Department of
Health

GOVERNMENT OF
WESTERN AUSTRALIA

Framework for bereavement support after an expected death in WA

Important disclaimer

Using the term Aboriginal

Within Western Australia, the term Aboriginal is used in preference to Aboriginal and Torres Strait Islander, in recognition that Aboriginal people are the original inhabitants of Western Australia. Aboriginal and Torres Strait Islander may be referred to in the national context and Indigenous may be referred to in the international context. No disrespect is intended to our Torres Strait Islander colleagues and community.

Contents

Executive summary

Bereavement touches everyone's lives at some point. Grief, a natural response when someone dies, can be experienced before the death, during the illness, after the death or at any stage in the life of the bereaved person.[1]

The *Framework for bereavement support after an expected death in WA* (the framework) provides a strategic guide for services providing end-of-life and palliative care to develop local solutions to support bereaved families and carers after an expected death.

It recognises that bereavement support is applicable to all services offering end-of-life and palliative care to people with life limiting illness in WA and that collaborative approaches provide the best outcomes. The framework can be used to inform local planning, delivery and evaluation strategies at a service level.

Bereavement support is an essential component of end-of-life and palliative care services[7, 8], as recognised by Priority Four of the WA End-of-Life and Palliative Care Strategy 2018 -2028 (the Strategy)[5], Implementation Plan One 2020-2022 (IP1)[6] and Recommendation 9 of the Sustainable Health Review. The framework outlines service considerations for each of the Strategy priority areas and provides a brief discussion of models of bereavement care and support interventions.

Service considerations by WA End-of-Life and Palliative Care Strategy 2018–2028 priority area

Priority 1

Care is accessible to everyone, everywhere

I have access to good quality end-of-life and palliative care, regardless of who I am, or how I live

Bereavement support for the family and carers of those dying from an expected death should be equitable across diagnoses. Appropriate, practical information should be made available to families and carers prior to death and cover biopsychosocial elements of self-care. The needs of vulnerable populations should be given particular attention to ensure respectful and responsive interactions. Religious and spiritual beliefs and needs should be acknowledged. Clinical planning, resourcing and calculations of workload should take bereavement support into consideration.

Priority 2

Care is person-centred

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account.

The person and their family and carers should be kept well-informed about the disease trajectory and management options and involved in decision-making and care planning as early as possible. Advance care planning and goals of patient care processes and tools should be used to guide conversations in an appropriate physical space. Advance care planning documents should be acknowledged and the individual's preferences and decisions respected. Support should be respectful and sensitive to cultural beliefs and norms and social support networks.

Priority 3

Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly.

Facilities should develop structured internal processes and pathways to ensure the bereaved receive the level of care they need, with clear referral pathways for transition across settings. Primary care should be recognised as best placed to provide access to specialist therapeutic support. Families and carers should be empowered to access care and services from across the care continuum of service provision. Identified and consistent measures should be used to evaluate the impact of services on families and carers.

Priority 4

Families and carers are supported

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family and carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

Practical advice, information and support for bereaved families and carers should be easily accessible. Risk should be determined via routine multidisciplinary team-based psycho-social assessments. A consistent approach to screening and assessment processes is needed with the use of a validated tool considered. Further research into the definition, prevention and management of family and carer grief should be conducted. Solutions to privacy and consent issues should be investigated.

Priority 5 All staff are prepared to care

Wherever/whenever I am cared for, all relevant staff have expertise, empathy and compassion.

Education and training about loss, grief, bereavement and cultural awareness should be accessible to staff, volunteers and other community providers. Support and counselling should be provided to all staff and volunteers involved in bereavement support. Clear staff service models should be embedded and communicated and should include the approach to screening and the mechanism for allocation of staff members. The time taken for bereavement support should be factored into staffing models and Aboriginal workforce strategies should be implemented.

Priority 6 The community is aware and able to care

I feel supported and empowered to make decisions. My individual preferences are expressed through Advance Care Planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Shared models of care should be encouraged between health services, primary care and community-based organisations. Community awareness of end-of-life planning and care, palliative care, grief and bereavement should be raised as well as access to local service directories. Community preparedness and readiness to support those involved in voluntary assisted dying should be addressed. Health, community and aged care providers should be educated about grief and how to facilitate family access to spiritually and culturally appropriate bereavement support.

Models of bereavement care

Bereavement support interventions after an expected death in Australia, commonly include multiple components, such as:

- compassionate interventions from members of the multidisciplinary team that acknowledge people's loss
- quality information
- remembrance and legacy acknowledgement either individualised or institutional
- community based responses to people affected by grief and bereavement.

Models of bereavement care should frame practice around contemporary available evidence and build in mechanisms for ongoing evaluation, collection of service data and involvement in clinical research. Collaborative discussion and additional research are required to further refine the approach to bereavement support provision in WA.

About framework

Purpose

The *Framework for bereavement support after an expected death in WA* (the framework) provides a strategic guide for services providing end-of-life and palliative care to develop local solutions to support bereaved families and carers after an expected death.

The framework aims to increase awareness and understanding of the service considerations associated with the provision of bereavement support after an expected death, rather than act as a clinical guideline.

Scope

The framework addresses bereavement support considerations for families and carers following an expected death, including death through voluntary assisted dying (VAD).

It recognises that bereavement support is applicable to all services offering end-of-life and palliative care to people with life limiting illness in WA and that collaborative approaches provide the best outcomes. The framework can be used to inform local planning, delivery and evaluation strategies at a service level. Issues of funding and resourcing are out of scope for the framework.

Unexpected death due to suicide, accidents, sudden acute illnesses and perinatal death are not covered by the framework but many of the principles and practices discussed would be applicable.

The grief experiences of healthcare providers are also beyond the scope of this document.

