ELDAC
End of Life Directions for Aged Care

Grief and Bereavement:
Core Concepts for Clinicians

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Definitions

Grief

Grief is a natural response to any loss. A loss may be the experience of a death, or other losses, such as a diagnosis or a change in health. Grief includes:

- Feelings (e.g. sadness, fear, anger, relief)
- Thought patterns (e.g. disbelief, difficulty concentrating, questioning beliefs and views about the world)
- Physical reactions (e.g. fatigue, gastrointestinal upsets), and
- Behaviours (e.g. sleeplessness, appetite changes, restlessness, withdrawal from family and friends).

PRACTICE POINT: Periods of transition can be associated with increased grief responses for older people and their families. These periods include moving into residential aged care,[1] deterioration and the end of life. It is important to pay particular attention to support needs around these times.

Anticipatory grief (or pre-death grief)

Anticipatory grief (or pre-death grief) involves grief responses that may arise due to a death that is pending but has not yet happened (e.g. due to the diagnosis of a life-limiting illness, or declining health).[2-4] Anticipatory grief may involve multiple losses such as the loss of a sense of control, physical well-being, independence, role, social connections, mental integrity, and the ability to make future plans.

PRACTICE POINT: Carers may not realise that some of their responses relate to anticipatory grief, or grieving before a death has happened. It can be helpful to acknowledge and normalise grief responses. This may include support to express conflicted or difficult feelings (e.g. feeling guilty about grieving while a family member is living).

PRACTICE POINT: Ageism may lead to older people not receiving accurate information and support after a death. Sometimes clinicians make incorrect and unhelpful assumptions (e.g. that older people are less aware of a loss, or that losses in later life have less impact).[5] Providing support and information about grief to older people is a vital aspect of care.

Bereavement

Bereavement is the experience of grief after the death of a significant person. Most older people will manage bereavement with the support of family, friends and others within their own community.[4, 6] However, some people face additional challenges in bereavement, such as physical and mental health issues.[7-10]

PRACTICE POINT: Older bereaved people may experience physical health concerns that initially seem unrelated to grief (e.g. pain, cardiovascular symptoms, and problems with sleep).[11] After careful assessment of any underlying physical causes of symptoms, it is important to consider how grief may impact the health and wellbeing of an older person.

When grief becomes complicated

Most people will not need professional help with grief or bereavement, and will manage with the support of others in their lives – such as family, friends, or co-workers. However, a small number of people will be at risk of negative outcomes after experiencing the death of a significant person.[12, 13]

Grief and bereavement may become challenging in different ways:

- Older people and their family or carers may experience poorer **mental health** during an illness, caring or bereavement. They may also experience the exacerbation or onset of mental health conditions during end of life and in bereavement (e.g. anxiety disorders, depression, and post-traumatic stress disorder).[6, 14]
- About 7-10% of bereaved adults may experience **Prolonged Grief Disorder (PGD)**.[15, 16] Older adults may be at increased risk of developing PGD.[15] This is a persistent and severe grief response following a death. PGD includes symptoms such as persistent preoccupation with the deceased, avoidance of reminders of the death, identity disruption and intense emotional pain. To meet criteria for PGD, the death had to have occurred at least 12 months ago, with symptoms that; exceed expected social, cultural or religious norms within the individual's culture and context; and lead to significant impairment in personal, family, social, educational, occupation or other important areas of functioning.[17]

Risk and protective factors

Risk factors

It is important to be aware of risk factors that are associated with negative outcomes related to grief and bereavement (e.g. PGD and other mental health concerns) for an older person, family member or carer. Examples of key risk factors may include:[12, 13, 18]

Background factors

- A close relationship to the dying person
- An insecure attachment style
- Mental health concerns (i.e. pre-death grief or depressive symptoms)
- Low social support.

Care-related factors

- Where the person with a life-limiting illness experienced aggressive medical intervention (e.g. intensive care, ventilation, resuscitation)
- Ambivalence or family conflict about treatment
- Economic hardship related to illness or treatment
- Caregiver burden.

Death or bereavement-related factors

- Death of a child or partner
- Violent or traumatic/unnatural death
- Bereavement overload (several losses in quick succession)
- Low acceptance of or feeling unprepared for a pending death
- Dissatisfaction with death notification.

