There are 2.7 million carers in Australia. More than one in every ten Australians is a carer. Carers can be partners, parents, sons or daughters, siblings, other relatives, friends or neighbours. Some carers provide constant help with things like bathing, dressing and toileting. Other carers support someone who is fairly independent, but needs emotional support or help with their shopping, housework or finances.

Many carers say caring gives them a sense of purpose, achievement and satisfaction. Carers also benefit our economy, saving governments more than $60 billion dollars every year in paid care. However, caring can be hard. Carers often experience financial stress, poor health outcomes and low wellbeing.

A carer is any individual who provides care and support to a family member or friend who has a disability, mental illness, drug and/or alcohol dependency, chronic condition, terminal illness or who is frail. Carers come from all walks of life, cultural backgrounds and age groups.

Respite is a service that gives carers a break from their caring role by providing replacement care. Respite can take place in the home or in a special facility, during the day, overnight or for longer periods of time. Respite often takes the form of leisure and/or learning activities for the person requiring care.

A range of services exist to help carers. One of these services is respite. Many carers find respite gives them much needed time out from caring, allowing them to focus on their own health and wellbeing, spend time with family members and friends, or pursue education or employment. However, there is simply not enough respite to go around. As our disability and aged care systems focus more and more on care recipients, it is getting harder for carers to access the respite they need.

In August and September 2016, Carers NSW conducted a survey of 1,803 carers across Australia, on behalf of the National Network of Carers Associations. We wanted to find out more about why carers use, or don’t use, respite. We endorse disability and aged care supports that are tailored to the needs of care recipients, but we believe that carers’ needs are just as important.

This paper summarises key findings from our survey. You can find the full report at www.carersnsw.org.au/research

Typical Respondent

The typical respondent was a woman aged between 45 and 64 caring for her son or daughter with disability, who has high care needs and cannot be left alone for long, if at all.
WHAT THEY SAID

More than one in three carers had not used respite before – but this was not necessarily because they did not need it. Their reasons had more to do with how difficult it was to access respite that suited their particular needs. This is an important finding, because governments are increasingly telling us that carers don’t want respite. Our survey shows this is not the case.

One of the most common forms of respite carers had used was respite from family members or friends. While this is not really a respite service, it shows how important these informal connections can be. However, research indicates that many carers do not have family members and friends to call on when they need help.

Respite needs to be made more accessible to carers rather than having to ring around various departments and being put on a waiting list that you never hear back from.”

<table>
<thead>
<tr>
<th>TOP 3 REASONS FOR NOT USING RESPITE</th>
<th>%</th>
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<tbody>
<tr>
<td>I don’t know where or how to access it</td>
<td>30%</td>
</tr>
<tr>
<td>I can’t find anything that suits the needs of the person I care for</td>
<td>18%</td>
</tr>
<tr>
<td>I can’t afford it</td>
<td>15%</td>
</tr>
</tbody>
</table>

“Respite is extremely important for me as I don’t have any family support. And the small breaks I get help me to refresh and go again. I find if I don’t get a break my health suffers and it becomes extremely difficult to give my daughter the care she needs.”

WHO RESPONDED TO THE SURVEY?

Carers from every state and territory responded, with the largest numbers coming from New South Wales and Queensland. Over 80% of respondents were female, and most were of working age. Disability, mental illness and chronic illness were the most common reasons the people they cared for needed assistance.
Whether or not they had used it, carers felt respite was a service primarily for carers, rather than the people they care for. Most saw the main purpose of respite as giving carers a break and an opportunity to look after their own health and wellbeing. Respite was also seen as an important tool for helping carers continue to care.

**TOP 3 MAIN PURPOSE(S) OF RESPITE**

<table>
<thead>
<tr>
<th>Purpose</th>
<th>%</th>
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<tbody>
<tr>
<td>It gives carers a break from their caring responsibilities</td>
<td>84%</td>
</tr>
<tr>
<td>It gives carers an opportunity to look after their own health and wellbeing</td>
<td>76%</td>
</tr>
<tr>
<td>It helps carers sustain their caring role</td>
<td>68%</td>
</tr>
</tbody>
</table>

These findings are particularly significant because the focus of respite-type services is shifting from carers to care recipients. Increasingly, carers are only considered to the extent that services help them continue caring. However, our survey shows that carers think they deserve a break in their own right, and that their own health and wellbeing is just as important as sustaining their caring role.

“Carers’ needs include respite breaks and being able to talk about this as a normal aspect of being a carer not something you have to beg for, or buy or try and get.”

Carers who had used respite said that it was highly important. However, satisfaction with respite wasn’t so high, especially with the amount of respite they used. Satisfaction with respite increased considerably when respondents had used respite more frequently. These findings suggest that the key issue with respite is the amount available to carers.

Word cloud based on written comments carers made in the survey.
SUMMARY

• Respite gives carers a much needed break, but is getting harder for carers to access.

• Increasingly, governments are assuming that carers don’t need respite, and that improving supports for the people they care for should have a ‘respite effect’.

• Our survey found that a lot of carers want to use respite services but don’t because they can’t get services that suit them.

• Carers also said that a lack of information about respite options, complicated pathways to access respite and the cost of respite prevented them from accessing these services.

• Carers saw respite as a way of getting a break and maintaining their health and wellbeing.

• Even with improving disability and aged care supports, a carers’ own need for a break should be respected. Flexible respite services that focus on carers’ needs should continue to exist.

WHAT CAN I DO?

• Order more hard copies of this publication by calling 1800 242 636 or emailing policy@carersnsw.org.au and give them to your relatives, friends or service providers.

• Share the online version of this publication via email, Facebook or Twitter by visiting our website.

• Write to your local Federal Member of Parliament asking to meet them in person. Take a copy of this publication to the meeting to share with them.

• Write to your local newspaper highlighting key issues and sharing your experiences of respite.

• Contact the Carers NSW Policy Team and share your story and help us to advocate for change.

SOURCES OF INFORMATION


