

Policy Statement

Grief and Bereavement



August 2018

This is a joint policy statement from Palliative Care Australia (PCA) and the Australian Centre for Grief and bereavement (ACGB)

Palliative Care Australia is the national peak body for palliative care in Australia. PCA provides leadership on palliative care policy and community engagement. Working closely with consumers, its Member Organisations and the palliative care and broader health workforce, PCA aims to improve the quality of life and death for people with a life-limiting illness, their families and carers.

Australian Centre for Grief and Bereavement is an independent, not for profit organisation which opened in January 1996 and is the largest provider of grief and bereavement education in Australia. Its mission is to build the capacity of individuals, organisations and communities in order to enhance well-being following adverse life events.

Everyone at some point will experience the death of someone close to them. Grief is the normal emotional reaction to loss, but the course and consequences of bereavement will vary for each individual. Palliative care integrates the psychological, spiritual and cultural aspects of care, and offers a support system to help carers and families cope during the person's illness and in bereavement.

Grief can be experienced across many domains including emotional, physical, cognitive and spiritual, where a person's experience of grief can vary widely, often influenced by culture, gender and belief systems. Bereavement can be emotionally intense, destabilising and exhausting.

Palliative Care Australia (PCA) and the Australian Centre for Grief and Bereavement (ACGB) expects that all providers of palliative care (whether generalist or specialist) have the capacity to assess where family members and carers sit along a continuum of need for bereavement support and refer accordingly. Support for those experiencing grief can be from many informal and professional sources, however for approximately 7%ⁱ of the grieving population who have prolonged grief disorderⁱⁱ, targeted specialist services should be available regardless of socioeconomic status or geographic location.

Some people receive palliative care for a short time, while others may receive it for many years. PCA and the ACGB emphasise that advance care planningⁱⁱⁱ for the end of life can assist with preparing for death and coping with grief by assisting people to know what to expect, what treatment and support is available, and help to avoid making difficult decisions at a time of crisis. Many people want to know what to expect as they themselves, or their loved ones approach their final days, however this information can be confronting to read or talk about. Structured information and support should be provided with respect, compassion and sensitivity at various points, including at appropriate intervals along the illness trajectory, admission to a specialist palliative care service, and when death is imminent.

PCA and ACGB promote support that is delivered in a manner sensitive to social, cultural and spiritual beliefs, values and practices of individuals. It is important to understand that for a person close to death and their family and community, the impact of the loss and grief is often compounded by earlier experiences. Grief and bereavement are often compounded by a lack of understanding and/or policies and procedures of health services, including palliative care services, that impact on the ability of people to follow tradition, such as those of Indigenous Australians and Culturally and Linguistically Diverse communities. This may include large gatherings towards the end of life, smoking ceremonies and the need to have family surrounding a person at all times, including after death.

It is also essential for carers and family members to be aware of their own needs as there is often a heavy emotional strain associated with caregiving at the end of life, with individuals experiencing fatigue, resentment, social isolation and stress. This may include seeking support with anticipatory grief, feelings of loss of hope and unresolved relationship issues. The death of a family member brings grief to the whole family, yet each member will experience and respond to bereavement differently. Children (including adolescents) experience and process grief in a variety of ways depending on their family circumstances, age and stage of development. Death can threaten their sense of safety and control and it is vital

Palliative care is person and family-centred care provided for a person with an active, progressive, advanced disease, who has little or no prospect of cure and who is expected to die, and for whom the primary treatment goal is to optimise the quality of life. Dying is a normal process with palliative care offering a support system to help people to live their life as fully and as comfortably as possible until death and to help families cope during this illness and in their bereavement.

People are approaching the **'end of life'** when they are likely to die within the next 12-months.

Grief is the response to loss that can affect thoughts, behaviours, beliefs, feelings, physical health and relationships with others.

Bereavement is the process of grieving and the period of mourning that is entered after someone has died.

Original Date: August 2018

that a child's physical and emotional needs are met to support them in adapting to the loss.

With 35% of all deaths in Australia occurring in residential aged care^{iv} PCA and ACGB believe there is a need to ensure awareness of grief and bereavement of all staff, including non-clinical, as often long-term and close relationships are formed with residents and their families. Upskilling the aged care workforce in this area would not only assist in supporting the families and carers of the person who has died, but also foster an environment of support and resilience for other residents and the staff themselves.

Grief within a workplace can be difficult to navigate, and in some instances the life-limiting illness of a person or their death can have an impact on a number of employees or across the whole workplace for an extended time period. PCA and ACGB note that while the workplace does not need to be experts in bereavement, there should be practices and processes in place that enable an understanding of the impact of grief and how to respond appropriately.

In addition to providing care for bereaved family members and carers, PCA and ACGB are of the view that grief support for all health professionals should be a key component of self-care. The level and structure of support will be dependent on the nature of the health profession and the individual professional's needs, and may include mentoring and professional supervision, case reviews, access to confidential support programs and opportunities for consultation with experienced bereavement clinicians.

PCA and the ACGB recommend and advocate for:

- The promotion of community awareness of bereavement issues and recognition by the establishment of a National Grief Awareness Day
- Improved education and understanding of grief and bereavement, including identification of prolonged grief disorder, for health and aged care professionals. There must be ongoing access to professional development and inclusion in undergraduate curricula and vocational training pathways
- Recognition of the specialised skills required to effectively treat individuals with prolonged grief disorder, and development of referral pathways to assist in timely access
- Australian workplaces to consider and compassionately respond to grief through development of extended bereavement leave policies^v
- Health services to review their policies and procedures to reflect support that enables people to follow cultural and traditional practices relating to death and dying.

02 6232 0700 | pcainc@palliativecare.org.au | palliativecare.org.au

03 9265 2100 | counselling@grief.org.au | www.grief.org.au

ⁱ Kersting et al (2011) 'Prevalence of complicated grief in a representative population-based sample'. *Journal of Affective Disorders* Vol. 131(339-343). doi:10.1016/j.jad.2010.11.032

ⁱⁱ Prolonged grief disorder (also known as complicated grief) is where there is a persistent and pervasive grief response, characterised by longing for the deceased or persistent preoccupation with the deceased accompanied by intense emotional pain, that has persisted for more than 6 months, and clearly exceeds expected social, cultural or religious norms for the individual's culture and context. World Health Organisation (2018) ICD-11 (6B42) Prolonged grief disorder.

ⁱⁱⁱ Advance care planning enables the coordination of access to resources and services to match anticipated care needs, and offers individuals the opportunity to take control of decisions which affect their care. PCA and ACPA (2018) 'Policy Statement: Advance Care Planning & Advance Care Directives'

^{iv} PCA, Economic Research Note 4, 2017

^v Per the *Fair Work Act 2009* Australian employees are entitled to compassionate (bereavement) leave of 2 days each time an immediate family or household member dies or suffers a life threatening illness or injury. Australian Government Fair Work Ombudsman.