Language and key concepts

The following key concepts are specific to grief and bereavement support:

Bereavement

Bereavement is the state of loss when someone close to an individual has died. How people experience this loss can vary from one person to the next, and with the circumstances of the death.

Grief

Grief is a normal, natural and inevitable response to loss. It can affect every part of life, including thoughts, behaviours, beliefs, feelings, physical health and relationships with others.

Grief may occur before the death related to the losses already occurring such as not being able to do usual activities together, and after the death from the death itself as well as flow on losses by not having that person in one's life anymore.

Some bereaved individuals (~10%) experience prolonged grief (also referred to as complex or complicated grief), which may be accompanied by severe physical and mental health problems.[8] Prolonged grief is a persistent form of intense grief where people find it very difficult to live with the loss and it does not follow expected timelines. Instead of gradually thinking more positively, thoughts may become stuck in a dark, sorrowful place.[13]

An expected death

An expected death is the result of an acute or gradual deterioration in a patient's health status, usually due to advanced, progressive, incurable disease. The death is anticipated, expected and may, to a variable extent, be predicted. For the purposes of this Framework, an expected death includes death through VAD and explicitly excludes accidental death, death by suicide and sudden death from causes other than progressive illness.

Families and carers

For the purpose of this framework, the term 'families and carers' recognises that family comes in very different forms and diversity must be positively responded to. According to the *Carers Recognition Act 2004*, "a carer is someone who provides unpaid care and support to family members and friends who have disability, mental illness, chronic condition, terminal illness or general frailty. Carers include parents and guardians caring for children."

Voluntary assisted dying

Voluntary assisted dying (VAD) is a legal option that is available to adults in WA who have a terminal illness and meet specific criteria. It is provided only by clinicians that have undergone the approved training and is overseen by the Voluntary Assisted Dying Board.

The following definitions used in this document, are based on the definitions provided in the WA End-of-Life and Palliative Care Strategy 2018–2028[5]; terms used by the Australian Institute of Health and Wellbeing and the Australian Commonwealth Government:

End-of-life

End-of-life is the timeframe during which a person lives with, and is impaired by, a life limiting or fatal condition, even if the prognosis is ambiguous or unknown. Those approaching end-of-life will be considered likely to die during the next 12 months.

End-of-life care

End-of-life care is care needed for people who are likely to die in the next 12 months due to progressive, advanced or incurable illness, frailty or old age. During this period, people may experience rapid changes and fluctuations in their condition and require support from a range of people, including health services, as well as family and carers.

Palliative care

Palliative care is an approach that improves the quality of life of individuals, their families and carers facing problems associated with life-threatening illnesses/conditions, through the prevention and relief of suffering. Palliative care recognises the person and the importance and uniqueness of their family and carer. It serves to maximise the quality of life and considers physical, social, financial, emotional, and spiritual distress. Such distress not only influences the experience of having a life-limiting illness but also influences treatment outcomes.

Specialist palliative care

Specialist palliative care is undertaken by a professional palliative care team or service with recognised qualifications or accredited training in palliative care. The role of the specialist palliative care services includes providing consultation services to support, advise, educate and mentor specialist and non-specialist teams to provide end-of-life and palliative care and/ or to provide direct care to people with complex palliative care needs.

Terminal care

Terminal care refers to the care of a person in the last days or weeks before they die (i.e. the final part of palliative care).

Background and context

Bereavement touches everyone's lives at some point. Grief, a natural response when someone dies, can be experienced before the death, during the illness, after the death or at any stage in the life of the bereaved person.[1]

In most circumstances, support from social and community networks is enough to enable resolution of the grief, waning of bereavement and a resumption of activity. Services should therefore encourage and support bereaved people to recognise and use their existing informal social networks and provide information about community-based social and primary care services that can be accessed if needed. Referral for formal assessment and support is rarely required.

However, approximately 10 per cent of people suffer extreme and disabling grief[2, 3] and require referral to appropriate specialist services, including psychiatric services when needed. Bereavement support services aim to 'reduce immediate distress while ameliorating long-term morbidity associated with unresolved grief'.[2,3,4] Access to these services has been shown to assist families and carers to process their grief.

An expected death enables time for services to work with families and carers, provide support and information and to assess family and carer responses to the approaching death. It also enables assessment and facilitation of coping mechanisms at the time of death and the following period. The time prior to death can provide the opportunity for the families and carers to deal with unfinished business and unresolved conflict, discuss unfulfilled plans and allow time to say, 'I love you'.

Consistent pathways should be developed for all services involved in providing bereavement support in relation to an expected death. This includes family who are often involved in the person's journey of those who have chosen an expected death by VAD. A needs-based public health approach provides access to a basic level of services for everyone and specialised services for those with a higher level of need.[1, 2, 4]

At a minimum, bereavement services should:

- commence informal assessment and provide support as soon as a patient is accepted by an end-of-life or palliative care service
- include verbal and written information about the dying process and the practical aspects of coping after a death that is culturally appropriate
- acknowledge the death (immediate and on anniversaries, where practical)
- provide or facilitate access to an ongoing process of assessment for those at risk of prolonged grief[4] and referral for specialised services when appropriate.

Bereavement support is an essential component of end-of-life and palliative care services.[7,8] Priority Four of the WA End-of-Life and Palliative Care Strategy 2018 -2028 (the Strategy)[5] and Implementation Plan One 2020-2022 (IP1)[6] identify improved awareness and access to bereavement support services as a core function of end-of-life and palliative care. Recommendation 9 of the Sustainable Health Review also advocates the promotion and integration of 'social approaches to dying, death and bereavement in everyday lives'. It is widely accepted that bereavement support services can contribute to the wellbeing and 'recovery' of people affected by loss.[4] The evidence though, is unclear about which aspects of these interventions are most effective or result in the greatest impact. The importance of informal support networks and local communities in providing bereavement support should also be acknowledged. Services should actively encourage the bereaved person to identify, use and develop the relationships and resources that will help meet their needs whilst they learn to live every day with the absence of the person who has died. Where formal Compassionate Communities models exist, they may provide a useful pathway to the provision of community-based bereavement support.

