A26 - A consumer guide to getting the most out of respite services for carers of people with dementia

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Despite the widespread availability of respite services in Australia, uptake by consumers has been lower than expected. While service availability and flexibility can present barriers to use, carer-related factors also create barriers, such as lack of sufficient information and not recognising or accepting the need for respite.

In 2011, the Dementia Collaborative Research Centre – Carers and Consumers conducted a survey of 336 Australian carers of people with dementia about their respite experiences. The survey contained many open-ended questions which yielded rich information about carers’ experiences, some of which could be directly translated into suggestions for other carers about effectively utilising respite. Carers not as familiar with respite might benefit from hearing the words of other carers, helping them to feel more comfortable trying respite themselves. Thus, we used material from this survey to develop a consumer respite guide from the carers’ point of view. We also sought direct input from the Consumer Dementia Research Network (CDRN) for additional suggestions.

Importantly, the guide is designed to act as a source of information from the carers’ perspective, and in that way goes beyond the standard information sources, which tend to be in the form of information from professionals and organisations rather than peers. Also making this guide unique is its use of illustration and story-telling to provide information and advice, as well as a section of specific advice gathered directly from other carers. The CDRN are being continuously consulted as the draft develops, such that the final version will constitute a carers’ resource contributed to and approved by other carers.

The Consumer Guide will be added to the DCRC website and also produced as a booklet of stories and advice. Examples of illustrated stories and carer advice will be included on the poster.