Framework for bereavement support after an expected death in WA

Consultation draft

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Contents

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About the Framework

Purpose

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

The framework is not intended to be a clinical guideline for the management of grief and bereavement but aims to increase awareness and understanding of the service considerations associated with the provision of bereavement support after an expected death.

Scope

The framework addresses bereavement support considerations for families/carers following an expected death, including death through voluntary assisted dying and recognition and management of anticipatory grief.

It recognises that bereavement support is applicable to all services offering end-of-life and palliative care to patients with life limiting illness in WA and that collaborative approaches provide the best outcomes.

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

Language and key concepts

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

Bereavement

Bereavement is a broad term that encompasses the entire experience of family members and friends in the anticipation, death and subsequent adjustment to living following the death of a loved one[5]. It is the process of grieving and the period of mourning that is entered after someone has died. There is, however, a group of bereaved individuals (~10%) who experience prolonged grief, accompanied by severe physical and mental health problems.[8]

Grief

Grief, our response when someone dies, is a natural and individual process and not an illness but its effects can sometimes be devastating.[1, 12]

Prolonged grief (also referred to as complex or complicated 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].

Anticipatory grief

Someone with anticipatory grief experiences the emotions associated with grief before the expected loss actually happens. Rather than grieving the loss of a person, anticipatory grief might be better understood as grieving the loss of experiences, possibilities or an imagined future together[14].

An expected death

An expected death is a death that occurs after the individual is diagnosed with a terminal illness or life-limiting condition and whose health status, based on current medical knowledge, is not

expected to improve but likely to deteriorate; this would include death through Voluntary Assisted Dying. For the purposes of this Framework, an expected death explicitly excludes accidental death, death by suicide and sudden death from causes other than progressive illness.

Voluntary assisted dying

Voluntary assisted dying is now a legal option that is available for some adults who meet various criteria to seek medical help to end their life if they have a disease or illness that is so severe it is going to cause their death and their suffering cannot be relieved in a manner tolerable to them.

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/ 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, our 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]

However, approximately 10% of people suffer extreme and disabling grief[2, 3] and require identification and referral to appropriate specialist services. Bereavement support services aim to 'reduce immediate distress while ameliorating long-term morbidity associated with unresolved grief'.[4] Access to services has been shown to assist family/carers to process their grief. 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.

An expected death enables anticipatory grief and provides time for the services to work with families, provide support, information and assessment of the family/carer responses to the dying of a loved one. The phase prior to death can allow the chance to ask for forgiveness, to deal with unfinished business, unresolved conflict, unfulfilled wishes, closure on important issues, and a last 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 patient journey of those who have chosen an expected death by voluntary assisted dying. 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 as early as possible after contact is made with end-of-life and palliative care services
- include verbal and written information about the dying process and the practical aspects of coping after the death of a loved one that is culturally appropriate
- acknowledge the death (immediate and on anniversaries, where practical)
- provide or facilitate access to an ongoing process of assessment for risk of prolonged grief[4] and referral for specialised services for those with or at risk of prolonged grief.

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.

Bereavement services after an expected death in WA

A national survey of Australian palliative care services in 2019[10], (n = 163), found that 91% of services provided bereavement support. 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 Western Australia (WA), the reasons for gaps and the challenges experienced by the services.

Responses confirmed that standard care in WA varies considerably[11], consistent with the situation across most of Australia.[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.

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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 One: 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/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/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]

The existence of clear referral pathways, based on respect, compassion and sensitivity, developed in consultation with families/carers, particularly those from vulnerable groups, will significantly improve service access. Due to the infancy of voluntary assisted dying in WA, and considering its complex and emotive nature, families/carers and the individual require specific consideration at this time. There is limited evidence to support specific recommendations for the assessment of bereaved family/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/remote areas of WA, and people living with mental health challenges. Considerations that may impact access for these populations include:

- People living in regional and remote Australia often have reduced access to palliative care[17], and consequently reduced access to bereavement support, and in some cases may prefer to have support outside their community for privacy reasons.
- 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/carers in end-of-life protocols and keeping them updated regarding their loved one'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 health care 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)](health.wa.gov.au).

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.

> **Service considerations for Priority One**
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> - Bereavement support for the family/carers of those dying from an expected death should be equitable across diagnoses.
> - Appropriate information should be available to families/carers. The information should:
>   - be responsive to the range of needs e.g. available in multiple languages
>   - commence prior to death, where possible
>   - cover practical information e.g. financial, funeral planning
>   - cover biopsychosocial elements of self-care and information about grief.
> - 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.
> - Bereavement support activity should be reported on and included in calculations of clinical workload e.g. ePalCIS, Palliative Care Outcomes Collaboration (PCOC) Phases 3 (deteriorating), 4 (terminal) and 5 (post death).

Priority Two: 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 for 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 patient and the family/carers, giving consideration to all options including voluntary assisted dying.

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 patient's consent can inform and empower families and build trust.[9] They can help families to better understand what the person's death could look like and that grief is a normal process.[18] The patient should feel reassured that their loved ones will be able to access support after their death through access to bereavement care.

It can be comforting for the patient and their loved ones if the family/carer is included sensitively in open discussion and decision-making about their disease trajectory and care. Advance care planning and goals of patient care processes provide opportunities for the patient to express their wishes and can be used to provide structure to these discussions.

