

Respite needs of older carers and those caring for the elderly



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Carers exhibit among the lowest health and wellbeing outcomes of any group studied in Australia (Cummins et al, 2007) but in order for carers to sustainably maintain their caring role, their wellbeing must be supported. The ability to take a break from caring responsibilities is a crucial mechanism by which carers' ongoing wellbeing can be sustained. In 2016 Carers NSW conducted a national survey to identify carers' respite needs and their experiences of using respite.

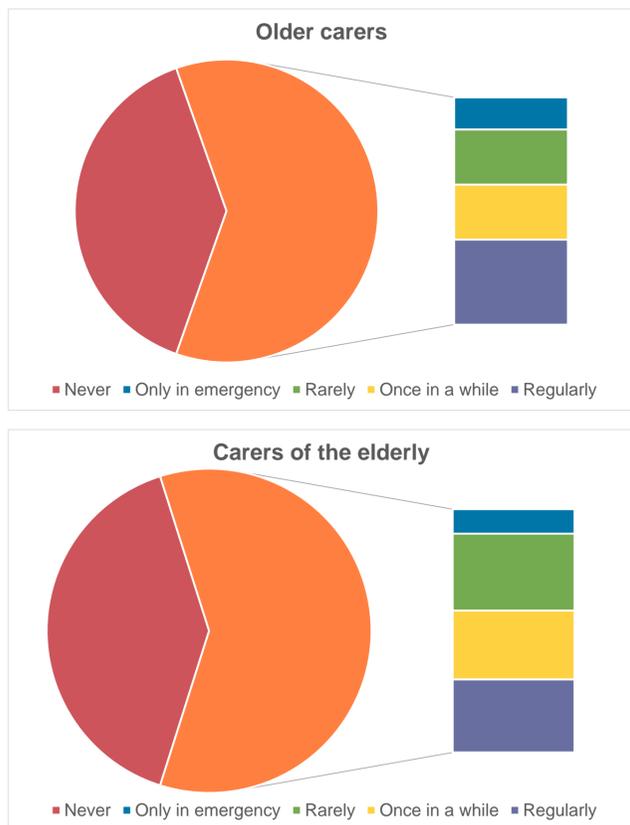


Figure 1. How often do you use respite?

Do carers want respite?

339 survey respondents were aged 65 years and over and 301 respondents were caring for a frail aged person. 86 of these respondents fell into both categories. Around 40% of all three cohorts did not use respite (Figure 1). Their top reasons for not using respite were:

- 1) I don't know how to access it
- 2) I can't find anything that suits the needs of the person I care for
- 3) I can't afford it

These responses indicate that many older carers and carers of the elderly are missing out on a service that they would like to access, if they knew how, and if it met their needs.

What do carers get out of respite?

Responses from older carers and carers of the elderly indicated that respite was highly valued as an opportunity to take a break, look after their own health and sustain the caring role (Figure 3). Carers clearly benefited personally from respite and commonly used a mix of planned and emergency respite (Figure 2). Respondents' frequency of respite use ranged broadly from 'regular use' to 'rarely' with fewer carers indicating that they only use respite in an emergency (Figure 1). Despite this relatively even spread of frequency, carers of the elderly reported lower satisfaction with the amount of respite they were receiving (44%) with the older carers having only a slightly higher rate of satisfaction (52%) (Figure 4).

