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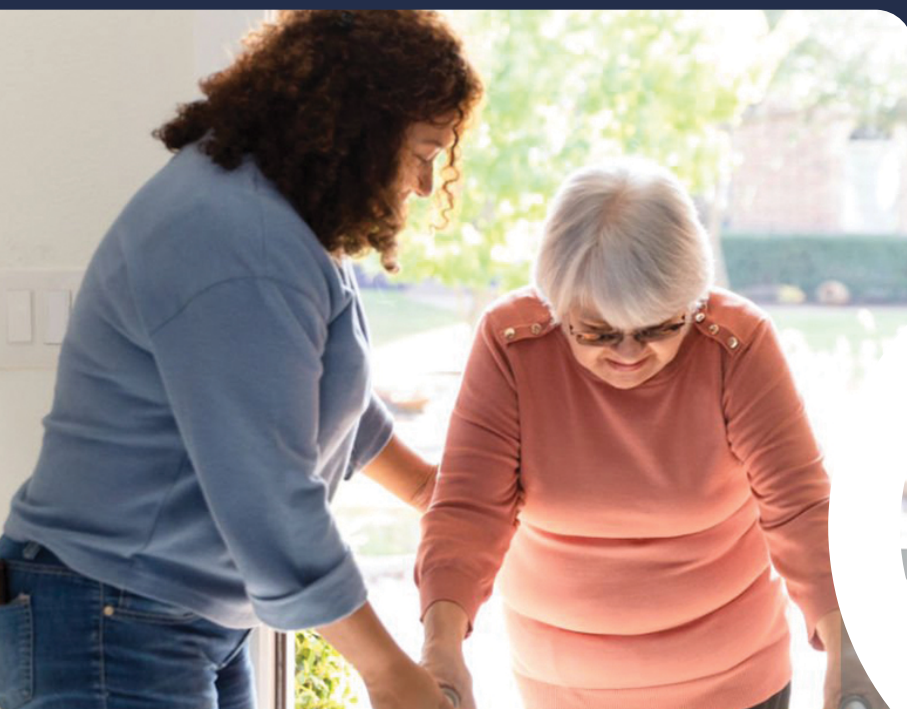
**Research Centre for  
Palliative Care, Death & Dying**

# **Unpaid Carers' Forum:** **Recognition, Support, Action**

**A report of the RePaDD Unpaid Carers' Forum**

**Professor Jennifer Tieman**  
**Dr Sara Javanparast**

**Published by the Flinders Research Centre for Palliative Care, Death, and Dying**



## About RePaDD

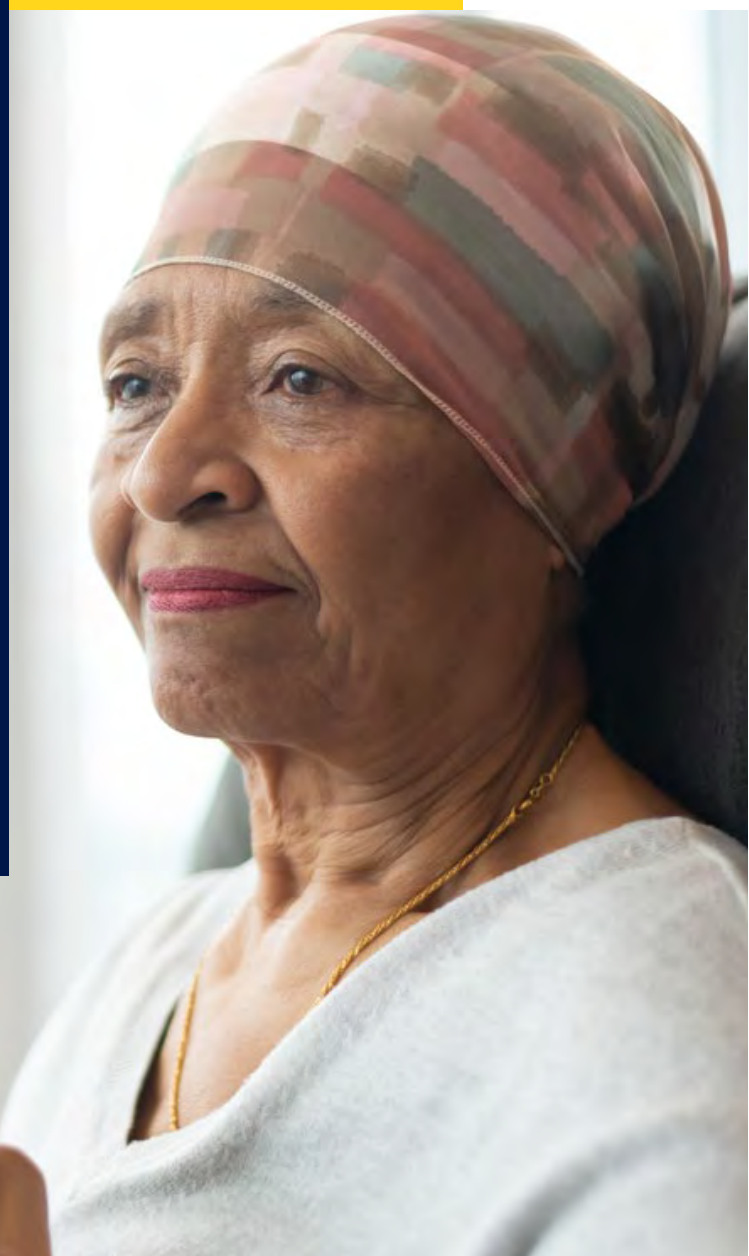
The Flinders Research Centre for Palliative Care, Death, and Dying (RePaDD) works to make a difference to the care of persons at the end of life.

