



Supporting the Grief, Loss and Bereavement Needs of Families of Older People Living in Residential Aged Care

A white paper published by the Flinders Research Centre for Palliative Care, Death, and Dying

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About this White Paper

This publication is a RePaDD White Paper and Research Report. The RePaDD White Paper and Research Report Series provide researchers and policy makers with evidence-based data and recommendations. By organising, summarising and disseminating previous and current studies, the series aim to inform ongoing and future research in palliative care, death, and dying.

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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

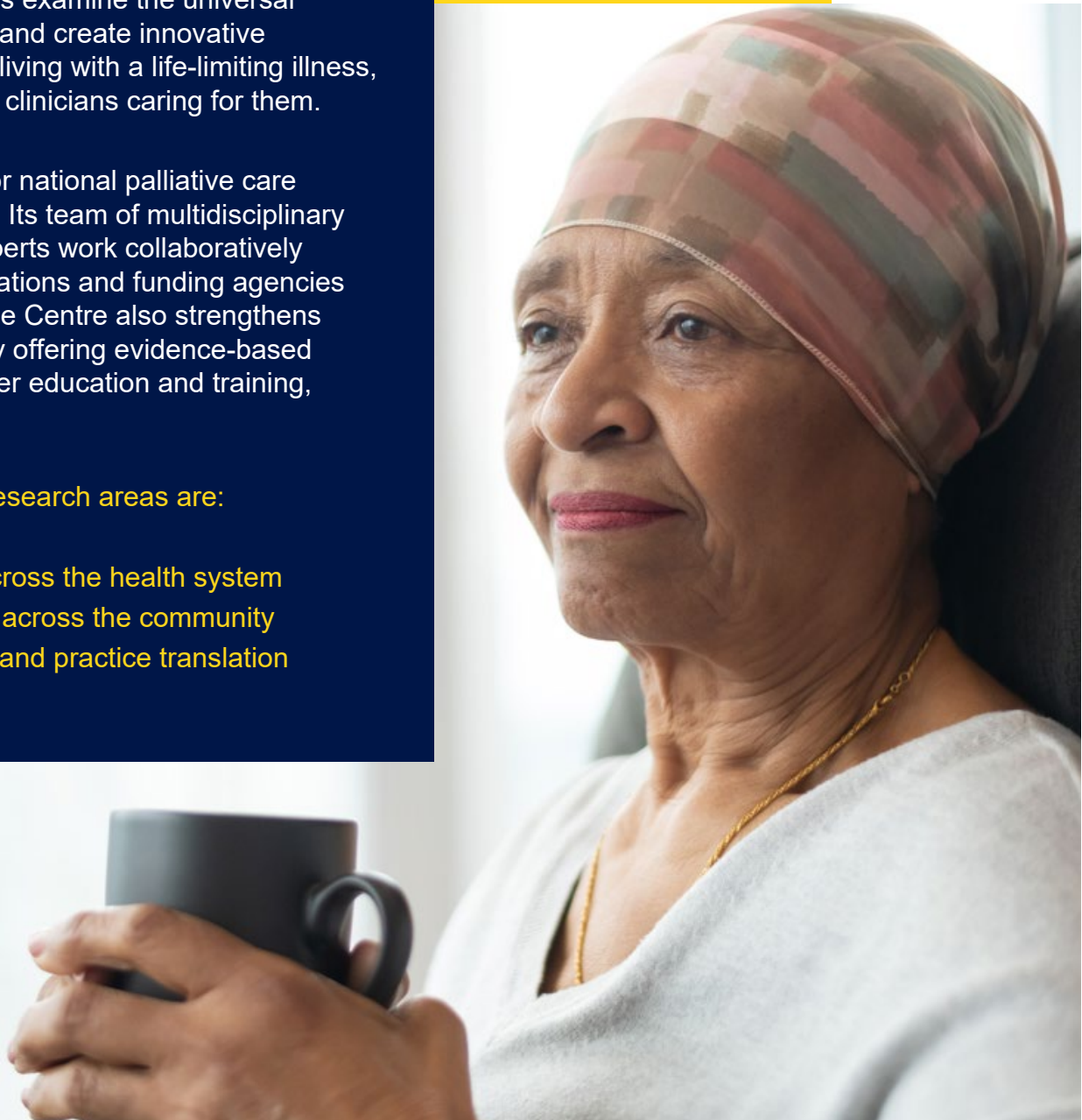


Table of Contents

EXECUTIVE SUMMARY	6
INTRODUCTION	7
ACTIVITY 1: SYSTEMATIC REVIEW	9
ACTIVITY 2: INTERVIEWS AND FOCUS GROUPS	10
ACTIVITY 3: DEVELOPMENT OF GRIEFLINK PAGES	11
ACTIVITY 4: BEREAVEMENT BOOKLET DEVELOPMENT	12
DISCUSSION AND CONCLUSIONS	15
REFERENCES	16

Executive Summary

In Australia, a significant number of families are affected by the decision to enter – and subsequent death of someone in – residential aged care. While a sense of grief and loss is common among the caregiving families of aged care residents, there is evidence that families' experience of loss and grief can be complicated or relieved by the process of transition to aged care, and that there is scope to augment supports for people experiencing loss and grief in this setting.

This White Paper reports on a project that was undertaken to understand the bereavement, grief and loss needs of the families of those living in, or entering, residential aged care in South Australia. The Project involved a systematic review of key literature pertaining to grief, loss and bereavement, interviews and focus group discussions with families, caregivers and aged care staff, and the development of electronic and print resources to help families and caregivers of people living in, or entering, residential aged care deal with their sense of grief, loss and bereavement.

Our research team found that the experience of grief, loss and bereavement in a residential aged care context is not well understood, and that information for families and caregivers regarding the practical and emotional challenges of transitioning to aged care – and how to manage them – is lacking. These findings were used to inform the development of two new resources to support families and caregivers: a printed booklet and grief pages held on GriefLink.