Protective factors

Some factors may also be protective. For instance, where family/carers are well prepared for a death, this may support adjustment in bereavement.[19] Individuals with a level of resilience also tend to use:

- Personal resources (e.g. a belief in a just world, the ability to gain comfort from thinking or talking about someone who has died), and
- External resources (e.g. able to connect with family and community, high levels of practical support).[20]

Remember that good-quality end-of-life care, guided by your relationship with an older person and knowledge of their family and carers, can positively impact bereavement and possibly reduce the risk of complicated grief.[21]

Exploring risk and protective factors

Consideration of factors that may influence grief and bereavement for older people and their family/carers is an ongoing process. Regular review over time is needed, as support needs can change during end of life and bereavement.[22] The process of reviewing risk and protective factors:

- Starts when an older person and their family and carers are first known to a service, and should be revisited during end of life, at the time of death, and after a death, and
- Is a shared responsibility of staff involved in care.

A 'conversational' approach may be helpful for exploring factors that may shape grief and bereavement.[12] To support this approach, use the **Conversational Prompts** (see next page) to guide your ongoing conversations with older people and their family and carers.

Where older people or family/carers present with several risk factors that appear to impact their coping in a negative way (e.g. increased difficulty engaging with aspects of day-to-day life, changes in mood, withdrawal from others), it is important to discuss specific support options, such as counselling.

The ELDAC Toolkits (Residential Aged Care, Home Care, Dementia) include more information about how to approach grief and bereavement support in your setting or context. Review the **ELDAC Bereavement Practice Tips for Clinicians** for more information about how to provide support and respond to people with complex needs.

Conversational Prompts

Conversational prompts for exploring grief and bereavement-related risk factors with older people or their family/carers: A resource for clinicians[12, 13, 18]

- These prompts are to support conversations (prior to or after a death) about some of the key factors that may increase the risk of negative outcomes (e.g. Prolonged Grief Disorder, other mental health concerns) for an older person and their family and carers.
- Adapt these prompts according to individual needs and situations.
- Prompts should not be read as a list, or necessarily covered in one conversation alone. Prompts should be used as needed to explore relevant issues during interactions over time.

Where an individual has several risk factors that appear to be having a negative impact on their coping, provide information about available support and services and assist the person to connect with these.

Factors		Conversational prompts and observations
Background factors	Close relationship	• **Prompt:** Can you tell me a little about your relationship with [name]? What does/did [name] mean to you?
	Mental health and pre-death grief	• **Prompt:** Sometimes experiencing other mental health issues can make [ageing/caring/grieving] more challenging. Have you ever struggled with your mental health or difficult thoughts and feelings? • **Prompt:** How are you coping at the moment? What is the most difficult part of your grief? • **Observe:** Are/were the person's grief responses or distress high or particularly intense, pre-loss?
	Level of social support	• **Prompt:** Who is around to support you? • **Prompt:** What kinds of support have you been offered by others? Was this helpful? • **Prompt:** Is there support you've needed that hasn't been offered or isn't available?
Care-related factors	Caregiver burden	• **Prompt:** What is/has it been like to care for [name]? How has being a carer for [name] had an impact on your relationship? • **Prompt:** Is/was it difficult to get help from your family or others in taking care of [name]? • **Prompt:** How does/has caring for [name] impacted on your daily life, such as seeing friends? • **Prompt:** How does/has caring impacted upon your health and well-being?
	Financial strain	• **Prompt:** Have you experienced financial hardship because of costs related to [name's] illness or needs? (e.g. Accrued debt, had to borrow money from friends or family, had a major drop in income).
	Experience of medical intervention	• **Prompt:** Did [name] have recent admissions to hospital or need recent medical treatment? What was your experience of this/what was that like for you? • **Prompt:** Sometimes in families, people have different views about someone's treatment and/or care – what has this been like in your family?

Factors		Conversational prompts and observations
Death or bereavement-related factors	Loss relationship	• **Observe:** Is the bereavement related to the death of a partner or child?
	Preparation for death	• **Prompt:** Were you expecting [name] to come to the end of their life when they died? In what ways did you feel prepared or ready for this (or unprepared)? • **Observe:** Do you think that this person feels/felt well-prepared for the death?
	Experience of death	• **Observe:** What is this person's perception of the death – did they find aspects of the care or death traumatic or confronting?
	Bereavement overload	• **Prompt:** Have you been through any other losses recently? How did you manage these? • **Observe:** Are you aware of other recent or multiple losses or deaths experienced by this person?