RePaDD researchers examine the universal experience of dying and create innovative solutions for people living with a life-limiting illness, their carers, and the clinicians caring for them.

RePaDD leads major national palliative care projects in Australia. Its team of multidisciplinary researchers and experts work collaboratively with various organisations and funding agencies to deliver impact. The Centre also strengthens research capacity by offering evidence-based resources, researcher education and training, and scholarships.

RePaDD's current research areas are:

- Palliative care across the health system
- Death and dying across the community
- Online evidence and practice translation



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*Over two and a half million Australians are unpaid carers. Many people don't see themselves as carers. They describe themselves as just the children, parents, partners, relatives or friends who look after someone close to them.*

*A carer (under the Australian Government Carer Recognition Act 2010) is "someone who gives care and support to a relative or friend who has a disability, has a medical condition (terminal or chronic illness), has a mental illness or is frail because they are old".*

## Introduction

Many people provide regular and ongoing care and help to a partner, relative or friend. This may involve a few hours a week or all day every day, depending on the level of support needed. People often provide care to someone who is older, seriously ill or has a disability. For those caring for someone who is seriously ill or has an ongoing health condition, the caring role often continues as the person comes to the end of life. These carers are more likely to face issues around death, dying, grief and bereavement. We heavily rely on carers to provide support to these members of our community, and they are integral to our health, aged care and community care systems. Research shows that helping carers manage their daily challenges can make a big difference to their lives and improve overall health and wellbeing.

During National Palliative Care Week in May 2024, the Flinders Research Centre for Palliative Care, Death and Dying (RePaDD) hosted a forum for unpaid carers of palliative patients, titled: *Unpaid Carers' Forum: Recognition, Support, Action*. The forum provided the opportunity to hear from high profile speakers on policies and support systems related to unpaid carers in Australia, as well as showcase key findings from research projects led by RePaDD members.



Image 1: Forum Program

The forum was also an opportunity to facilitate discussion of vital issues for unpaid carers of palliative patients with considerations for the future being identified. Stakeholders from government, community-based organisations, academics, clinicians, carer advocacy groups as well as carers with lived experiences were invited to attend the forum. The program is included as Attachment 1.

# Critical Considerations from the Speakers

Presenters shared the reality of lived experience, reported on carer data and surveys, shared findings about their projects, and looked to policy activities at the state and national levels.