It is hoped that this White Paper will contribute to an awareness of some of the key challenges facing the families and caregivers of those entering, living within, or dying in a residential aged care setting. It is also hoped that the resources discussed in this paper will help to support families who are navigating such challenges better prepare both practically and emotionally for the grief, loss and bereavement that often arise in residential aged care settings.

Introduction

There are 18,112 residential aged care places across 285 South Australian aged care services. In 2017, there were 4,281 deaths in the residential care setting, which represents approximately 30% of total deaths for the state. Each year a significant number of South Australian families are affected by the decision to enter residential aged care or by the death of someone in residential aged care. This is likely to continue to increase with an ageing population and increasing care needs. A sense of grief and loss is common among the caregiving families of an aged care resident. A recent SA study looked at the experience of loss and grief associated with a move into residential aged care and elements of the transition which complicate or relieved loss and grief responses. They suggested that there is scope to look at augmenting supports for people experiencing loss and grief in this context.¹

While lack of preparedness for the patient's death is known to be associated with complicated grief among caregivers, there is limited information and support available to families of people living in residential aged care regarding preparedness for death and on how to deal with grief and loss. A review undertaken by staff at the University of Wollongong noted that bereavement and its effects on staff, residents and families is under-recognised and underacknowledged and remains a silent experience.²

Project Aim and Objectives

The aim of this project was to support the bereavement, grief and loss needs of the families of those living in, or entering, residential aged care by providing access to information and resources. Four specific objectives were set:

1. Conduct a rapid review of the literature on the grief, loss and bereavement needs of family/caregivers of older people in the last year of life entering or living in residential aged care.
2. Carry out discussions with consumers who have a family member living in residential aged care to identify specific grief and loss related needs of family/caregivers.
3. Carry out discussions with representatives of residential aged care services (e.g. professional caregivers, managers, and palliative care providers) to explore stakeholders' views on important items that could support family/caregivers' grief and loss related needs.
4. Develop electronic and print resources that will help family/caregivers of people living in, or entering residential aged care setting, appropriately deal with their sense of grief, loss and bereavement.