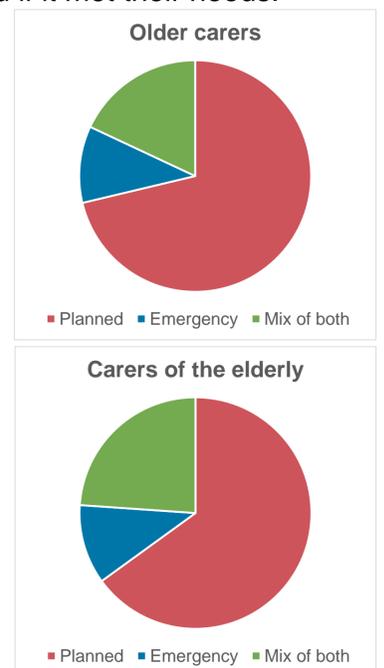


Figure 2. Types of respite used

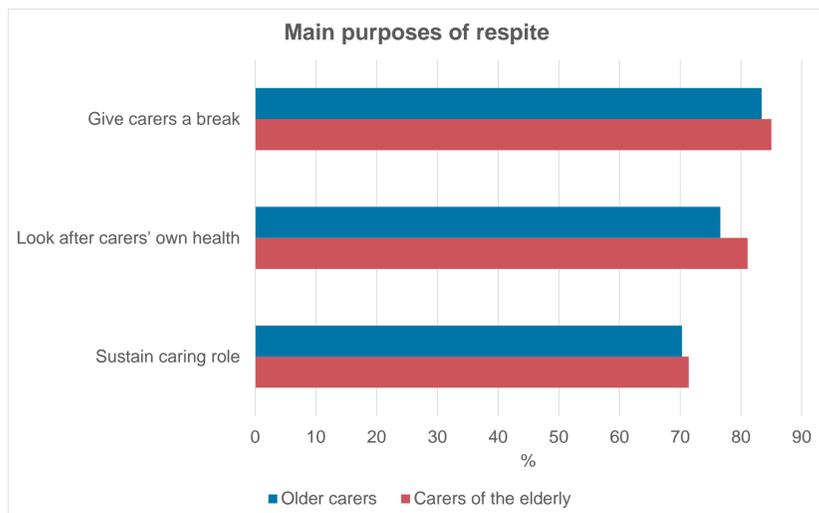


Figure 3. Main purposes of respite

Is respite meeting the needs of older carers and carers of older people?

Qualitative responses to the survey indicated an overwhelming preference for flexible forms of respite that can be delivered at a time that is convenient for the carer, allowing them to participate in certain activities or see friends and family at times when they are available. Respite activities also need to match the abilities and interests of the person being cared for, but after hours and weekend respite is rare. Some care recipients reject respite because they are not engaged with activities that they enjoy, or because their care needs exceed the capabilities of a given respite service. Responses made it clear that in order for respite to have the desired effect for both carer and care recipient it must engage the recipient and be delivered in a time and manner that allows a carer to undertake a meaningful activity at the same time.

Do older carers and those caring for the elderly have the same respite needs?

No. Just as consumer directed care and individualised funding reflects an understanding that the care recipient has unique needs and preferences, so should the diversity of carers' needs be recognised. **Older parent carers** may be experiencing increased frailty or health issues and have unique concerns about sustaining care in poor health, planning alternative future care and promoting the independence of the care recipient through respite. **Carers of an ageing parent** are more likely to be of working age, juggling work and family life in conjunction with caring for a parent, meaning that their respite needs could be associated with maintaining employment, undertaking studies or taking extended breaks for time with family. **Spousal carers**, like older parent carers may also be dealing with declining health or frailty alongside caring for a partner with similar conditions. Behavioural issues associated with dementia or physically demanding tasks are significant challenges for spousal carers.

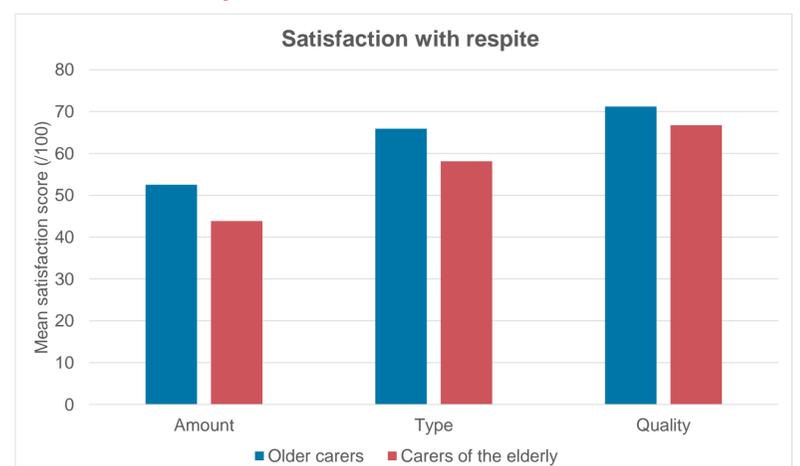


Figure 4. Respite satisfaction