

## Background

ReThink Respite was a research project and community intervention designed by researchers at the University of Wollongong.

It aimed to promote the benefits of respite to carers of people with dementia and redress barriers to using respite.

Respite is an essential support for carers. Some of the benefits of respite include:

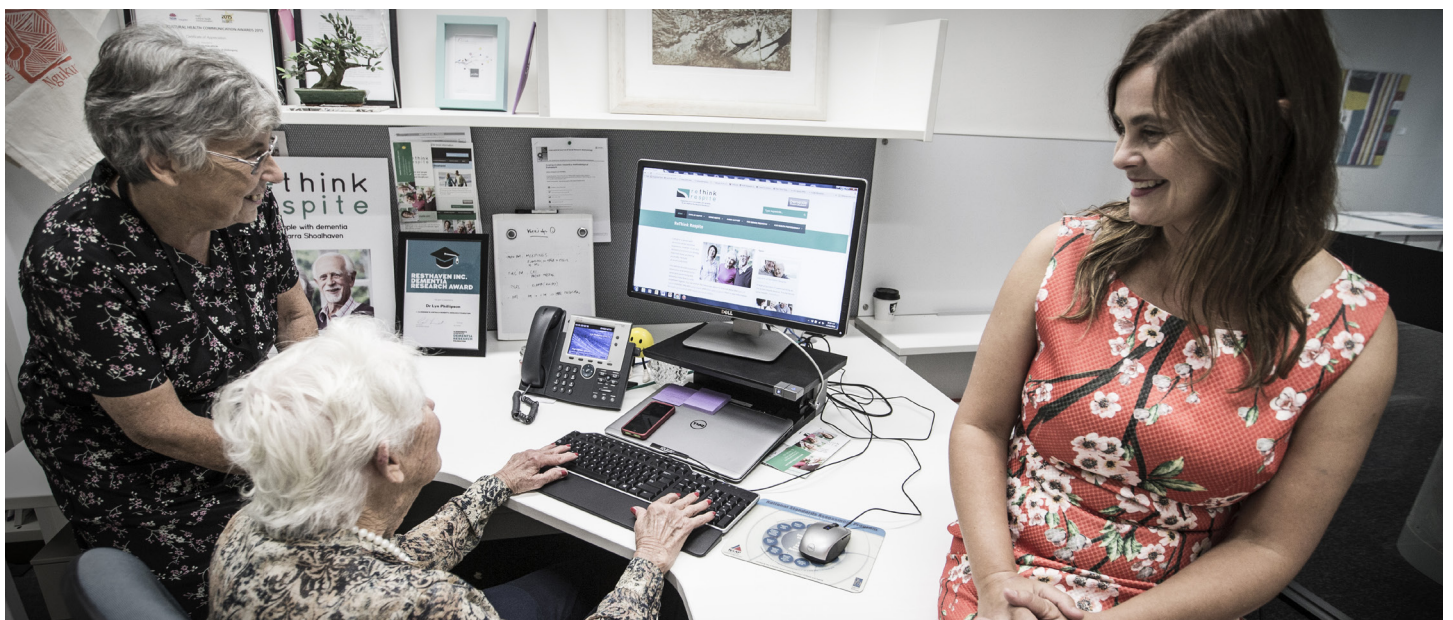
- Opportunities for carers to take time out and look after their own needs
- Increased social participation of carers such as attending support groups or taking time to meet with friends
- Increased social participation of people with dementia and opportunity to pursue activities of interest
- Keeps the carer healthy and this improves the quality of care they provide
- Sustains the carer so they can continue their caring role and the person with dementia can stay at home longer
- Provides an experience of different care facilities that may be required in future.

Carers of people with dementia consistently identify respite as one of their critical unmet needs. But the proportion of carers in Australia who use respite tends to be low. This is due to several factors including:

- Complexity of health services environment
- Absence or delays in diagnosis
- Issues with communication about or referrals to support services
- Carers' perceptions of poor service quality and expectations of negative outcomes
- Carers' feelings of guilt or failure at not fulfilling all aspects of the caring role.

## Formative Research

Over thirty consultations were conducted with service providers, carers and carer support groups, health professionals, researchers and government organisations involved in providing care and services for people with dementia and their carers. Findings informed the development of materials and resources for the ReThink Respite intervention.