Annie Dullow was a keynote speaker, bringing a carer perspective and the reality of providing care at the end of life to shape the conversation. She shared her experience as a daughter with caring responsibilities across the dementia-frailty trajectory through end of life and describing how demanding and emotionally exhausting this can be.<sup>1</sup> She also indicated the growing set of research about carer needs.<sup>2,3</sup>

The forum was timely as both the *National Carer Recognition Act 2010* and the *South Australian Carers Recognition Act 2005* were under review at the time of the forum. There was a consensus that carer legislation needs to have actionable and proactive measures built in to increase awareness and visibility of carers with a validation of and accountability to their role. Ms Louise Miller-Frost, Federal MP for Boothby, South Australia (SA) was a member of the Government Standing Committee on Social Policy and Legal Affairs looking at the recognition of unpaid carers. The need to acknowledge the contribution and recognise the rights and human needs of carers was highlighted. She noted that work had been completed and 22 recommendations made.<sup>4</sup>

Data from Carers SA presented by Marianne Lewis and David Militz showed that, on average in South Australia, carers provide 101 hours of caring each week,

with 47% providing 24/7 care – with a national average of 103 hours and 49% respectively. These figures partly explain the issues and concerns that carers face with 1 in 2 experiencing high or very high psychological distress, 1 in 6 experiencing financial distress and over half being socially isolated.<sup>5</sup>

Several researchers and departmental staff presented information on specific palliative care initiatives and research relating to carers. Kate Swetenham spoke about the palliative care resources offered within SA, including an updated Advance Care Directive kit and the Palliative Care Navigation Service which has the ability to help families connect with resources and local services. Dr Sara Javanparast, Associate Professor Aileen Collier and Professor Jennifer Tieman outlined findings from research that identified carer concerns and the need to contextualise resources and supports that recognise cultural and community diversity.

Examples of RePaDD research findings had been detailed in an evidence brief circulated to participants (see Attachment 2). It described carer-related RePaDD research projects providing evidence-based information, tools and resources to support carer health and well-being and findings that highlighted unmet needs and system disparities. Studies relevant to the forum discussions included a recent article investigating unpaid carers' experiences in accessing information and resources to support patient care and self-care,<sup>6</sup> national resources developed to support carers through the CarerHelp website,<sup>7</sup> and grief experience of families of those who died in residential aged care.<sup>8</sup>



# Voices of the Forum Participants

There was a strong sense of enthusiasm and engagement from participants as they joined others in roundtables specifically addressing one of the following unpaid carers' issues around equity, engagement, research and policy. Each table was challenged to report back on their discussion and on the top three research priorities or pieces of evidence needed to bring about change in how carers are acknowledged and supported.

During reporting back, key issues were raised. Information that is available when it is needed, and in formats and through avenues that make sense to the user, is essential. The example of information being brokered through the church for the Greek community was provided. Information can be available online but might need to be delivered in print by a friend or agency. This also needs to be sensitive to cultural and language differences surrounding a term such as an unpaid carer.

The role of networks and advocates to support the carer and reduce burden was also discussed. Identifying a transition from family member or partner to carer can help with both recognition and acknowledgement of the carer role, but also with availability of support and services. Supporting carers needs to be strengthened in current service and practice. There also needs to be more active engagement with carers from the health and aged care providers given the hands-on care that carers are providing as well as the social and spiritual care they offer to people living with a life-limiting illness.

The need to ensure that carers are represented in the development of policy and service practice and needs to address the diversity of people providing care was raised by many participants. The detrimental impacts on females, particularly in terms of carer burden, financial loss and social isolation, needs to be addressed. The benefits to carers of support from culturally competent providers and from those with lived experience was also reported.

Aside from acknowledgement, there needs to be greater recognition and visibility of the value that carers provide, not only to their families but to the community and to the economy. This not only supports the person providing care but building community awareness of the role and contribution of unpaid care for people who are coming to the end of their life. Understanding the carer role is part of a need to build awareness and willingness to address palliative care, death and dying. Without this, we will continue to marginalise those who are ageing, caring and dying within our community.



*Image 2: Forum participant sharing outcomes of table discussion with the wider group*

# Identified Research and Evidence Directions

The feedback from each of the roundtables was collated to summarise the research and evidence strategies. Theming of responses highlighted sets of strategies that could benefit carers. They are summarised below.

## General Awareness Across Communities

Participants saw that the community did not acknowledge and respect the contribution made by carers and saw the need to build awareness generally and within those providing health and aged care services. Strategies were suggested at the general media level, as well as more specifically targeted to those who would have reasons to engage with unpaid carers such as cultural groups and community groups. The need to ensure that the health, aged and social care workforce are sensitive to unpaid carers was also seen as critical.