The resources developed include information and practical tips on how to identify and deal with the sense of grief and loss that can manifest in different ways across residents' stay at aged care facilities (pre-admission to death or discharge). These resources are hosted on the [GriefLink](#) website and available for access by the public. The resources were also posted to residential aged care facilities across South Australia for distribution.

Availability of these resources was also shared via social media, websites and conferences.

Project Management

The project work was overseen by the Investigator Team comprising representatives from Flinders University, GriefLink and SA Health. Flinders University was responsible for the management of the grant. The Investigator Team met fortnightly or monthly during the project. Membership comprised:

- Professor Jennifer Tieman (Flinders University): Project Lead
- Dr Priyanka Vandersman (Flinders University)
- Dr Mary Brooksbank (GriefLink)
- Ms Kate Swetenham (SA Health)

As there were some delays with recruitment due to Covid19, an extension to complete the project was negotiated to the end of February 2021.

Activity 1: Systematic Review

Systematic Review Study Team

The systematic review was undertaken by Flinders University staff led by Professor Jennifer Tieman. The Systematic Review Study Team comprised Professor Tieman, Dr Amal Chakraborty, Dr Priyanka Vandersman and Ms Sue Hammond, an expert health librarian, who undertook the search strategy development and execution. The study was conducted between July 2020 and December 2020.

Study Methods

The specific objective of this systematic review was to identify grief, loss and bereavement related information and support needs of bereaved family members, or family/caregivers of older people in the last year of life entering or living in residential aged care. The review was based on the study protocol registered with PROSPERO (CRD 42020201720) and follows the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.

A PICOS (Population, Intervention, Comparison, Outcome, and Study Design) framework was used to define eligibility criteria of the study selection process.

Key Findings

Over 2,000 articles were retrieved for screening with 34 being included in the final review analysis. The review identified a range of supports provided to families and residents and a smaller number of interventions designed to support grief and loss concerns at entry, during their residency or at death.

A qualitative analysis of the article text highlighted a diverse range of considerations relating to bereavement and loss in the context of residential aged care, from which nine main themes emerged:

- Emotions and feelings
- Acknowledging and addressing bereavement needs
- Knowledge, information and communication needs
- Organisational supports and services
- Quality of relationships with staff
- Informal and social supports for family and residents
- Decision making around residential aged care placement
- Family relationships
- Costs of residential aged care

In undertaking the qualitative analysis, it was clear that grief and loss were experienced not only from the point of death but across a broader period from recognising the need for residential aged care through entry into a facility and then through to decline, death and bereavement. Creating a set of timepoints enabled the focus of the study in relation to the family and resident trajectory to be documented.

Five critical time points were identified:

- Before residential aged care placement
- Transitioning to residential aged care
- Living in residential aged care
- End of life in residential aged care
- Post death in residential aged care

The findings were shared with the GriefLink Team Management Committee and GriefLink Project officer, Dr Katherine Hodgetts to assist the development of the GriefLink. The review findings also informed the development of the [Bereavement Booklet](#).

Activity 2: Interviews and Focus Groups

Qualitative Study Team

The Qualitative Study Team was led by Professor Jennifer Tieman. Dr Georgia Rowley and Dr Amal Chakraborty conducted the interviews and focus groups. Ms Laura Nesbit provided administrative support. Drs Chakraborty, Rowley and Vandersman contributed to the qualitative analysis.

Study Methods

This qualitative study aimed to explore the grief, loss and bereavement needs of family care givers of people who are: (i) about to enter, (ii) are living in, or (iii) have died in a residential aged care facility (RACF). Ethical approval was received through the Human Research Ethics Committee of Flinders University (Project number 2302).

