

Evidence Brief: Carer Research

Research Centre for Palliative Care, Death and Dying

The Research Centre for Palliative Care, Death and Dying (RePaDD) works to make a positive difference to the care of persons in palliative care and at the end of life by examining the issues and challenges experienced by people living with a life-limiting illness, their carers, and the health and care professionals supporting them.

Comprised of a diverse, multidisciplinary team, the Centre works collaboratively with organisations and funding agencies across South Australia and Australia to improve the quality and delivery of palliative care across the health system by undertaking and translating high impact research into evidence-based resources and better outcomes for those at end of life.

RePaDD Carer Research

There are more than 2.8 million carers in Australia, with around 861,000 being primary carers providing the most informal support to a family member or friend. Understanding their needs, perspectives, and challenges is critical if we are to offer them meaningful and timely support and resources.



Drawing on extensive experience with research projects investigating the complex needs of carers, RePaDD's suite of carer-related research projects provide evidence-based information, tools and resources to support carer health and well-being.

This evidence brief provides information on a number of carer-related RePaDD research projects, and showcases the Centre's activities in this important area.



Carer Research Projects

CarerHelp

Those who provide physical, emotional, and practical support to people approaching the end of their lives can feel overwhelmed, isolated and experience psychological and/or financial distress. Following a literature review of key issues facing carers, a scoping scan of existing online resources, interviews and focus groups with carers and user testing, CarerHelp (carerhelp.com.au) was created to support and empower carers of people who are seriously ill or dying.

This open access online resource provides reliable and trustworthy information and tools (including videos, training modules, and information packs) to help carers feel both informed and prepared for the experience of caring for a dying person. Ongoing evaluation also explores emerging needs and the usefulness of the resources.

Researchers: Prof Jennifer Tieman, Assoc Prof Mark Boughey, Dr Kristina Thomas, Ms Di Seward, Prof Peter Hudson, Prof Deb Parker
Partners: Flinders University, Carers Australia, University of Melbourne
Funding: Australian Government Department of Health and Aged Care

CareSearch

Australia's National Palliative Care Strategy acknowledges the critical role carers and families play in supporting people at the end of life. The CareSearch Project (caresearch.com.au) synthesises and consolidates online palliative care knowledge and makes it available to carers, families, older people and the general community. There are specific evidence based resources for patients and carers developed with the community.

Researchers: Prof Jennifer Tieman, Dr Katrina Erny-Albrecht
Funding: Australian Government Department of Health and Aged Care

Carers Health Assessment

A person living with a life-limiting illness and their caregivers can have different information and support needs across the end-of-life period. This Masters research project explored the benefits of a separate psychological assessment of carers and those at the end-of-life during the clinical care processes. Having separate time and privacy for carers in the clinical setting to reveal fears and feelings related to end-of-life care can have a positive impact on their health and wellbeing.

Researcher: Kate Swetenham
Supervisors: Prof David Currow, Prof Phyllis Butow, Prof Jennifer Tieman



Review of the Literature on End-of-Life Care

Families and carers are integral to end-of-life care and health care providers need to understand and consider the perspectives of these two groups. The Australian Commission on Safety and Quality in Health commissioned RePaDD to undertake two literature reviews on end-of-life care to inform revisions to the *National Consensus Statement: Essential Elements for Safe and High-Quality End-of-Life Care*.

These reviews identified families and carers as integral partners in the care and bereavement journeys, revealed a lack of carer knowledge on death and dying, and highlighted the importance of public education to improve death literacy among carers and others.

Researchers: Ms Deb Rawlings, Assoc Prof Kim Devery,
Prof Jennifer Tieman, Dr Paul Tait, Dr Amal Chakraborty
Funding: Australian Commission on Safety and Quality in Health (ACSQHC)

Carers' Experience of Access to Information & Support

For carers of palliative patients, access to information and support services is crucial for their caregiving role and self-care. This study explored caregivers' experiences accessing palliative care and self-care information, resources, and services. Through interviews, focus groups and an assessment of carers' death literacy, the study is revealing new insights into the experience of carers navigating systems, looking after their own health, as well as how carers can be important collaborators in policy design and implementation.

Researchers: Dr Sara Javanparast
Partners: Carers SA
Funding: SA Health, SA Department for Health and Wellbeing

Families, Grief and Residential Aged Care

Many older people live in residential aged care and most will also die there. The grief and loss felt by their families and family carers through entry, and subsequent decline and death, is under-recognised.

Based on a systematic review of key literature pertaining to grief, loss and bereavement and interviews and focus group discussions with families, caregivers and aged care staff, an evidence-based bereavement booklet was produced and distributed (via print and [electronically](#)) to residential aged care facilities across South Australia. Issues in bereavement for carers were further explored by researchers in the RePaDD as part of a national project funded by the Medical Research Future Fund (2023) to identify the mental health effects and support needs of carers bereaved during and following Covid-19.

Researchers: Prof Jennifer Tieman, Dr Priyanka Vandersman,
Kate Swetenham, Dr Mary Brooksbank
Partners: Flinders University, GriefLink,
SA Department for Health and Wellbeing
Funding: SA Department for Health and Wellbeing



When someone dies in residential aged care:
Grief and loss for families

Death Preparedness & Bereavement Services for Carers

Family caregivers take on much of the burden of end-of-life care for most patients. Provision of bereavement information and support is an expected function of specialist palliative care services. This PhD research showed that the provision of bereavement information and pathways to support provides a 'safety net'. Importantly, the decision to make use of bereavement services was related to self-assessed need and not simply because of contact.

Researcher: Dr Kate Jurgens
Supervisors: Prof David Currow, Prof Jennifer Tieman

Implications for Policy and End-of-Life Care

As the Australian population rapidly ages and the demand for palliative and end-of-life care continues to grow, so too does the importance and value of those who provide much-needed care for those who need palliative care or are dying. Family members and others who provide physical, emotional, and practical support to people approaching the end of their lives not only contribute to the quality of life of those approaching death, but significantly reduce the pressure on an overburdened health care system. Acknowledging the contribution of carers and understanding their perspectives, needs and challenges is therefore critical to ensuring that adequate support is provided to this increasingly important group.

RePaDD Carer-Related Research Products

- Adams A, Miller-Lewis L, Tieman J. [Learning Designers as Expert Evaluators of Usability: Understanding Their Potential Contribution to Improving the Universality of Interface Design for Health Resources](#). Int J Environ Res Public Health. 2023 Mar 5;20(5):4608.
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- Marco DJ, Thomas K, Ivynian S, Wilding H, Parker D, Tieman J, Hudson P. [Family carer needs in advanced disease: systematic review of reviews](#). BMJ Support Palliat Care. 2022 Jun;12(2):132-141.
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- Rawlings D, Miller-Lewis L, Tieman J. [Community Views on 'What I Want 'Before I Die'](#). Behav Sci (Basel). 2018 Nov 30;8(12):111.
- Rawlings D, Tieman J. [Patient and carer information: Can they read and understand it? An example from palliative care](#). Aust Nurs Midwifery J. 2015 Nov;23(5):26-9.
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- Tieman J, Vandersman P, Brooksbank M & Swetenham K. [Supporting the Grief, Loss and Bereavement Needs of Families of Older People Living in Residential Aged Care](#). RePaDD White Paper. Adelaide, South Australia: Flinders University Research Centre for Palliative Care, Death and Dying; 2021.