The following strategies were seen as priorities:

- 1. Public Awareness Campaigns:** Utilise media and community events to raise awareness about the role and challenges of carers.
- 2. Community Engagement:** Partner with community organisations and leaders to disseminate information about available support for carers.
- 3. Professional Networks:** Ensure that professionals across different sectors (social services, education, etc.) are aware of carer issues and resources.

## Education for Professionals/Clinicians/General Practitioners

General Practitioners (GPs) and other health professionals have a critical role in engaging with the person needing care and are both a key resource and a partner for the unpaid carer. The need to recognise, acknowledge and engage with the carer is essential in ensuring the well-being of the patient and the carer. Carers highlighted the importance of being seen as part of the care team and having their voice and insights listened to and valued. Developing the capability of the health professional workforce in carer support is needed. Engaging family caregivers as partners in care has been seen to be a critical part of quality patient care if the patient and families are to have the best possible outcomes when facing serious illnesses.<sup>9</sup>

The following strategies were put forward to develop a more informed and supportive workforce:

- 1. Training Programs:** Develop comprehensive training for healthcare professionals to recognise and support carers effectively.
- 2. Integration in Education:** Incorporate modules on carer support into medical and allied health education curricula.
- 3. Continuous Professional Development:** Provide ongoing education to keep clinicians updated on best practices in carer engagement and support.

## Navigation Support

Complexity in finding and managing information in a sequenced and timely way is a major barrier. Carers of people living with a terminal illness are having to address multiple layers of information while providing increasing amounts of care and support. Carers are also having to acquire new skills, locate needed resources and services, manage relationships with care providers, aged care services, pharmacists as well as the core health team. They are also likely to be dealing with financial matters, family communications and other forms of planning and decision making. Establishing meaningful pathways to support and services is needed.

The following strategies were prioritised:

- 1. Resource Hubs:** Establish centralised information centres or online portals where carers can access guidance and support.
- 2. Case Management:** Provide personalised navigation assistance to help carers understand available services and navigate complex systems.
- 3. Clear Pathways:** Develop streamlined pathways for carers to access information and support services efficiently.

## Understanding Carer Journey

Not enough is known about the carer journey. There has been useful research on carer needs but effective support mechanisms, ways of assessing needs, and measurement of how effectively needs are being met are not yet well established.

Mapping the differences and similarities in carer journeys over time could help support strategies around identifying, personalising and tracking how well we are meeting the needs of carers in the carer journey.

The following three strategies were highlighted for research action:

- 1. Assessment Tools:** Develop tools to assess carers' needs and stages in their caregiving journey.
- 2. Personalised Support Plans:** Tailor support interventions based on the specific challenges and needs identified at each stage.
- 3. Feedback Mechanisms:** Incorporate feedback loops to continually improve support strategies and adapt to evolving needs.



## Cultural Appropriateness and Sensitivity

Australia's diversity is well established and continues across the life course through to the end of life. The networks and needs can differ between groups. A group can be unintentionally excluded from access to services or may be offered services that are not appropriate to the context and culture. This issue had been highlighted in a summary policy paper produced by the Australian Government in 2019.<sup>10</sup>

The following strategies were seen as offering a way to develop more sensitive and appropriate recognition and support for carers who reflect Australia's diversity:

- 1. Localised Information:** Provide information in culturally relevant locations (e.g., community centres, places of worship) and languages.
- 2. Community Networks:** Engage and utilise community networks and leaders to develop and disseminate information and provide culturally sensitive support.
- 3. Gender Sensitivity:** Address gender-specific needs and roles within caregiving through targeted outreach and support initiatives.

## Access to Advocacy and Support Networks

Carers frequently identified the time and effort in finding services and supports they needed, and the frustration they experience in trying to provide complex care to the patient while dealing with bureaucracy and multiple agencies.

Access to advocacy and support networks were seen as important strategies to support carers and facilitate access to needed services, resources and supports.

- 1. Advocacy Roles:** Establish roles for advocates or liaison officers within service settings to support and advocate for carers.
- 2. Peer Support Networks:** Facilitate peer support groups and networks where carers can share experiences and advice.
- 3. Technology vs. Face-to-Face:** Offer a mix of virtual and in-person support options to cater to different preferences and needs of diverse groups of carers.

## Information Access and Formats

While the need for timely and meaningful information was acknowledged by all involved in the forum, the need for information that was in preferred styles and reflecting health and digital literacy was noted.