Bereavement services after an expected death in WA

A national survey of Australian palliative care services in 2019, (n = 163), found that 91 per cent of services provided bereavement support.[10] However, later studies cite many gaps in bereavement care and conclude that it is not routinely or systematically provided in most Australian hospitals, often mirroring levels of access to palliative care.[4]

A snapshot survey was conducted in 2022 to broadly describe the bereavement support available after an expected death in WA, the reasons for gaps and the challenges experienced by the services.

Responses confirmed that standard care in WA varies considerably, consistent with the situation across most of Australia.[11,9] Thirty-eight survey responses were received, with some sites providing multiple responses, reflecting the range of bereavement support services provided. Many sites have comprehensive and well-resourced bereavement support programs, whilst others provide a more ad hoc service. Insights from the survey plus key subject expert interviews, have been built into this framework.

Service considerations aligned with the End-of-Life and Palliative Care Strategy 2018 – 2028 priority areas

Many of the following considerations are applicable across all priority areas but are dealt with under the most relevant, where appropriate.

Priority 1 Care is accessible to everyone, everywhere

I have access to good quality end-of-life and palliative care, regardless of who I am or how I live my life

Access to information covering the practical and emotional aspects of bereavement, and the support available from agencies, is key to enabling families and carers to know what to expect and where they might get assistance with bereavement and their grief. Failure to access appropriate bereavement support can exacerbate family and carer grief and negatively impact coping mechanisms. This can be addressed by ensuring the timeliness of targeted support and consistency of relationships between the service and the bereaved in order to build rapport and trust that the service will be able to assist after death.[8, 15]

A consistent and systematic approach, that considers the evidence base and allows for innovation and varied service delivery models, is vital to ensure equity of access to bereavement support.[4] Consistency relies in part on systematic allocation of resources. Planning and resourcing bereavement support activities is complex. Bereavement services are seldom recognised as part of the clinical workload because the recipient is not an admitted patient of the palliative care service.

The existence of clear referral pathways, based on respect, compassion and sensitivity, developed in consultation with families and carers, particularly those from vulnerable groups, will significantly improve service access. Where local councils have supported the development of community-wide initiatives for bereavement care, the bereaved may also be directed to formal pathways to access broader community support.

There is limited evidence to support specific recommendations for the assessment of bereaved families and carers from vulnerable groups.[16] Vulnerable groups include Aboriginal people, people from Culturally and Linguistically Diverse (CaLD) communities, people with disabilities, people experiencing disadvantage, people in regional or remote areas of WA, people living with mental health challenges and children. Considerations that may impact access for these populations include:

- People living in regional and remote Australia often have reduced access to palliative care, and consequently reduced access to bereavement support, and in some cases may prefer to have support outside their community for privacy reasons.[17]
- Culturally appropriate information, resources and care about grief, bereavement and loss support services, regardless of age, gender, culture, language, sexual orientation, socioeconomic status, religious belief, physical or other disability, ability to pay or place of residence, need to be routinely available to families and carers before and after the death.

- For Aboriginal people at end-of-life, cultural needs may outweigh medical needs. Inclusion of family and carers in end-of-life protocols and keeping them updated regarding the dying person's expected journey can substantially reduce the risk of prolonged grief. There is a need to balance a person's right to confidentiality with cultural and family considerations and services and healthcare workers can explore a person's preferences in this regard. Further information about facilitating an Aboriginal person's preference to remain on or return to Country in the final stages of life is included in the Aboriginal End-of-Life and Palliative Care Framework (health.wa.gov.au).
- Like adults, children experience, express and process grief in a variety of ways depending on their age, stage of development, personality, family culture, understanding of death, past experiences of loss and the context of their bereavement. When considering how best to provide support, the child's unique grieving needs should also be considered. With good information, love and support, most children can learn to understand and work with their grief. Where concerns arise, accessing formal support via a health professional may be required.

VAD requires specific consideration in relation to bereavement because it is a relatively new way to die in Western Australia and a choice that is not always understood or supported by family and carers. The complexities of grieving after a VAD death may raise unique and conflicting emotions in the bereaved that may need to be explored by end-of-life services.

There is often a sensitivity around VAD because of the legal and ethical issues surrounding it, so family members might be at an increased risk of experiencing what is known as disenfranchised grief. This is where their grief may not be acknowledged or socially supported. This can negatively impact their mental health, such as through increased loneliness, shame or anxiety. It can sometimes be useful for family and friends to speak to someone who has had a similar experience who can listen and empathise if this can be arranged.

Service considerations for Priority 1

- Bereavement support for the family and carers of those dying from an expected death should be equitable across diagnoses.
- Appropriate information should be available to families and carers. The information should:
  - be responsive to the range of needs e.g. available in multiple languages, culturally and age appropriate
  - commence prior to death, where possible, ideally from the diagnosis of a progressive, life limiting illness
  - cover practical information e.g. financial, funeral planning
  - cover biopsychosocial elements of self-care and information about grief and bereavement.
- The needs of people from vulnerable populations and groups should be recognised and given additional attention. Interactions with people and their families from those groups should be respectful and responsive. e.g. Aboriginal people, people with disability, children.
- Religious and spiritual beliefs should be acknowledged with referrals made to Aboriginal health workers, spiritual or pastoral care as required (in consultation with the person).
- Bereavement support should be included in statewide end-of-life and palliative care clinical planning and resourcing, including access to support for those living in rural and remote WA.
- Bereavement support activity should be reported on and included in calculations of clinical workload e.g. via electronic Palliative Care Information System (ePalCIS), Palliative Aged Care Outcomes Program (PACOP), Palliative Care Outcomes Collaboration (PCOC) Phases 3 (deteriorating), 4 (terminal) and 5 (post death).