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

> **Service considerations for Priority Two**
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> - The patient and their family/carers should be well-informed about the disease trajectory and management/care options through written information and regular opportunities to speak openly about the person's illness and death.
> - The person and their family/carers should be involved in decision-making and care planning as early as possible, focusing on improving quality of life, recognising and managing anticipatory grief and planning for clinical deterioration, end-of-life care, death and bereavement.
> - Education and information should be provided to the dying person and their family/carers about advance care planning (ACP) including the option of voluntary assisted dying.
> - 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 Guardianships, should be acknowledged and the patient 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 family/carers' wishes and views prior to death, at the time of death and after death including accommodating voluntary assisted dying.

Priority Three: 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/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/carer 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/carers experiencing different levels of grief.

A key challenge is retaining a co-ordinated, structured approach while making room for patient and family-centred flexibility, heterogeneity and innovation in care delivery that will be required by some patients and families, within general resource constraints. As patients often access multiple services, it can be unclear which service, and who within that service, is responsible for bereavement support.[11]

The National Palliative Care Standard Six[8] 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". 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 Three

- 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 via GP mental health management plans and Better Access Initiative benefits.
- Families/carers should be empowered to access care and services from other places, particularly community-based social structures and organisations.
- Identified and consistent measures should be used to evaluate the impact of services on families/carers.

Priority Four: 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/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. Mechanisms to screen and assess

family/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 two levels - universal and high risk.

Approximately 60% of the bereaved experience 'normal' levels of grief in response to the death of a loved one. 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[20] 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.

Table 1 describes bereavement support interventions by level of need, the type of services needed and who is best placed to provide these. The percentages stated have been validated.[23]

Table 1: Bereavement support interventions by level of need

% bereaved by level of need (validated)	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.

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 27, 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/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.

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 family/carers with potentially distressing and personal questions, though bereaved caregivers have indicated[11] that carers could choose whether to engage or not. For family/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[8] call for multiple opportunities for the bereaved to self-identify their need to access services. Self-reporting allows family/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[27] and retain a person-centred approach to risk screening.

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

Since the diagnosis of prolonged grief can only be made by a doctor or specialist mental health practitioner 12 months after the death of a loved one[32] the best timing for interventions/referral is unclear and should be carried out on a case-by-case basis.

In the interim, the focus should be on an ongoing process of determining the family/carer's level of distress and risk for prolonged grief.

> **Service considerations for Priority Four**
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> - Risk should be determined via routine MDT based psycho-social assessments, as part of the usual approach to clinical assessment.
> - Strategies should be put in place to improve access to practical advice, information and support for bereaved families/carers.
> - A validated tool should be used to gauge the signs and symptoms of persistent and intense distress in bereaved family/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/carer grief, particularly for those belonging to niche or vulnerable groups, should be conducted.
> - Solutions to privacy and consent issues should be investigated.

Priority Five: 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.

A consistent approach to pathways across all settings and staff will help to ensure the best possible bereavement care is provided. Specialist palliative care services should employ staff with appropriate training and skills to support families/carers in their experience of loss and grief.

The multidisciplinary team (MDT) involved with bereavement support and screening is diverse, including nurses, occupational therapists, social workers, doctors, mental health professionals, counsellors, Aboriginal health workers, pastoral care, cultural and spiritual advisers and volunteers.

Allocation of a staff member to bereavement support and screening follow up may be based on the service model, pre-existing relationships with family/carers and/or availability. It is often decided on a case by case basis at an MDT 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 DSM 5 diagnosis of persistent complex grief disorder or prolonged grief[32] 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.

The complexities of screening have been discussed under Priority Four. There are staff who would prefer to rely on their own professional skills and observational powers[27] to supplement the use of screening tools or in situations where it isn't possible to apply a tool. Regardless of method, the important role of written documentation in clarification and accountability is clear. [11] Additionally, there is a staff tendency to gatekeep or shield family/carers from emotionally loaded situations, often adding to their own burdens.[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.

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."

Service considerations for Priority Five

- Education and training about loss, grief and bereavement should be accessible to staff, volunteers and other community providers.
- The most passionate 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 patient 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 Six: 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.

Services should develop partnerships with a range of community organisations able to support people who are anticipating or living with loss.[8] Most people grieve within their social networks and do not seek professional support.[33] Care must be taken as there is no evidence that sharing and disclosing feelings helps to lessen the intensity of the grief experienced for those categorised as experiencing normal grief.[26]

Community capacity in providing bereavement support is underdeveloped. As highlighted by the COVID-19 pandemic[34, 35], communities can play a vital role in supporting the grieving and bereaved. The Compassionate Communities movement has developed to reskill and reactivate historical community based support for those 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 provide access to community-based support. These should include online resources such as the My Grief app[36] developed by Grief Australia.

Service considerations for Priority Six

- 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/carers are supported to undertake death and grief-related practices and rituals.

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Models of bereavement care

Bereavement support services after an expected death in Australia, commonly include multiple interlinked interventions, 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/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/ carers - it is useful to remember that family/ carers often also develop a relationship with the institution
  - screen and assess to determine the family/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 from the loved one's dying journey (health and death literacy)
  - practical information regarding funerals, finances, support
  - grief literacy, how it typically unfolds, the red flags, and when/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/carers are happy to be approached early in their bereavement process[11] and conclude that bereavement support interventions can mitigate poor outcomes and might help to prevent/ameliorate prolonged grief.

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 family/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 • Follow-up telephone call to explore issues associated with complicated grief • Referral to local or specialist services	Universal High Risk 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 • Diagnosis of prolonged grief can now be made by a psychologist or doctor	Universal 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 family/carers. Collaborative discussion and additional research are required to further refine the approach to bereavement support provision in WA.

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