Building the health and digital literacy of carers was seen as important, as was understanding the points of intersect in the carer journey where information and supports could make a difference.

Core strategies for further research and evidence were noted:

- 1. Varied Formats:** Provide information in multiple formats (text, video, audio) to accommodate diverse learning styles and accessibility needs.
- 2. Digital Literacy Support:** Offer training or assistance to improve carers' digital literacy for better access to online resources.
- 3. Accessible Locations:** Ensure information is available in easily accessible locations and platforms for carers at different points in their journey.

## Policy Development and Implementation Challenges

The role of policy had been discussed at different points during the forum. The importance of policy being evidence based and reflecting an understanding of the characteristics and barriers experienced by carers was seen as essential. A call for evaluation that monitored the effectiveness of directions was seen as necessary to underpinning meaningful change.

The need for ongoing review of national and international initiatives was also seen as a pre-requisite for continuing relevance.

- 1. Research and Evidence-Based Policies:** Prioritise research to inform evidence-based policies that address the unique needs of diverse carer populations, including CALD communities and LGBTQ+ carers.
- 2. Evaluation and Monitoring:** Policy frameworks should include provisions for ongoing evaluation and monitoring of outcomes to gauge policy effectiveness and identify areas for improvement.
- 3. Policy Review and Adaptation:** Establish processes for periodic policy review and adaptation based on changing societal needs, advancements in caregiving research, and feedback from carers and stakeholders.

# Discussion

The forum has shown consistency between issues raised by speakers and both the tabletop discussion and the recommendations for future research and evidence. Carers continue to feel unrecognised and underacknowledged given the significance of the contribution being made. The need for carers to be recognised and acknowledged was repeated across the forum. This requires self-identification as a carer when somebody provides care to a loved one. This first step underpins carers' help-seeking behaviours. Being recognised by health professionals, particularly GPs, is also important. Carers' physical and emotional status being assessed separately from the patient with life-limiting conditions and being involved in decision making and information sharing are critical to meaningful care provider relationships. Carers are excellent sources of knowledge when it comes to patient assessment, care planning and monitoring. This knowledge needs to be recognised, respected and utilised.

In a summary panel at the forum, a question was posed of what would happen if we did not have sufficient carers to meet the needs of people who are living with, and dying from, a terminal illness. The panel of carers, experts and decision makers noted there is not a fall-back position. The care systems are reliant on unpaid carers to support people in the last years, months and days of life in the community and in aged care. This perspective of the panel accords with recent published research internationally which highlights the significance and potentially the vulnerability associated with an unacknowledged reliance on unpaid carers.<sup>11</sup>

Remembering the impacts of an ageing population, the care demands associated with dementia progression and end of life also need to be considered. Most primary carers of people with dementia provided continuous rather than episodic care, and almost half of primary carers of people with dementia were providing an average of 60 or more hours of care per week.<sup>12</sup>



*Image 3: Summary panel discussion during the Unpaid Carers' Forum*

Specific considerations around advance care planning, behaviour management and transitions are also likely to be challenging for those providing care to people coming to the end of their life and living with dementia.

For carers, there is another noteworthy change that has occurred within the palliative care system. Many countries and all states in Australia have now introduced Voluntary Assisted Dying (VAD). However, there is limited research on the experience and impacts of VAD on family carers.<sup>13</sup>

Increasingly, carer networks of family members are all taking on parts of a carer role. This requires health and care teams to consider how to best communicate with a group of people providing care collectively or with carers who are not geographically proximate. Skills and frameworks are required to communicate difficult decisions and conflicts, while respecting privacy and confidentiality.

Navigation of health and social systems is also complex. Despite programs and support services in place, finding the right service at the right time is a major challenge for carers. They simply do not have time to navigate online resources, complete overwhelming paperwork and go through bureaucratic processes. The statewide Palliative Care Navigation Service seems to be promising in removing some of these barriers by accessing navigators who are able to liaise with services and make referrals. Considering cultural and social needs of the diverse groups of carers including marginalised communities is also critical to ensure equity in access to support services.

Efforts to review and update Australia's national and jurisdictional legislations and policies on unpaid carers is a step forward. This provides an opportunity to hear the voices of carers and their advocates. However, a take home message from the forum was that a good policy is not enough unless it gets translated into real actions and improves carers' experiences.