Priority 2 Care is person-centred

I am seen as an individual, and I have the opportunity to be involved in honest discussions with those important to me about my care. My values, culture and spirituality are respected and taken into account when care is given.

Palliative care aims to facilitate as good a death as possible for the person at end-of-life. Key to achieving this is respect for the person's perspective and reality. Structured, open and honest communication regarding the person's wishes and what matters the most to them can be helpful for the person and their family and carers, giving consideration to all preferences. This includes but is not limited to where people would like to be when they are nearing death, spiritual and religious needs and access to VAD, if requested.

Positive experiences during the end-of-life period have been shown to ameliorate the development of prolonged grief.[18] Early interventions such as family meetings held with the person's consent can inform and empower families and carers and build trust.[9] They can help families to better understand the transition from active treatment to end-of-life care, what the person's death could look like, what happens in situations where the death is reportable to the coroner, and that grief is a normal process.[18] The person may feel reassured that the people that are important to them will be able to access bereavement support after their death.

It can be comforting for the person if their family and carer is included sensitively in open discussion and decision-making about their disease trajectory and care. Advance care planning and goals of patient care discussions provide opportunities for the person to express, debate and inform others about their wishes.

For Aboriginal people and those from other vulnerable populations nearing the end-of-life, it is particularly important that the service knows how to explore what is most important to the person, their family and community.

Service considerations for Priority 2

- The person and their family and carers should be well-informed about the disease trajectory and management and care options through written information and regular opportunities to speak openly about the person's illness and death.
- The person and their family and carers should be involved in decision-making and care planning as early as possible, focusing on improving quality of life and planning for clinical deterioration, end-of-life care, death and bereavement.
- Facilities should consider access to appropriate physical spaces for sensitive conversations or people requiring support or privacy.
- Education and information should be provided to the dying person and their family and carers about advance care planning (ACP), including the option of voluntary assisted dying if raised.
- Advance care planning and goals of patient care processes and tools should be used to guide conversations.
- Advance care planning decisions and documents, including Advance Health Directives and Enduring Powers of Guardianship, should be acknowledged and the person should be reassured that their preferences and wishes will be respected.
- The support provided should be respectful and sensitive to cultural beliefs and norms and should not undermine social support networks.
- Care and health service accommodation and services should be sufficiently flexible to allow responsiveness to the dying person and their families' and carers' wishes and views prior to death, at the time of death and after death, including accommodating voluntary assisted dying.

Priority 3 Care is coordinated

I receive the right care at the right time, in the right place, from the right people. My care occurs within a coordinated/collaborative approach, enabling care to be delivered seamlessly

People at the end-of-life are cared for across different settings and encounter multiple staff and service models. A compassionate, coordinated and consistent approach to bereavement support assists relationship building and can address any confusion this might cause. Perceptions about grief are complicated and inconsistent. There is often an expectation that grief will decrease steadily over time then stabilise, which is seldom the case.[19] However, receiving compassionate support and relevant information can help those experiencing normal grief to understand the processes and prevent escalation to a higher level of need.

The key purpose of bereavement support services differs across the stages of bereavement. Before death, it is important to establish rapport with the family and provide the level of information they can absorb, in digestible language. At and after death, services primarily provide immediate, and often practical, assistance. Subsequently, the focus is on achieving recovery and return to normal function, while recognising that a person may continue grieving for some time and still be functioning.[20] There is an ongoing need throughout to identify family and carers who are at risk of severe or prolonged grief and need professional treatment and support.

The National Palliative Care Standards recommend that services develop strategies and clear referral pathways, in partnership with community-based providers, primary care and other relevant structures.[8] Up-to-date directories containing comprehensive information about available support should be accessible to the family, carers and community organisations.

Clear referral pathways facilitate transition across settings and levels of care, including metropolitan and rural areas. They help to facilitate referral to specialist bereavement, mental health and/or counselling professionals when clinically indicated and allow for an effective balance between the services needed by families and carers experiencing different levels of grief.

A key challenge is retaining a co-ordinated, structured approach while making room for person and family-centred flexibility, heterogeneity and innovation in care delivery that will be required for some people and families, within general resource constraints. As people often access multiple services, it can be unclear which service, and who within that service, is responsible for coordinating bereavement support.[11] Organisations should clearly identify who is responsible for making referrals and what the referral triggers are when developing their own internal processes. Organisations should also consider whether job description forms need to explicitly state employee responsibilities in relation to bereavement processes.

The National Palliative Care Standard Six states that “the risk assessment process begins on intake to the palliative care service and continues throughout the service’s involvement with the person and beyond”.[8] It is implicit that the bereaved are referred to appropriate services according to need but unclear who might be responsible for coordination or referral and what the referral triggers are, if any.[11]

Aoun et al recommend that ‘Palliative care services might do better investing their efforts principally in assessing and supporting family caregivers during the pre-bereavement period and developing community capacity and referral pathways for bereavement care’.[15]

Service considerations for Priority 3

- Clear referral pathways should be embedded to facilitate transition across settings and levels of care.
- Facilities should develop structured internal processes and pathways that ensure the bereaved receive, or are referred for, the level of care they need.
- Pathways should be based on current, evidence-based information regarding grief processes and management.
- Primary care should be recognised as best placed to provide access to specialist therapeutic support. This may be via GP mental health management plans and Better Access Initiative benefits.
- Families and carers should be empowered to access care and services from across the care continuum of service provision, particularly community-based social structures and organisations.
- Identified and consistent measures should be used to evaluate the impact of services on families and carers.

