



Respite care

DEMENTIA CARE

This evidence theme on respite care is a summary of one of the key topics identified by a scoping review of dementia research.

Key points

- Respite care refers to the temporary provision of care for a person living with dementia, at home, in the community, or a residential care setting, by people other than the primary carer.
- Evidence from five systematic reviews showed that respite care reduced responsive behaviours and improved carer-related outcomes such as the impact of supporting someone living with dementia and well-being.
- The evidence for benefit of respite care in outcomes such as carer depression and sense of social support is inconclusive.
- Studies found no relationship between respite care attendance and outcomes such as carer anxiety, and time to admission to residential aged care.

What is respite care?

Respite care refers to the temporary provision of care for a person living with dementia, at home, in the community, or in a residential setting, usually by paid staff or volunteers. [1]

Respite care can take place:

- In the home of the person living with dementia
- In a centre-based day service
- Through supported activities in the community
- In a residential setting.

The care provided may also vary in duration, ranging from a few hours to several weeks. Respite care may be planned or unplanned and may involve overnight care or daytime-only care. Ideally, the person living with dementia and carer should be able to choose the type of respite care that suits them, but often only one type of care is available in any one geographical area. [1]

Is respite care effective?

We found five systematic reviews that assessed the impact of respite care. Multiple studies report the benefits of respite care for people living with dementia and their family carers. However, most studies focused on family carer outcomes.

These include improvements in:

- Carer mood fluctuation [2]
- Carer sense of competence [2, 3]
- Carer psychological well-being. [2]

These also include reductions in:

- Responsive behaviours for the person living with dementia [4]
- The impact of supporting someone living with dementia (sometimes referred to as 'carer burden'). [2, 4]

The evidence of the effectiveness of respite care is less conclusive for some outcomes. For example:

- Carer sense of social support [1, 2]
- Carer depression. [1, 2]

This is because some studies reported benefits, while others did not.

Studies have assessed the relationship between respite care and carer anxiety, but no benefit was found. [1] One study reported that centre-based day services were associated with accelerated time to admission to residential care. [4]

Overall, respite care appears most likely to be associated with better outcomes (for both those with dementia and family carers) when carer support and education are incorporated. [4]

Evidence limitations

The reviews highlighted concerns about the methods used in some of the studies. This reduces the degree of certainty we might have about the benefits of respite care. For example:

- What respite care involved was often unclear (e.g., how long people participated, how often, and the type of activities offered). [1-3]
- Potentially important outcomes have not been assessed yet (such as the views and experiences of the person living with dementia). [5]
- Some studies only had a small number of participants. [1, 3]
- There was not much information about the effectiveness of in-home respite care programs. [4]

What can an individual do?

- Familiarise yourself with the range of carer supports that are available, including respite. These might be offered by your organisation or by other services. See www.carergateway.gov.au

- Be alert for signs of carer stress, distress, isolation, elder abuse, and other signs that further support is needed for both the person living with dementia and their carer.
- When providing care for someone who is living with dementia, find time to make their family carer aware of what supports are available, including respite, and offer information and referral. These supports should be offered to all family carers. You do not need to wait until there are signs that the carer is not coping.

What can the organisation do?

- Develop flexible, reliable respite programs that meet the needs of people living with dementia in a meaningful way and support their family members.
- The Aged Care Standards require family carers to be included in planning and feedback, and for their relationship with the person living with dementia to be supported. Use this as an opportunity to consider the needs of both the person living with dementia and the needs of their carer.
- Consider how you can actively support the family carer with information and education, including while the person living with dementia is in respite care.
- Actively promote those of your services that can be accessed as a respite option. Develop systematic processes and resources to refer the family members of people living with dementia to the Carer Gateway for the full range of options. See www.carergateway.gov.au/
- Ensure that all staff are upskilled in the available options, and in sensitively offering referrals and support to family carers.
- Where your organisation provides respite in the home of the person with dementia, discuss with their family carer how you can also meet their needs. For example, you might support the person with dementia to take part in meaningful activities outside of the home so that their carer gets a break at home.
- As an organisation, build connections and partnerships with other organisations that support family carers and/or provide respite.

References

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