Finally, there was discussion on how research can make a difference in carers' lives. Engaging carers in every step of research—including design, implementation and evaluation—was felt to be essential. A research project presented by NALHN and Flinders researchers provided an example of engaging with carers to identify information needs and codesign solutions in a hospital setting. Research needs to focus on strategic changes and outcome measures, developing new tools and resources, understanding economics of activity, undertaking comparative analysis of value and effectiveness of various support services, and exploring the contribution of digital technology to knowledge and practice. Learnings from successful international models of carer support might be helpful. Equity impact assessment should be a key element of carers research and services.

# Implications for RePaDD

As this forum has shown, carers of people living with a terminal illness is an important area of research and there is a need to ensure access to a growing body of evidence around effective practice. RePaDD already has significant collaboration with carer and community organisations as well as carer-based research partnerships. There is an opportunity for us to strengthen our networks and build capacity and capability in the area alongside the Caring Futures Institute and the Centre for Social Impact at Flinders University.

The forum has provided us with a research agenda in the field which we could take forward and which aligns with existing capabilities and work in progress. The teaching team and the national projects are already creating education for health professionals, GPs and the aged care workforce. There is a natural opportunity to promote the importance of professional awareness of the carer role and carer needs and to promote existing resources to workforce groups.

RePaDD can also continue to promote the role of unpaid carers in palliative care and the contribution that carers make to the individual, the health and aged care systems, and to the society as a whole. Such promotion could involve inclusion of carer issues as part of the RePaDD seminar series, and blogs in partnership with the national projects based at Flinders.

Given our partnership with SA Health's Palliative Care Connect project, we have already been engaged in promoting carer navigation in the palliative care context.

Further work with navigators could support navigation for marginalised groups of carers to better support their needs.

More research on the carer journey in different contexts is needed. Understanding specific needs for caring in the context of ageing, frailty and dementia and from underserved populations could help to structure packages of resources that could better support carers. Working with carers could also identify what is needed and what is more useful. A carer research advisory committee should be considered to contribute to the design, implementation and evaluation of research. The group will also provide a thoughtful direction for future research grants with community partners.

Further research relating to communication avenues, digital literacy and health literacy would also support the development of more relevant, accessible and meaningful carer resources. Mapping what is already available could provide a critical starting point for groups of different carers.

Finally, policy research is often limited. The current policy reviews at the state and national level provide a significant baseline to understand what changes are being suggested and potentially how effectively it can change the carer experience. Real time tracking of change could be initiated to compare the state and federal responses to carer legislation.



# Conclusion

Effective support for carers requires a multifaceted approach that addresses their diverse needs and challenges.

By focusing on education, awareness, navigation support, cultural sensitivity, advocacy, and accessible information, we enhance the support infrastructure and ensure equitable outcomes for all carers.

Continued research and engagement are essential to further refine and improve these strategies in response to evolving needs and expectations.

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# **Attachment 1:**

## *Forum Program*



**Flinders  
University**

Research Centre for  
Palliative Care, Death & Dying

# Unpaid Carers' Forum

## Recognition, Support, Action

Discussing vital issues for unpaid carers of palliative patients in Australia and considerations for the future

### FORUM PROGRAM

Wednesday 22 May - 9:00am to 2:00pm  
Flinders City Campus, Adelaide



@RePaDD1



@RePaDD



[flinders.edu.au/repadd](https://flinders.edu.au/repadd)

Presented by Flinders University Research Centre for Palliative Care, Death and Dying

The Unpaid Carers' Forum will give you the opportunity to hear from high profile speakers on policies and support systems related to unpaid carers in Australia, as well as showcase key findings from a number of research projects led by RePaDD. The forum will also facilitate discussion of vital issues for unpaid carers of palliative patients with considerations for the future.

