Rethinking respite: resources to support carers to access respite services

Caring for a person living with dementia can be physically and emotionally challenging. Despite this, a large proportion of carers currently do not access respite services which give them a break from their usual caring roles.

Through consultation with carers and service providers, the 2016 ReThink Respite research project aimed to better understand the reasons why people weren’t accessing respite services and to develop resources to change this.

Led by Dr Lyn Phillipson at the University of Wollongong, the project was funded by the Alzheimer’s Australia Dementia Research Foundation using funds made available through the Resthaven Incorporated Dementia Research Award.

The resulting Rethink Respite project website contains a wealth of information and resources for carers and people living with dementia in Australia to locate, access and use respite services.

The project research identified a number of reasons why carers weren’t accessing respite. Reasons included feeling guilty that they were avoiding their responsibility, fearing the person they care for won’t want to be part of a respite service, or the carer worrying the person won’t enjoy the experience.

Carers may be concerned that the behavior or mood of a person living with dementia may be negatively impacted after a period of respite.

Consequently, a project outcome was to create a decision guide for carers to help them work through the issues that may prevent them from accessing respite services. The guide aims to support carers to feel more confident about their decision and to explain it to others if necessary.

‘It gave me encouragement, direction and confidence to face our future life’s journey, and it provided me with confidence to organise respite services,’ commented one carer about using the guide.

Carers want respite to be affordable, reliable, flexible and tailored to meet the needs of the person they care for as well as their needs as a carer.
A later outcome of the research project was that the Rethink Respite website was enhanced to become a national resource. It provides checklists for carers to use to find out more about whether a particular respite service will suit their needs.

For example, carers will want to find out about the activities available, training of staff or whether the service caters for particular medical, cultural or mobility needs.

A decision aid and videos are also available.

The Rethink Respite resources are available free to both carers and organisations to encourage the use of respite services by carers.

This Resthaven-funded research has ongoing benefit for the Australian Community.