Interviews were conducted with family caregivers and aged care staff. A pragmatic recruitment approach was undertaken with potential participants being recruited through RACFs across South Australia. As this project was conducted during the COVID-19 pandemic, the recruitment and data collection activities were all conducted virtually/electronically. The Covid19 context meant that recruitment was slowed.

Participants were invited to take part in a semi-structured interview via telephone or a teleconference tool (e.g. Zoom, MS Teams) of their choice. The focus group and the semi-structured interviews were guided by two separate question routes, one for family caregiver participants and one for staff participants. Data was managed using NVIVO 12 software. Data analysis was carried out using thematic analysis.

Key Findings

Out of the 30 RACFs approached, nine agreed to be involved in this qualitative study. From across these nine RACFs, 38 participants were recruited including staff participants (n=28) and family participants (n=10).

A series of themes emerged from the coding:

- Transition into a nursing home is an emotionally difficult time
- Transition occurs amidst factors that could exacerbate the sense of grief and loss
- Acknowledging the value add of the nursing home placement can minimise the sense of loss and grief
- Continuing meaningful family involvement is important
- Formal and informal supports to resident and family are needed
- Transition engagement could facilitate ongoing engagement with family caregivers
- COVID related limitations in visits exacerbated the sense of separation and loss
- Timely End of Life (EOL) conversations and planning are essential
- Supporting family's presence while the resident is dying
- Value of after-death rituals
- RACF & family connections continue well past the resident's death

The findings were shared with the GriefLink Management Committee and GriefLink Project officer, Dr Katherine Hodgetts to support the development of the GriefLink pages. The findings also informed the development of the Bereavement Booklet.

Activity 3: Development of GriefLink Pages

GriefLink Team

Dr Mary Brooksbank led the GriefLink Team Management Committee. Dr Katherine Hodgetts undertook the content review and drafting of the Residential Aged Care page. GriefLink had been in the process of developing a page on Grief associated with Dementia page and these two pages were finalised together.

Key Output

The key output was new pages in the GriefLink website which are publicly available at the site: grieflink.org.au

Project Methods

The GriefLink Project Officer, Dr Katherine Hodgetts reviewed the findings of the systematic review and the qualitative study and developed content in a style similar to other pages in the GriefLink website. The page content was reviewed by the Investigator Team prior to being built within the website.

Page content covered the following topics:

- Grief and loss in residential aged care
- When someone you care for moves into residential aged care
- Feelings of guilt and relief
- Feelings of disconnection and loneliness
- Feelings of powerlessness and anxiety
- Anticipatory grief
- Conversations about the end of life
- Loss and grief among aged care residents
- Bereavement in aged care
- When a loved one dies in residential aged care
- Grief among staff in residential aged care

Activity 4: Bereavement Booklet Development

Production Team

The Flinders University Team was responsible for the content, design, printing and distribution of the [bereavement booklet](#). Professor Tieman was responsible for drafting the content. Ms Mariane Umali, the CareSearch Marketing Officer, assisted in content planning and imagery selection. Jo Koehler (ChinaShop) undertook the graphic design of the booklet. Finsbury Green undertook the printing and distribution to the aged care services within South Australia.

Production Process

Prior to drafting of the content, the Flinders Project team reviewed the findings from the systematic review and the qualitative interviews and focus group to assess the consistency of the findings and to identify critical issues to be covered in the booklet. Dr Vandersman completed a data convergence exercise creating data labels to points of convergence between the two data sets.³ This showed that the two data sources had significant points of agreement and that the interview and focus group data could enhance the systematic review findings by highlighting the human and personal voice.

These findings are outlined in Table 1. These themes underpinned the structure of the bereavement booklet.

The booklet includes information about the key issues raised in the systematic review and within the interviews and focus groups with families and with staff. The booklet

content was enhanced by a set of tips for families. The voice of staff and families is directly included through the use of quotes derived from the qualitative analysis. There was also brief content on issues associated with people living with dementia and with the implications of Covid-19.