## FORUM PROGRAM

Time	Activity	Speaker
9:00am	<b>Registration</b> with tea and coffee station	<i>Confirmation of photo consent</i>
9:30am	<b>Opening of the Forum</b>	<i>Professor Jennifer Tieman and Louise Miller-Frost MP</i>
9:55am	<b>Sharing the Carer's Experience</b>	<i>Annie Dullow, Carer and Consumer Representative</i>
10:10am	<b>Carers in South Australia: Facts, Figures and Life Experiences of Carers</b>	<i>Marianne Lewis, Carers SA</i>
10:20am	<b>How Does South Australia Currently Support Carers of Someone with Terminal Illness?</b>	<i>Kate Swetenham, SA Department for Health and Wellbeing</i>
10:30am	<b>Carers' experience of access to palliative care and self-care information, resources and services</b>	<i>Dr Sara Javanparast, RePaDD</i>
10:40am	<b>Caregiver perspectives of caregiver information needs when a person is in hospital – a codesign study</b>	<i>A/Prof Aileen Collier, RePaDD/NALHN</i>
10:50am	<b>Questions</b>	
11:00am	<b>Morning Tea</b>	<i>Light refreshments provided</i>



Time	Activity	Speaker
11:20am	<b>Round Table Discussions</b>	
	<p><b>Each table will focus their discussion on one of six key questions that will cover the following relevant areas:</b></p> <p>Policy   Research   Equity   Engagement</p>	
11:55am	<b>Sharing outcomes of table discussions</b>	<p><b>Facilitator:</b>  <i>Dr Raechel Damarell</i></p>
12:30pm	<b>Panel Discussion</b>	
	<p><b>Panel Members:</b>  Annie Dullow  David Miltz  Kate Swetenham  Shyla Mills</p>	<p><b>Facilitator:</b>  <i>Professor Jennifer Tieman</i></p>
1:00pm	<b>Conclusion of Forum</b>	<i>Professor Jennifer Tieman</i>
1:10pm	<b>Lunch</b>	<i>Lunch boxes provided</i>



### **Keynote Speaker: Annie Dullow**

*“My personal experience of palliative care was with my mum who was provided with excellent non-specialist palliative care in an aged care setting. As a family, we felt supported, listened to and encouraged to be with Mum for as long as we wished and assist with her end of life care.”*

Living in a rural area and listening to other people’s experiences of palliative care – as well extensive experience working in health as a paediatric nurse, researcher, and in policy – Annie is interested in sharing her knowledge of palliative care as a carer/consumer.

*Presenters, Titles and Panel Members may be subject to change*

## FORUM SPEAKERS & PANEL MEMBERS



**Prof Jennifer Tieman**

Matthew Flinders  
Professor and Director,  
*RePaDD*



**Louise Miller-Frost MP**

Member of the Australian  
House of Representatives  
for Boothby, SA



**Shyla Mills**

Chief Executive Officer  
*Palliative Care  
South Australia*



**Dr Sara Javanparast**

Senior Research Fellow  
*RePaDD*



**David Militz**

Chief Executive Officer  
*Carers SA*



**Marianne Lewis**

Manager Strategic Policy  
*Carers SA*



**Kate Swetenham**

Clinical Lead –  
End of Life Care  
*SA Department of  
Health and Wellbeing*



**A/Prof Aileen Collier**

Associate Professor  
of Palliative Care and  
Aged Care Nursing  
*RePaDD and NALHN*



**Dr Raechel Damarell**

Senior Research Fellow  
*CareSearch and palliAGED  
RePaDD*



### **Access *Evidence Brief*: Carer Research Online**

Scan the QR code to see the digital version of  
our *Evidence Brief* and access direct links to  
the RePaDD Carer-related research products.



@RePaDD1



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flinders.edu.au/repadd

# **Attachment 2:**

## *Evidence Brief:*

## *Carer Research*





## Evidence Brief: Carer Research

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

Family and friends who are caring for someone 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](http://carerhelp.com.au)) was created to support and empower carers of people who are seriously ill or dying.

The CarerHelp website 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. Continuing research addresses specific carer needs within our diverse population.

<b>Researchers:</b>	Prof Jennifer Tieman, Assoc Prof Mark Boughey, Dr Kristina Thomas, Ms Di Seward, Prof Peter Hudson, Prof Deb Parker
<b>Partners:</b>	Flinders University, Carers Australia, University of Melbourne
<b>Funding:</b>	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](http://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. Engagement studies showed the importance of the voice of patients, carers and families in developing and sharing resources.

<b>Researchers:</b>	Prof Jennifer Tieman, Dr Katrina Erny-Albrecht, Dr Raechel Damarell
<b>Funding:</b>	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.

<b>Researcher:</b>	Kate Swetenham
<b>Supervisors:</b>	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

March 2023

Flinders University

Research Centre for  
Palliative Care, Death & Dying



# 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.

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