Priority 4 Families and carers are supported

Those close to me and/or caring for me are supported and involved in my care. The contributions made by my family/carer are recognised and valued by those providing my care, including their need to be supported during and after my death.

Palliative care is by definition “family centred, with the patient and their family forming the unit of care”.[9, 21, 22] The advantage of palliative care services over any stand-alone bereavement program is the involvement with family pre-death.[23, 24] Every opportunity should be taken to involve families and carers in decision-making and inclusion in care both formally and informally.

Pathways for bereavement support interventions should begin as early as possible and include the provision of practical and psychosocial information. Focusing on answering questions, managing expectations and implementing support structures around families and carers during the dying process may reduce the risk of prolonged grief and the need for formal high-risk bereavement support. Use of applications such as the ‘Help’ app may assist with this. Mechanisms to screen and assess families and carers for the risk of prolonged grief responses and the capacity to provide or refer for individual needs-based support are also important service considerations which should be undertaken in the context of the services’ abilities to respond to identified need or refer on.

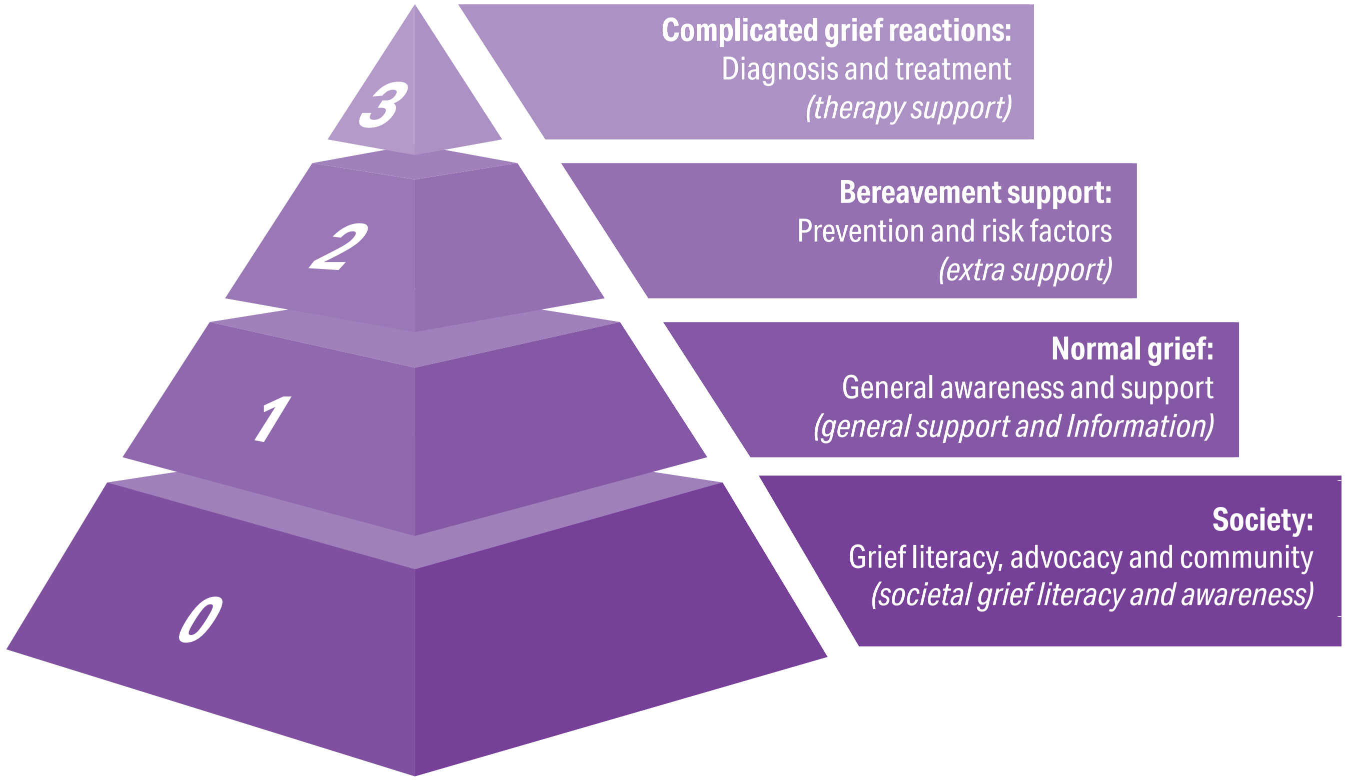
Many models, including the public health approach in WA[2] and the NICE three-component model[1], advocate the adoption of a tiered approach to bereavement support, where services are staggered according to the level of risk and need of the bereaved. These models define three levels of need whereas pathways[7] developed to operationalise the Victorian bereavement standards[25] specify only 2 levels - universal and high risk.

The majority of bereaved people experience ‘normal’ levels of grief in response to a death. Care should be taken not to medicalise their grief which is usually managed through their own internal characteristics, resilience, coping mechanisms and social support. There is no evidence that grief counselling improves outcomes for those with normal grief, which means that resources can be directed towards those deemed to be at a higher level of risk, as long as the assessment process is appropriately and thoroughly implemented.[20]

Table 1 describes bereavement support interventions by level of need, the type of services needed and who is best placed to provide these.[23] Figure 1 shows the European Grief Conference’s (EGC) adaptation of the Four-tiered needs-based bereavement care model which suggests that all people who experience a bereavement have some level of need.