Topics included in the booklet:

- We are getting older
- What is residential aged care
- Advance care planning
- Living with dementia
- Entering residential aged care
- Planning for entry
- Things will change
- When someone dies
- After the death
- Covid-19
- Grief and bereavement

After drafting, the content and preliminary design was reviewed by the Investigator Team, members of the Systematic Review Study Team and by two community members. Feedback was reviewed and changes made as necessary.

Key Outcome

The bereavement booklet was designed, printed and posted to all SA residential aged care services in March 2021. Requests for additional copies and feedback from services was collected. Electronic versions of the booklet are held on the [RePaDD](#), [CareSearch](#) and [palliAGED](#) websites.

Table 1. Data convergence of systematic review themes and qualitative analysis of interviews and focus groups

Theme	Systematic review data [34 studies]	Qualitative data [38 family and staff participants]	Data convergence
General perspective on grief			
<i>Grief occurs well before death</i>	For many families, grief starts long before the resident's death. While transition to RACF could be the point of where grief starts for many, family caregivers of people with dementia start grieving much earlier- as dementia starts to impact the personhood of the family member.	Participants noted the presence of anticipatory grief among family caregivers long before the resident's death. Sense of grief and loss was reported by family caregivers, which is much more pronounced among family caregivers of residents with dementia.	Confirm
Transition to RACF and family caregivers' sense of grief and loss			
<i>Transition to RACF is an emotionally difficult time for family caregivers and the resident</i>	Family caregivers experience difficult emotions such as shame, guilt, loss, and grief surrounding the time of the resident's transition to RACF.	Resident's transition to RACF was noted as an emotional time for family and the resident. Feelings of loss, separation, abandonment and guilt were noted.	Confirm
<i>Acknowledgement of the value-add of RACF transition could assist family caregivers in dealing with grief and loss experienced at the time of their loved one's RACF transition</i>	Family caregivers felt a sense of relief and freedom knowing the resident's transition will enable quality care which they would not have been able to provide at home.	Family caregiver participants noted the acknowledgement that the resident's transition to the RACF was in the interest of their wellbeing and care to be useful in dealing with their sense of grief and loss. Similarly, staff participants noted the importance of reaffirming to family caregivers the value-add of resident's transition to the RACF as useful in supporting families, particularly those experiencing the loss of the caregiving role.	Confirm
<i>Various contextual challenges are present at the time of RACF transition</i>	The decision of transition to an RACF can come unexpectedly and at a time of crisis (for example hospitalization) which could exacerbate the sense of grief and loss that the resident and family feel.	For many people (and their family caregivers), the decision for transition to an RACF is made by someone else and at an unexpected time. Participants noted cases of residents who transitioned to RACF following an unplanned hospital admission, and the decision for their transition was made by the treating team/doctor.	Enhance
	Financial matters including the cost involved in transitioning to an RACF and ongoing care costs seems to add to the sense of stress experienced by families.	The time of admission to the RACF was noted to be peppered with challenges such as financial matters and simply information overload.	Confirm Enhance
<i>Family caregivers need formal and informal support at the time of their loved one's RACF transition</i>	Family caregivers seem to find great value in informal support they receive from their family and friends, social support groups, and faith communities during the transition of their loved into an RACF.	Staff participants noted provisioning support to the resident and the family caregivers at the time of transition into the RACF. This included use of compassionate and empathetic communication to formalised support provided through the pastoral care workers, and social workers.	Confirm