## Aims of the Program

ReThink Respite aimed to improve knowledge about, attitudes toward, and uptake of, respite services for people with dementia and their carers in the Illawarra and Shoalhaven regions.

Additionally, it worked to improve the capacity of the local service system to promote and provide flexible respite services, and understand the impact of current disability and aged care reforms on respite use in the region.

## ReThink Respite Resources

The community intervention ran from February to October 2016. The intervention provided informational and navigational resources for people with dementia and their carers, respite service providers, and those promoting access to respite services throughout the Illawarra and Shoalhaven (including primary health care nurses).

Resources focused on the benefits of using respite. They guided carers about the types of services, how to choose appropriate respite, and find local services. Resources included:

- The ReThink Respite website ([www.rethinkrespite.com](http://www.rethinkrespite.com)) which now includes information of national relevance.
- Local respite services directories (searchable and downloadable PDF).
- 'ReThink Respite Decision Guide' downloadable PDF to assist carers to make decisions about using respite.
- 'ReThink Respite Checklists' to advise on what to look for/ask about when choosing specific types of respite services.
- 'ReThink Respite Experiences' videos where people with dementia and their carers discuss the benefits and their experiences of different types of respite services.
- ReThink Respite promotional materials including flyers, bookmarks and fridge magnets.

Resources were distributed via community events, community education sessions, website promotions and blogs, and project newsletters.



## ReThink Respite Activities

More than twenty community education presentations were made to over 330 people via carer support groups, community groups, primary health care nurses, Aged Care Assessment Teams, Regional Assessment Teams and respite service providers.

## Service Provider Workshops

The ReThink Respite intervention targeted service development through two workshops for service providers. Staff from eight respite services participated in the first workshop, and staff from ten services participated in the second workshop. Topics covered included:

- The features of quality respite services for people with dementia and their carers.
- Tools to audit the quality of their service.
- Brainstorming activities to identify strategies to improve quality and flexibility of services.

## Community Campaign

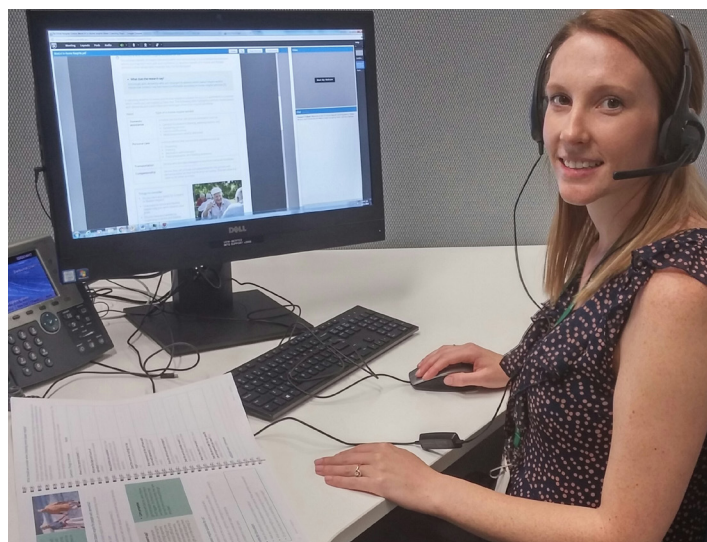
Promotion of respite as part of positive caregiving was supported by mainstream and social media including television news, local newspapers, aged sector news, community radio, community events, website blogs, Facebook and Twitter.

## ReThink Respite Coaching

ReThink Respite Coaching was conducted with people with dementia and their carers (22 dyads) who opted to receive additional support. This goal oriented program was designed specifically for the project and delivered by health professionals in participants' homes.

Five coaches (provisionally registered psychologists) were trained to use the coaching and other project resources. They supported participants to identify their respite goals and complete the coaching either via phone or in their homes.

ReThink Respite Coaching resources included workbooks and trainer manuals. Coaching also utilised project resources available on the website including checklists, decision guides and the local respite services directories.



## Evaluation: Service Provider Workshop

Both workshops received positive evaluation ratings on their usefulness to service providers.

*'Very motivating workshop, informative. Have the 'advocate for change' motivation ... Great to network and share best practice with other service providers.'* [Workshop 2 participant]

## Evaluation: Carer Intervention

An initial survey was completed by 84 carers of people with dementia living in the Illawarra and Shoalhaven regions in 2015. A follow-up survey was then completed by 44 of the 52 carers who were still eligible in 2016. The

survey measured changes in knowledge, attitudes, uptake of respite services, carer burden and unmet respite need.