% bereaved by level of need	Who is best placed to provide/ steer services	Type of services needed
60% experience normal grief. *Universal - NICE* *Universal - Victorian standards*	HEALTH SERVICES initially Then encouragement to harness SOCIAL AND COMMUNITY-BASED NETWORKS	**Grief and bereavement support:** acknowledgement, compassion, reassurance, information (written/ online), information about where to get help if needed. **Purpose:** to help bereaved people to understand grief is a normal reaction to loss and help person to identify when they need further help.
30% need additional support. *Selective or targeted - NICE*	PEER / GROUP SUPPORT Compassionate communities, social, spiritual groups, niche groups e.g. VAD	**Grief counselling:** access to more formal opportunities to reflect on grief. May involve individual/group sessions, peer support, friendship groups, niche groups. **Purpose:** address grief and promote healthy adaptation.
10% are at risk of/ experience prolonged grief. *Indicated - NICE* *High risk - Victorian standards*	SPECIALIST MENTAL HEALTH PRACTITIONERS	**Grief therapy:** specialist interventions. Access to Better Health Initiative via primary care. **Purpose:** address prolonged grief.

Figure 1: Four-tiered needs-based bereavement care model



Level 0:	Here public education about grief empowers individuals, communities, and decision-makers to increase the public's understanding of bereavement and support needs of bereaved persons.
Level 1:	Here the focus is on having access to information and adequate support, for example, available from family, social, and care networks.
Level 2:	A range of identifiable risk factors contribute to the fact that some bereaved people need additional organized support, for example in the form of peer-led groups, psycho-education in community settings.
Level 3:	Smaller proportions of bereaved people with additional stressors and disruptions to their grief will require specialist therapeutic responses.

Source: European Grief Conference (EGC). Four-tiered needs-based bereavement care model. Accessed from https://europeangriefconference.org/ on 17 September 2024.[14] **Note:** Model is inspired by the evidence-based public health model as advanced by NICE (UK), Samar M Aoun, and others. Credit to the Irish Hospice Foundation for developing the pyramid model of types of bereavement care.

Risk screening and assessment

Bereavement assessment that addresses emotional, behavioural, social, spiritual and physical domains, should be ongoing and structured, recognise that individual grief patterns and trajectories differ vastly and start at first contact with palliative care. It should take into account the known risk factors for prolonged or complex grief related to:[7 26-28]

- **background** - close kinship to the dying person (especially loss of spouse or child); female gender (especially mothers, although this is less evident in contemporary studies[19]); minority ethnic status; identification with a vulnerable group, religion, spiritual beliefs and meaning making, relational or interpersonal issues e.g. insecure attachment style; child abuse, serious neglect, high pre-loss dependence
- **treatment –** aggressive medical intervention; ambivalence and/or family conflict about treatment; economic hardship caused by treatment; caregiver burden
- **situational factors –** multiple losses close together; low acceptance of impending death; violent death and sight of body thereafter; death in hospital not home; issues around death notification.
- **pre-death** prolonged grief symptoms.[12]

Although systematic, predictive screening of all recently bereaved people is not recommended, the use of standardised, validated tools to diagnose prolonged grief in those who have persistent signs and symptoms can assist in appropriate referral for treatment.[8] It is important to differentiate between the depression and anxiety experienced by carers and their risk of prolonged grief.[7] Also, family need will differ as the need of an adult will be different from that of a child.

This requires appropriate mechanisms in place to identify people who are at risk of, or who are experiencing a complex response to bereavement, and to facilitate access to experts in grief, loss and bereavement management. The timing and manner of assessment is complex. Staff are often reluctant to overwhelm families and carers with potentially distressing and personal questions, though bereaved caregivers have indicated that carers could choose whether to engage or not.[11] For families and carers whose access to palliative care starts late, pre-death interventions are less feasible. There is no clear consensus regarding how screening and assessment for prolonged grief should be carried out.[29]

Tools to screen, assess and measure grief responses have reported good reliability and validity but have generally not been assessed for use in the Australian palliative care setting.[30] A number of different tools are used across WA but there is no strong evidence to support the use of one tool over another. Caresearch also concludes that 'the special grief considerations for different groups such as parents, fathers, children, parents of children with chronic illness, spouses, those from different cultural backgrounds, with disabilities, and Aboriginal populations are areas with limited evidence to support clear recommendations for assessment'.[16]

Studies conducted in WA concluded there was no tool fit for purpose and recommended a carer-driven support tool in combination with a staff assessment tool.[31] In 2022, the Grief and Bereavement Assessment (GABA) tool was developed.[27] It is a brief self-report measure that is evidence-based, acceptable to caregivers, feasible for use on palliative care and requires psychometric validation. It is based on the self-report BRISQ, but briefer. It progresses the discussion regarding which assessment tools and processes should be adopted.

The national palliative care standards call for multiple opportunities for the bereaved to self-identify their need to access services.[8]

Self-reporting allows families and carers to play a part in ensuring their support needs are met.[27] Ongoing assessment with input from the multi-disciplinary team (MDT), in conjunction with involved primary care providers, combined with screening tools that include self-reporting would seem to drive more informed conversations and more valid screening outcomes and retain a person-centred approach to risk screening.[27]

Risk assessment raises issues of consent and privacy. Even if the families and carers have been admitted as part of the 'patient unit', consent for screening is not always obtained.

Self-identification of needs after a death can be problematic. Research shows that people with high grief symptoms are less likely to seek support, and many bereaved people don't link their health status to bereavement because of the strong myth that grief is a very short-term experience. The diagnosis of prolonged grief cfan only be made by a doctor or specialist mental health practitioner 12 months after a death.[32] However, the best timing for interventions and referral remains unclear and should be assessed on a case-by-case basis. In the interim, the focus should be on ensuring there is an ongoing mechanism for determining the family and carer's level of distress and risk for prolonged grief.

