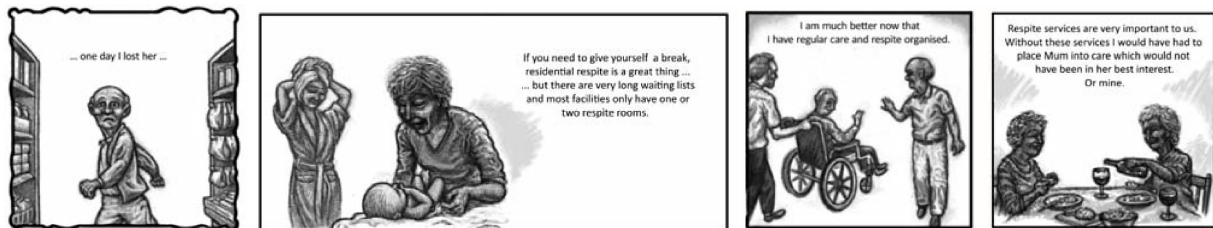


Respite experiences help carers know they're not alone

Maria O'Reilly, Elaine Fielding, Sandra Jeavons and Elizabeth Beattie introduce a new consumer guide for carers of people with dementia featuring the words and experiences of carers themselves



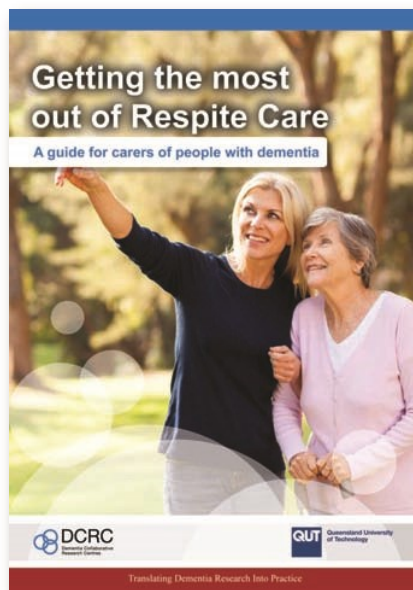
Illustrations by Greg Boylan, from *Getting the most out of respite care: a guide for carers of people with dementia*. Reprinted with permission

In 2011 more than 300 Australian carers of people with dementia were asked about respite care. The survey, by our research team from the Dementia Collaborative Research Centre: Carers and Consumers (DCRC:CC), included many open-ended questions which yielded rich information from the carers' perspective (Fielding *et al* 2012). The results indicated that respite care was largely appreciated by those who used it, but it was not without its challenges – with consumers saying they wanted more respite services, more flexibility and more information.

While we, as researchers, could not create additional and/or more flexible services, we *could* provide information. To achieve this, we looked to the words in the survey feedback from the 336 carers and recognised a plethora of personal stories and valuable advice for others. These stories were important to share, as a collective wisdom to help carers know that they are not alone.

Real and personal

The result is a free resource, called *Getting the most out of respite care: a guide for carers of people with dementia*, for and by carers of people with dementia,



covering day care, in-home respite and residential respite care. As well as using information from the DCRC respite survey responses to compile the guide, we also consulted with other carers through the Consumer Dementia Research Network (CDRN).

Getting the most out of respite care is the

first Australian guide of its kind in that it goes beyond standard health education materials, which tend to provide information from professionals and organisations rather than peers, and uses illustrations and storytelling in combination with specific carer-to-carer advice.

The carers' words and experiences have been incorporated into illustrated narratives (some of which are featured above) and the additional input from the CDRN was developed into direct advice for carers. The stories featured in the guide are very real and personal; told from the perspective of husbands, wives, sons and daughters.

The guide is designed to help carers navigate the steps, thoughts and feelings in the difficult decision to use respite care by sharing the experiences of others in their situation. It is an excellent example of how researchers, trainers and consumers can collaborate to develop something useful for the people who matter: carers and consumers living with dementia.

Where to get the guide

The Queensland Dementia Training Study Centre (DTSC) prints and

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What carers said

The key messages for family carers, from carers interviewed for the DCRC respite survey are:

- Good respite care is available.
- It helps to “recharge your batteries” and allows you to do the things you need to do like shopping, banking and working.
- When it comes to negotiating the system – ask other carers, do your research, be prepared (for example, have regular breaks booked ahead) and maintain open communication with the respite service.
- Don't be afraid to speak up if the service isn't meeting your needs.
- Don't feel guilty about using respite. Remember you need to maintain your own health and ability to attend to necessary tasks to keep caring for your loved one.

Suggested improvements for respite

- There needs to be a lot more information for both the carers and the care recipients about the types, locations and costs of all forms of respite.
- It would be helpful if both the carer and recipient could visit facilities (residential and day centres) before deciding what is needed.
- More good quality day respite centres throughout the community and suitable centres for people with younger onset dementia.

distributes the guide free of charge to service providers and carer groups, with almost 9000 copies ordered since its launch in late 2015.

An online version is also available. You can download a copy or order a hard copy from the DCRC website at <http://www.dementiaresearch.org.au/respitecareguide.html>. Bulk orders are also welcome from providers who may wish to distribute copies to clients and their families. ■

Acknowledgments

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References

Fielding E, Beattie E, Readford M, Neville C, Gresham M (2012) *Respite care in dementia: carer perspectives*. Report on full study. Brisbane: Queensland University of Technology, Dementia Collaborative Research Centre: Carers and Consumers.

■ At the time of writing, Dr Maria O'Reilly was a Research Fellow in the School of Nursing, Queensland University of Technology, Brisbane and a researcher with the DCRC:CC. She is now Senior Lecturer in Occupational Therapy at Central Queensland University, Bundaberg; Dr Elaine Fielding is DCRC:CC Senior Research Fellow; Sandra Jeavons is DCRC:CC Centre Manager and Qld DTSC Manager; and Professor Elizabeth Beattie is Director of the DCRC:CC and the Qld DTSC.

Lynn Chenoweth's article on pp32-35 of this issue highlights the positive impact of an Australian carer coaching program for families living with dementia in reducing feelings of isolation and encouraging carers' to use respite services for the first time.

Case study: Dennis

Dennis thought respite was invaluable but in need of more flexibility. On accessing in-home respite for his wife Barb, he was dissatisfied with the inflexibility of times offered because it tied him to those specific hours. Initially Barb was not happy about having a stranger in the house, but as time went on she got used to the situation.

However, Dennis worried that the respite staff sent to their home were not always well trained, with limited dementia-specific knowledge. Despite these problems, Dennis believed that the service was invaluable as it stopped him from becoming “burnt out” and prolonged the time when Barb would need long-term care.

It was his belief that caring for a person with dementia at home is preferable to residential care admission. In making suggestions about what would make respite better meet his needs, Dennis requested: more respite hours; respite over the weekend; consistency of staff even in an emergency; and a case manager to co-ordinate respite – a one-stop shop.

Source: *Getting the most out of respite care: a guide for carers of people with dementia* (Dementia Collaborative Research Centre: Carers and Consumers, Queensland University of Technology), <http://www.dementiaresearch.org.au/respitecareguide.html>.



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