



# Carer support interventions

## DEMENTIA CARE

This evidence theme on carer support interventions is a summary of one of the key topics identified by a scoping review of dementia research.

### Key points

- Interventions to support people living with dementia and/or their carers usually include providing education, training, support, or techniques to reduce carer stress.
- Evidence from 21 systematic reviews showed that supportive interventions improved neuropsychiatric symptoms for the person living with dementia.
- The evidence of the benefit of supportive interventions for outcomes such as responsive behaviours, quality of life, mood, ability to manage one's own self-care, and admission to residential aged care for the person living with dementia is inconclusive.
- Supportive interventions improved carer self-efficacy and quality of life.
- The evidence of the benefit of supportive interventions for outcomes such as the impact of supporting someone with dementia and carer psychological wellbeing is inconclusive.
- Studies that assessed the relationship between supportive interventions and outcomes such as carer knowledge, skills, coping, and stress found no benefit.

### What are carer support interventions?

*Note: we understand that not all family members are carers, and not all carers are family. We also understand the role of carer may not always be filled by a singular person. We use the term 'carer' throughout this page, but please note that this may often be relevant for family members or refer to multiple people.*

Many different types of interventions focus on improving the wellbeing of people living with dementia and their carers. These include providing education, training, support, or techniques to reduce carer stress (such as mindfulness or physical activity).

These approaches often aim to improve outcomes such as:

- The impact of supporting someone with dementia (sometimes referred to as 'carer burden')
- Carer wellbeing or competence
- Care outcomes for the person living with dementia
- The relationship between the person living with dementia and their carer (sometimes referred to as the dyad).

Most of these interventions are for individuals living in the community (i.e., home care), but some focus on improving the transition to residential care for people living with dementia and their carer or encouraging family involvement once the person living with dementia is in a residential care setting.

Please note psychological interventions for those living with dementia and/or for those providing care are summarised in a separate evidence theme. Please refer to ARIIA Knowledge Hub Resources.

## Are carer support interventions effective?

We found 21 systematic reviews about supportive interventions for people living with dementia and/or their carers. For people living with dementia, supportive interventions were associated with improvements in neuropsychiatric symptoms. [1]

The evidence of the effectiveness of supportive interventions is inconclusive for certain outcomes for people living with dementia, such as:

- Responsive behaviours (sometimes referred to as expressions of unmet need) [2-4]
- Quality of life [1]
- Mood [4]
- Daily activities [1, 4]
- Admission to residential aged care [1, 3-6]
- Falls. [7]

For the carer, supportive interventions were associated with:

- Quality of life [4, 6, 8]
- Self-efficacy [3, 9]
- Knowledge [9, 10]
- Skills [10]
- Attitude [10, 11]
- Competence [10, 11]
- Anxiety [9]
- Depression [9]
- Satisfaction [9]
- Perceived availability of formal and informal support. [11]

The evidence of the effectiveness of supportive interventions for carers is inconclusive for certain outcomes, such as:

- Impact of supporting someone living with dementia (sometimes referred to as 'carer burden') [1, 2, 4-6, 8, 9, 12-15]
- Psychological wellbeing [5, 16]
- Carer knowledge and skills [5, 9]
- Carer coping and stress. [9, 17]

This is because studies have assessed the relationship between supportive interventions and these outcomes, but no benefit was reported.

More research is needed to determine how certain interventions may benefit people living with dementia and their carers. However, interventions were more likely to be effective when:

- They had multiple components (e.g., skills training, professional support, and online support [16, 18])
- They were tailored to suit the individual. [3, 18]

## 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 supportive interventions. Gaps in the literature have also been identified. For example:

- Some studies only had a small number of participants. [2, 3, 6, 11, 12, 15, 17, 18]
- Impact of supporting someone living with dementia (sometimes called 'carer burden') was defined and measured in many different ways, making comparison of effectiveness on this particular outcome difficult. [18]
- Potentially important outcomes have not been assessed yet such as the additional pressure that participating in a program may have on a carer [5], the impact on secondary carers [16], and cost. [6, 19]
- It is unclear how long benefits last. [3, 6, 11, 16]

## What can an individual do?

- Assisting a person with dementia and their family carer to understand their diagnosis through a referral to Dementia Australia, participation in a course about dementia or talking with their GP or counsellor can assist the person to overcome the stigma often associated with dementia.
- Encourage individuals to seek information early on - supports that are available for the carer and programs to keep people with dementia connected to their hobbies and interests help maintain quality of life.
- Include the person with dementia and their carer in discussions about care, support, and planning ahead.

## What can the organisation do?

- Provide dementia-specific carer support programs to share concerns and connect with other people in their situation
- Provide respite services based on interests and needs that are meaningful to the person with dementia and that allow the carer time to rest or to gain support and information.
- Offer transition support from home to residential care to assist the carer to remain in their role of partner or relative.
- Provide information as changes are noticed and more care is needed.

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