



Creating a balanced view of caring for someone with dementia



What is the focus of the research?

Co-design a resource that reflects a balanced view of the diversity of experience of caring for someone with dementia.



Why is it important?

Caring for a person living with dementia is challenging and often portrayed in terms of negative outcomes, such as depression, burden and chronic stress. These adverse effects undoubtedly exist. The negative mental, physical and fiscal impacts associated with caring are real, but they are not the full picture.

Evidence shows that the vast majority of carers can identify at least one specific positive aspect of caregiving, and many describe it as an emotionally rewarding experience. Some carers say it helps them to build patience and understanding, strength and resilience, increased self-awareness and knowledge. Others report the strengthening of intimacy and emotional closeness as a result of caring for a spouse with dementia. Many children and grandchildren

value the opportunity to spend more time with their loved one and to get to know them more deeply. For a range of reasons, most carers of people living with dementia will experience both positive and negative aspects - sometimes perhaps even simultaneously.

The mental and emotional wellbeing of carers can be impacted by feelings of overwhelm and isolation. It is common for people to feel exhausted and alone. While it is important to acknowledge and deal with these feelings, it is also critical for carer wellbeing that a balanced perspective of caregiving is available. A balanced resource can remind people of the good moments, make them smile at the silly and unexpected, and give them strategies to help during the most challenging times.

Providing a more understanding of the realities of caregiving is even more important for new and prospective carers who may be feeling overwhelmed by the more heavily publicised negative impacts of caregiving. Dr Moore hopes that her research will help alleviate some of the distress by providing positive solutions and portrayals.



How will this happen?

Stage 1: conduct individual and group interviews with carers of people with dementia. Facilitate discussion on the challenges and difficulties of caring, on the positive experiences of caring, and what has helped the carer to navigate the experience thus far.

Stage 2: run a workshop for participants where findings about the care experience are shared. The group will identify the messages and principles that carers want to promote to other carers and prospective carers, as well as the way they want to do it (e.g. accessibility, tone, terminology), the best media format (e.g. animation, short stories, journey mapping, drawing) and a plan for its dissemination.

Stage 3: engage an appropriate designer or developer, based on the medium chosen, to create a pilot output.

Stage 4: present the drafted product to carers at a second workshop and seek input on its strengths, weaknesses and whether the product adequately conveys the key messages.

Stage 5: refine the product and disseminate the product.



What will this mean for experienced carers?

- The opportunity to tell their stories of both positive and negative aspects of caregiving.
- New strategies to help with the challenges of caring for someone with dementia.
- Better mental health and resiliency.



What will this mean for new or prospective carers?

- Access to a resource that demonstrates the full gamut of carer experiences which they can use when preparing for the future.
- A chance to see the creative ways other carers engage with the person they are caring for in moments of difficulty.
- A reminder that they are not alone and that they will survive this.
- Confidence that there are strategies to help them when they eventually need them.
- Better mental health and resiliency during their care experience.



Who's undertaking the research?

Dr Kirsten Moore, National Ageing Research Institute

Dr Moore is a social gerontologist and senior research fellow in the Melbourne Ageing Research Collaboration at the National Ageing Research Institute (NARI). She returned to NARI in 2020 after six years working at the Marie Curie Palliative Care Research Department at University College London, where she focused on dementia and palliative care.

Dr Moore completed an Alzheimer's Society senior fellowship on grief and preparation for end of life in family carers of people with dementia, and undertook research on extended aged care at home, falls prevention, and health and aged-care evaluations.

The title of Dr Moore's project is '*Creative caring: promoting a balanced view of caring for someone with dementia*'.