## Changes in Knowledge and Attitudes

Following the nine-month intervention, carers who participated in respite coaching significantly improved in their ability to name local services.

Coaching participants showed more positive attitudes to respite services being useful and beneficial to the person living with dementia. They were more likely to believe that respite would assist them to provide care for longer and they held less negative beliefs about the standard of care provided by respite services.

During the evaluation, attitudes towards respite among those who hadn't participated in coaching became more negative.

## Changes in Self-efficacy

Coaching participants improved their efficacy in finding information about respite services and accessing appropriate respite to suit the needs of the person with dementia.

*'[Coaching] made me feel I am prepared in the event of an emergency. [It] provided me with peace of mind that if anything happened all Mum's information is in one spot.'*  
[Carer 14]

Coaching participants became more certain that they could find answers to their questions about support services, arrange services for themselves and find ways to pay for services. They also showed improved levels of personal gain including increased awareness of inner strengths, self-confidence and growth as a person.

However, a negative change was found for respondents who had not participated in coaching in relation to finding organisations that provide services in the community to help them care for the person with dementia.

## Changes in Behaviour

The majority of survey respondents stated they would like more respite than they are currently receiving. Coaching participants showed more positive intentions to use respite

services (day, in-home, residential) than other respondents.

*'I have resumed swimming on a regular basis. I am now more positive about taking time away and conscious of the benefits of respite, so I will continue making time for it.'*  
[Carer 31].

All participants continued to consider general practitioners, carer support groups and family and friends as major sources of information about respite. However, coaching participants increased the number of sources they used to find information about respite. This increase was largely due to using the ReThink Respite website and Directory of Services. This change was not found with respondents who had not completed the coaching program.

Overall, the variety of respite services listed as being used by carers increased for both those who participated in coaching as well as those only exposed to the community level intervention. This may be due to an increase in perceptions that different types of respite services exist, rather than an actual increase in the number of services used.

## Lessons Learned

Evaluation of the project demonstrates there is still an unmet need for respite for people with dementia and their carers in the Illawarra and Shoalhaven regions.

Carers participating in the ReThink Respite Coaching had many positive improvements in knowledge, attitudes and intention to use respite. They also improved self-efficacy and personal gain during the intervention period.

This was not the experience for survey participants who did not participate in coaching, some of whom showed signs of worsening during the period of the intervention. This demonstrates the benefits of one-on-one coaching support to gain the confidence and skills needed to successfully navigate the aged care system.

The ReThink Respite project took part during a transition period of aged care reforms in Australia. This, and the progressive nature of dementia as a condition, will have impacted

on participants in the study and may account for the negative trends found for respondents in the survey who did not participate in the coaching program.

## Ongoing Resources

A number of resources are still available from the ReThink Respite project including the website, decision aid, checklist and videos.

Following the intervention, the website was enhanced to become a national resource. Local resources like the services directories for the Illawarra and Shoalhaven regions were transferred to a regional dementia support website: [www.dementiais.com](http://www.dementiais.com).

## Rethink Respite Developments

Following its success in this project, ReThink Respite Coaching was refined and developed for delivery online. It became available to carers of people living with dementia throughout Australia as part of a pilot project. The model has also informed the Integrated Plan for Carer Support Services (Department of Social Services).

## Acknowledgements

ReThink Respite was funded through an Alzheimer's Australia Dementia Research Foundation, Resthaven Inc. Dementia Research Award.

The research team included: Dr Lyn Phillipson (Project Leader), A/Prof Helen Hasan, Dr Danika Hall, Dr Liz Cridland, Dr Keryn Johnson (University of Wollongong), Dr Elaine Fielding (QUT), Dr Christine Neville (Uni of QLD) and Dr Christine Stirling (UTAS).

The ReThink Respite research team would like to thank people with dementia, their carers, service providers, primary health care nurses, Aged Care Assessment Teams and many other stakeholders who have participated and assisted in this project. Special thanks go to our Carer Reference Group and Service Provider Reference Group. The project would not have been possible without your informed input and enthusiasm.

[www.rethinkrespite.com](http://www.rethinkrespite.com)