Theme	Systematic review data [34 studies]	Qualitative data [38 family and staff participants]	Data convergence
Resident's life in the RACF and family caregivers' sense of grief and loss			
<i>Ongoing and meaningful engagement of family caregivers in resident's life post RACF transition is valuable</i>	Continued engagement of family caregivers in the resident's care including opportunities for care planning discussions, and hands-on care could help minimise the sense of loss and stress.	Meaningful engagement of the family beyond the point of transition to RACF is valued. Staff participants noted that they encouraged family to participate in care, leisure activities, and overall day-to-day life of the resident. Some family participants also noted a 'need' to engage in certain aspect of care/everyday life of their loved one after they had fully transitioned to the RACF.	Confirm Enhance
<i>Provision of formal and informal support from RACF to family caregivers is useful in assisting them deal with their sense of grief loss and bereavement</i>	Input from multidisciplinary team is valuable in supporting the grief and loss needs of family caregivers.	Participants saw open and empathetic communication with family as an important way of offering support and reassurance. Provision of appropriate and tailored input from the allied health team (social workers, pastoral care team, lifestyle team, and volunteers) was also reported by various staff participants.	Enhance
Resident's end of life and family caregivers sense of grief and loss			
<i>Timely conversation of health decline and EOL care planning discussion helps prepare the family</i>	Family caregivers' involvement in advanced care planning helps them be prepared for the resident's death. Family caregivers of residents with dementia valued receiving timely information on dementia progression as helping them prepare for EOL planning.	Timely and clear communication with family caregivers regarding resident's health changes/decline, and EOL care planning is essential. The importance of making families aware of what to expect when the resident is dying was highlighted by participants.	Enhance
<i>Enabling family presence at the time of resident's death is crucial</i>	Being present at the bedside with the actively dying resident, was noted to be immensely valuable and supportive by family caregivers.	Ensuring that families are made comfortable and supported to be present at the bedside when the resident is dying was noted by participants as crucial.	Confirm
After resident's death			
<i>After death rituals hold significant value</i>	After death ritual such as room blessing ceremony is appreciated by family caregivers as it offers them the opportunity come back to the RACF to connect with staff and other residents, with whom they might have formed a significant bond.	After death rituals that are held at the RACF (memorial service, involvement of staff at the funeral etc.) are meaningful to the family caregivers, and other living residents at the RACF as it symbolizes the acknowledgement and celebration of the resident's life before their death.	Enhance
<i>Limited formalized and professional support mechanisms to address family caregivers' grief loss and bereavement needs</i>	Throughout their caregiving journey family caregivers heavily rely on their informal social networks for grief, loss, and bereavement support.	Many family caregivers seemed to have extended their relationship with the RACF, long after their loved one had died. In these prolonged connections, both the family members and the RACF seem to support each other. The families seem to do this by the way of volunteering at the RACF, and the RACFs offered support to many family members long after the resident's death.	Enhance

Discussion and Conclusions

The experience of bereavement in a residential aged care context is not well understood. For those who place a relative with Alzheimer's disease or related dementia in aged care, grief is more likely to be associated with feelings of guilt and loneliness.⁴ This project has provided new information about these issues and also developed new resources to support South Australian families. The work has delivered a rapid review of the literature on grief, loss and bereavement needs of family/caregivers of older people in the last year of life entering or living in residential aged care. Interviews and focus groups have further highlighted issues for families and staff in looking at ageing, caring, dying and grieving for families where a person is entering or living in residential aged care. This knowledge from the review and interviews has informed the content for a printed booklet and for grief pages held on GriefLink.

Bereavement needs and bereavement supports are important and complex. In the residential aged care context, grief and loss is experienced not only at bereavement but from decision making about the need for residential aged care services through entry, across in-facility care and eventual dying. Families and residents face challenges in making decisions, adapting to the changed living circumstances, and confronting deterioration, decline and death. There is a lack of information around what happens and acknowledgement of the emotional responses to these changes. This can leave older people and families unprepared for the future.

The role of residential aged care is also important but complex.⁵ We are an ageing population where people are living longer than previous generations and are dying older. However, ageing is intimately and inevitably associated with dying and grieving. Building community awareness of this can support families who are navigating these changes and challenges and help prepare them practically and emotionally to acknowledge and address decline, dying and grieving.

This study provides insights into the grief and bereavement experiences and challenges of families of residents living and dying in aged care facilities. This research has been applied in developing practical resources for families to build their awareness of issues relating to ageing and dying within a residential aged care context and to support bereavement responses.

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