References

1. Zizzo G, Mackenzie C, Irizarry C, Goodwin-Smith I. Loss and grief: The experience of transition to residential aged care. Aust J Soc Issues. 2020;55(4):474-91.
2. Meichsner F, O'Connor M, Skritskaya N, Shear MK. Grief Before and After Bereavement in the Elderly: An Approach to Care. Am J Geriatr Psychiatry. 2020;28(5):560-9.
3. Coelho A, Barbosa A. Family Anticipatory Grief: An Integrative Literature Review. Am J Hosp Palliat Med. 2017;34(8):774-85.
4. Palliative Care Australia. National Palliative Care Standards for All Health Professionals and Aged Care Services. Palliative Care Australia. 2022. [cited 4 April 2025].
5. Fernandez Cabana M, Garcia-Gaballero A, Mateos R. Bereavement in Older Adults. In: de Mendonca Lima CA, Ivijaro G, editors. Primary Care Mental Health in Older People: A Global Perspective: Springer. 2019; p.167-76.
6. Neimeyer RA, Holland JM. Bereavement in Later Life: Theory, Assessment and Intervention. In: Lichtenberg PA, Mast BT, editors. APA Handbook of Clinical Geropsychology. Washington, DC: American Psychological Association; 2015. p. 645-66.
7. Boelen PA, Prigerson HG. The influence of symptoms of prolonged grief disorder, depression, and anxiety on quality of life among bereaved adults: a prospective study. Eur Arch Psychiatry Clin Neurosci. 2007;257(8):444-52.
8. Stroebe MP, Schut HP, Stroebe WP. Health outcomes of bereavement. Lancet. 2007;370(9603):1960-73.
9. Buckley T, McKinley S, Tofler G, Bartrop R. Cardiovascular risk in early bereavement: A literature review and proposed mechanisms. Int J Nurs Stud. 2010;47(2):229-38.
10. Lundorff M, Holmgren H, Zachariae R, Farver-Vestergaard I, O'Connor M. Prevalence of prolonged grief disorder in adult bereavement: A systematic review and meta-analysis. J Affect Disord. 2017;212:138-49.
11. Gerber K, Brijnath B, Lock K, Bryant C, Hills D, Hjorth L. 'Unprepared for the depth of my feelings' - Capturing grief in older people through research poetry. Age Ageing. 2022;51(3).
12. Hall C, Hudson P, Boughey A. Bereavement support standards for specialist palliative care services. Melbourne: Department of Health, State Government of Victoria; 14 November 2012. [cited 4 April 2025].
13. Neimeyer RA, Burke LA. Complicated Grief and the End of Life: Risk Factors and Treatment Considerations. In: Werth JL, editor. Counseling Clients Near the End of Life: A Practical Guide for Mental Health Professionals. 1 ed. New York: Springer Publishing Company. 2012. p.205-28.
14. Palliative Care Australia. National Palliative Care Standards for Specialist Palliative Care Providers 5.1 Edition. Palliative Care Australia 2024 [cited 4 April 2025].
15. Szuhany KL, Malgaroli M, Miron CD, Simon NM. Prolonged Grief Disorder: Course, Diagnosis, Assessment, and Treatment. Focus (American Psychiatric Publishing). 2021;19(2):161-72.
16. Thiemann P, Street AN, Heath SE, Quince T, Kuhn I, Barclay S. Prolonged grief disorder prevalence in adults 65 years and over: a systematic review. BMJ Support Palliati Care. 2023;13(e1):e30-e42.
17. American Psychiatric Association. Prolonged Grief Disorder [Internet]. Washington DC: APA. 2022 [cited 5 June 2025].
18. Buur C, Zachariae R, Komischke-Konnerup KB, Marello MM, Schierff LH, O'Connor M. Risk factors for prolonged grief symptoms: A systematic review and meta-analysis. Clin Psychol Rev. 2024;107:102375.
19. Schulz R, Boerner K, Klinger J, Rosen J. Preparedness for death and adjustment to bereavement among caregivers of recently placed nursing home residents. J Palliat Med. 2015;18(2):127-33.
20. Boerner K, Mancini AD, Bonanno G. On the nature and prevalence of uncomplicated and complicated patterns of grief. In: Schut H, Stroebe MS, Van den Bout J, editors. Complicated grief : scientific foundations for health care professionals. First edition. ed. New York: Routledge; 2013. p.55-67.
21. Wright AA, Keating NL, Balboni TA, Matulonis UA, Block SD, Prigerson HG. Place of Death: Correlations With Quality of Life of Patients With Cancer and Predictors of Bereaved Caregivers' Mental Health. J Clin Oncol. 2010;28(29):4457-64.
22. Blackburn P, Bulsara C. "You either need help…you feel you don't need help…or you don't feel worthy of asking for it:" Receptivity to bereavement support. Palliat Support Care. 2019;17(2):172-85.