Service considerations for Priority 4

- Strategies should be put in place to improve access to practical advice, information and support for bereaved families and carers.
- Risk should be determined via routine multidisciplinary team based psycho-social assessments, as part of the usual approach to clinical assessment.
- A validated tool should be used to gauge the signs and symptoms of persistent and intense distress in bereaved families and carers.
- Efforts should be made to work towards agreement across the sector on a consistent approach to screening and assessment processes.
- Consideration should be given to the use of tools that:
  - are brief, easy to administer
  - provide ongoing opportunities, commencing as early as possible
  - contain an independent carer self-report aspect and a matched staff input component
  - dovetail with the services' models.
- Further research into the definition, prevention and management of family and carer grief, particularly for those belonging to niche or vulnerable groups, should be conducted.
- Solutions to privacy and consent issues should be investigated.

Priority 5 All staff are prepared to care

Wherever and whenever I am cared for, all staff involved in my care have expertise, empathy and compassion. All staff provide confident, sensitive and skilful care, before, during and after my death.

The multidisciplinary team involved with bereavement screening and support is diverse, including nurses, occupational therapists, social workers, doctors, mental health professionals, counsellors, Aboriginal health workers, pastoral care, cultural and spiritual advisers, paid carers and volunteers. An individualised multidisciplinary approach is valuable, and good communication and handover within teams and across care settings is important to ensure continuity of care and appropriate bereavement risk management.

A consistent, well defined approach within a service helps to ensure the best possible bereavement care is provided. Specialist palliative care services should employ staff with appropriate skills to support families and carers in their experience of loss and grief, and/or provide the necessary education and training. Culturally suitable recruitment should be considered where possible, and cultural awareness training specifically addressing issues related to death and bereavement should be delivered.

In the previously mentioned WA survey, one respondent commented, "There are insufficient skilled therapeutic staff with an expertise in grief management and counselling. Staff are not confident or trained and feel overloaded." Practice, experience and training for difficult conversations is important and staff should be encouraged to normalise these conversations as opportunities arise rather than waiting for palliative care. Equally, staff should be adequately trained to offer techniques to manage anxiety and to identify, support and suggest general coping strategies.

The End-of-Life and Palliative Care Education and Training Framework is a reference tool to identify the knowledge and skills required by all health professionals and staff who care for people with end-of-life and palliative care needs and includes a section on loss, grief and bereavement.

Recruitment and retention issues of trained staff are confounded in rural and regional areas. Additional barriers that impact on staff ability to care include:

- operational silos
- policies, processes and guidelines that do not facilitate grief and bereavement care
- policies, processes and guidelines that do not facilitate collaboration or integration of care
- inadequate staff training, time and resources.

Allocation of a staff member to bereavement support and screening follow up may be based on the service model, pre-existing relationships with family and carers and/or availability. It is often decided on a case-by-case basis at a multidisciplinary team meeting.

Continuity of relationships is important and is an advantage palliative care services have over stand-alone bereavement services.[15] However, the need to wait 12-months before a Diagnostic and Statistical Manual of Mental Disorders (DSM-5-TR) diagnosis of prolonged grief disorder can be made means original staff are unlikely to be providing support at this diagnosis, their role is rather to screen for risk factors, support and to refer.[32]

The complexities of screening have been discussed under Priority 4. There are staff who would prefer to rely on their own professional skills and observational powers to supplement the use of screening tools or in situations where it isn't possible to apply a tool.[27] Regardless of method, the important role of written documentation in clarification and accountability is clear.[11] Finally, as prolonged grief, can only be diagnosed 12 months after the death by a mental health specialist or doctor, it is important that a healthcare professional with the right skills is available to make an assessment at this time.

It should also be acknowledged that there is a tendency for staff to gatekeep or shield families and carers from emotionally loaded situations, often adding to their own burdens.[11] The impact of dealing recurrently with distress related to death, dying and bereavement is well recognised. Organisations should therefore ensure mechanisms are in place for staff to access debriefing, support and clinical supervision when needed.

Service considerations for Priority 5

- Education and training about loss, grief and bereavement should be accessible to staff, volunteers and other community providers (See 2.5 Loss, grief and bereavement in the End-of-Life and Palliative Care Education and Training Framework).
- The most appropriate staff members should be encouraged to undertake training for counselling roles.
- Support and counselling should be provided to all staff (including reception staff) and volunteers involved in bereavement support.
- Clear staff service models should be embedded and communicated and should include the approach to screening and the mechanism for allocation of staff members.
- The time taken for bereavement support should be recognised and factored into staffing models and clinical workload calculations.
- Cultural awareness training should be emphasised, and culturally responsive person and family centred care should be promoted.
- Aboriginal workforce strategies should be implemented, and specific mechanisms developed to support the recruitment and support of Aboriginal staff members to provide bereavement support.

Priority 6 The community is aware and able to care

I feel supported and empowered to make decisions. My individual preferences are expressed through advance care planning (ACP) and reflected in my end-of-life and palliative care. My community is aware and able to support me and those close to me.

Most people grieve within their social networks and do not seek professional support.[33] There is no evidence that professional support helps to lessen the intensity of the grief experienced for those categorised as experiencing normal grief.[26] For those who do request or require additional support, services should develop partnerships with a range of community organisations able to support people who are anticipating or living with loss.[8] Community based organisations and providers benefit from early notification of patients who are nearing death, with patient consent, to allow better coordination of service and support to be mobilised in a timely manner.

Community capacity in providing bereavement support is underdeveloped. Conversations about dying, end of life and bereavement still need to be normalised. The identification and training of community networks and champions and volunteers can assist in raising awareness, promoting discussions about end-of-life, palliative care and bereavement and ensuring access to referral pathways for intervention when needed. As highlighted by the COVID-19 pandemic, communities can play a vital role in supporting the grieving and bereaved.[34, 35] The Compassionate Communities movement has been developed to reskill and reactivate historical community based support for those who are at end-of-life, bereaved and grieving. This model was supported by a respondent to the WA survey who said, "*An acute hospital provides support pre-death and at death for those experiencing normal grief 'to mitigate poor outcomes. Additional support is best done via a compassionate communities' model or peer groups, buddy systems*." Up-to-date directories of local services can effectively signpost to community-based support, which is particularly useful as for those who experience prolonged grief and may be less likely to be able to rely on support from where palliative care was provided. Online resources such as the My Grief app developed by Grief Australia may also be helpfully referenced.[36] Such information should also be provided in bereavement information provided to key contacts at the time of death.

