.
 - A respite decision aid.
 - A local calendar of other dementia education and events.
 - A portal for health professionals to dementia training and educational opportunities, including promotion of 'THINK GP' accredited 'carer modules' for primary health care nurses (PN) and GPs, PN education resources.
 - Service provider information.

Future evaluation

The impact of ReThink Respite on carer knowledge, attitudes and uptake of respite services and referral to services by GPs and PNs will be carefully evaluated using a quasi-experimental design. A survey to measure knowledge, attitudes, uptake of respite services, carer burden and unmet need among carers of people living with dementia in the Illawarra and Shoalhaven has been distributed through Commonwealth Respite and Carelink, and multiple service provider groups as well as carer support groups throughout the two regions. This will be repeated in October this year at the completion of the nine-month intervention phase.

Initial baseline analysis confirms a substantial unmet need for respite throughout the area. ■

For further information about the project visit www.rethinkrespite.com or contact Dr Lyn Phillipson (lphillip@uow.edu.au) at the University of Wollongong.

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Associate Professor Helen Hasan, Dr Danika Hall and Dr Keryn Johnson) in collaboration with Dr Elaine Fielding (QUT), Associate Professor Christine Neville (UQ) and Associate Professor Christine Stirling (UTAS).

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