

Carers' Experience

Carers have a significant personal relationship with a person living with dementia and provide the main source of emotional and practical support.

As the number of people living with dementia increases, more and more informal carers are relied upon for support. Understanding specific areas where carers need assistance is essential to help them provide effective care and support while maintaining their own wellbeing.

Many carers report unmet needs related to caring for individuals living with dementia. A lack of understanding of dementia can exacerbate feelings of distress and helplessness, leaving carers unprepared for the challenges they face.

Carers identified gaps in knowledge for dealing with:

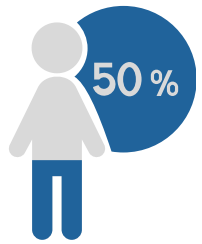
- deteriorating symptoms
- changed behaviours
- participating in care planning and identifying care preferences for the future
- how to access support services
- support to make decisions and progress transition to residential aged care

**“Am I ringing the ambulance too much? Am I not supposed to? I was back and forth to the hospitals just like you know a treadmill of doing the same things.”
(daughter)**



Unmet needs among carers of individuals living with dementia

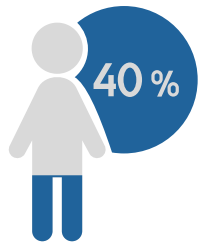
Most carers identified at least one unmet need



- Emotional wellbeing
- Worry about the future
- Feeling angry or frustrated

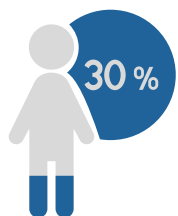


Carers reported an average of 16 out of 80 possible needs



- Managing stress
- Feeling sad
- Keeping up social activities or hobbies
- Coping with thinking for the person they support as well as themselves
- Feeling as though they are the only one supporting the person with dementia
- Navigating the My Aged Care website

- Awareness of trials or research
- Uncertainty about who will care for the person they support if something happens to them
- Understanding which symptoms are dementia and which are not
- Keeping the person they support motivated and physically active
- Finding meaningful and enjoyable activities for the person they care for



- Balancing the role of carer with other responsibilities
- Getting enough sleep
- Feeling unsure about how the person they support would like to be treated
- Explaining to others what they are going through
- Feeling lonely
- Finding information on treatments

- Knowing when the person they support should move to a nursing home
- Understanding the perspective of the person they support
- Accessing a home care package with enough help for the person they support
- Accessing dementia-specific care

Supporting carers in their role

Our research suggest carers lack support in navigating their responsibilities, particularly when it comes to decision making. This lack of guidance can intensify their emotions as they reflect on the adequacy of care they provide.

Feelings of relief among some carers were often intertwined with guilt when supporting the person they care for into residential care. Over time, this guilt diminished as they recognised that the person living with dementia was in a safe environment, "being well cared for", and receiving stimulating opportunities. Positive transitions and adjustment by the person living with dementia to life within a residential aged care facility also fostered feelings of relief.

Participants observed that treating clinicians generally focused on updating the severity of the dementia diagnosis. However, others found reassurance when their caregiving role was acknowledged. Importantly, information needs evolve, and health care professionals should regularly reassess these needs to provide ongoing support.

**"I just did not feel like that (geriatrician) was too helpful but then as I left he said to me, 'You are doing a good job.' Nobody had ever said that to me that was really good to hear."
(daughter)**

**"It was really hard; it was a struggle in the aspect of ... am I doing the right thing? Or should they be in a care facility?"
(daughter)**



INFORMATION SOURCES

White, J., Falcioni, D., Barker, R., Bajic-Smith, J., Krishnan, C., Mansfield, E., & Hullick, C. (2024). Persisting gaps in dementia carer wellbeing and education: A qualitative exploration of dementia carer experiences. *Journal of Clinical Nursing*, 33(11), 4455–4467. <https://doi.org/10.1111/jocn.17404>

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The National Dementia Helpline
Free call 1800 100 500
Email helpline@dementia.org.au

Useful links from the Dementia Australia website:

<https://www.dementia.org.au>

<https://www.dementia.org.au/living-dementia/family-friends-and-carers>



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