Service considerations for Priority 6

- Shared models of care should be encouraged between health services, primary care and community-based organisations.
- Community awareness should be raised to promote a better understanding of end-of-life planning, end-of-life care, palliative care, grief and bereavement.
- Community preparedness and readiness to support individuals, families and their supports involved in voluntary assisted dying should be addressed.
- Health, community and aged care providers should be educated about grief and how to facilitate family access to bereavement support.
- The bereaved and staff should have access to updated local service directories that community organisations and members can refer to for further assistance.
- Spiritual and cultural needs following death are understood and respected and families and carers are supported to undertake death and grief-related practices and rituals.

Models of bereavement care

Bereavement support interventions after an expected death in Australia, commonly include multiple components, such as:[10]

- **Compassionate interventions from members of the multidisciplinary team that acknowledge people's loss and:**
  - ideally occur prior to, at death and/or by follow up soon after (letter, email, phone)
  - include family and carers in decision-making and meetings pre-death
  - if possible, are carried out by team members who have a pre-existing relationship with the family and carers - it is useful to remember that family and carers often also develop a relationship with the institution
  - screen and assess to determine the family and carer's level of risk for prolonged grief and referral for appropriate management
  - continue with a possible diagnosis of prolonged grief after 12 months, following referral pathways as needed.
- **Quality information that includes:**
  - what to expect during the dying journey (health and death literacy)
  - practical information regarding funerals, finances, support
  - grief literacy, how it typically unfolds, the red flags, when and where to seek help
  - contact details of the service where possible or of other support organisations, including community based support.
- **Remembrance and legacy acknowledgement either individualised (coinciding with the person's death/birthday) or institutional (an invitation to an annual event).**
  - Studies show satisfaction with interventions such as receipt of a practical bereavement guide or legacy interventions e.g. a condolence card.[37, 38]
  - Research shows that families and carers are happy to be approached early in their bereavement process and conclude that bereavement support interventions can mitigate poor outcomes and might help to prevent/ameliorate prolonged grief.[11]
- **Community based responses to people affected by grief and bereavement.**
  - Identification and mobilisation of informal support networks and compassionate communities models to meet individual needs
  - Engagement with churches, synagogues, temples and other religious bodies can assist with supporting spiritual, emotional and pastoral aspects of a person's needs during bereavement.

Models of bereavement care should frame practice around contemporary available evidence and build in mechanisms for ongoing evaluation, collection of service data and involvement in clinical research. Table 2 shows a bereavement support interventions pathway developed to accompany the Victorian model of service delivery.[4] It provides examples of the frequency and intervals for reaching out to the bereaved families and carers and the accompanying actions. It does not deal with who is responsible or at which level of service.

Table 2: A bereavement support intervention pathway developed to accompany the Victorian Bereavement support standards for palliative care services 2012[4]

Timing	Action	Type
Anticipatory	• Have conversations about possibility of death, role and limits of medicine	Universal
Expectant	• Have discussions about dying	Universal
	• Provide bereavement info pack (including information about normal grief	Universal
	• Offer pastoral care/spiritual services	Universal
	• Identify issues related to prolonged grief risk factors with primary carer	Universal
	• Refer to multidisciplinary team (MDT) based on individual need	High Risk
At death or as soon as practical	• Assess practical needs/ response to bereavement with primary carer	Universal
	• Involve MDT based on need	High risk
	• Referral to local or specialist services	High risk
Follow up		
12 weeks	• Follow-up information sent to primary carers	Universal
	• Follow-up telephone call to explore issues associated with complicated grief	High Risk
	• Referral to local or specialist services	High risk
6 months	• Call via telephone to undertake formal bereavement assessment	High Risk
12 months	• Send condolence card to primary carer and invite to memorial service	Universal
	• Diagnosis of prolonged grief can now be made by a psychologist or doctor	High Risk

In their assessment of this model of service delivery the authors identified the subthreshold group – those who have elevated distress but are not part of the small group who meet the criteria for prolonged grief.[7] Another limitation is the lack specific focus on people from a culturally and linguistically diverse background and those from more vulnerable groupings e.g. children, Aboriginal families and carers. Collaborative discussion and additional research are required to further refine the approach to bereavement support provision in WA.

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Appendix: Useful resources and services

General services

- The Grief Centre of Western Australia provides understanding, support and recovery to people experiencing grief.
- Lifeline WA provides free grief and bereavement counselling.
- Relationships Australia provides counselling and support for grief and loss.
- Beyond Blue provides information, advice and support

Support for particular types of loss or population groups

Aboriginal and Torres Strait Islanders

- Death and Sorry Business

Carers

- Palliative Care Australia
- Carers Australia WA or call 1800 007 332.

Children

- Healthy WA brochures for children for when someone is dying

Help for migrants

- Metropolitan Migrant Resource Centre

Losing someone to cancer

- Cancer Council of WA or call 13 11 20.
- Leukaemia Foundation of WA
- Solaris Cancer Care

Loss of a baby

- SANDS or call 1300 072 637.
- Red Nose Grief and Loss has a 24 hour support line on 1300 308 307.

Loss of a child

- Compassionate Friends Western Australia

Loss of spouse or partner

- Solace Grief Support WA

Men

- MensLine has a telephone and online counselling service on 1300 789 978

Regional support services

- Anglicare WA provides rural and remote phone counselling on 1300 114 446.

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