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health

Bereavement support standards for specialist palliative care services

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1. Background

Providing bereavement support is an essential component of palliative care service delivery; however, there is currently little evidence-based guidance for health professionals and others providing this support. While loss and grief are fundamental to human life, the course and consequences of bereavement will vary for each individual. For highly resilient individuals, significant grief may be limited to a few weeks (Bonnano & Kaltman 2001) and for most people the acute experience of grief subsides over time. For a subgroup of people, around 10–15 per cent, the symptoms of distress following the death of a family member or friend are more intense and persistent (Prigerson et al. 1996; Latham & Prigerson 2004).

Known variously as complicated grief (Prigerson et al. 1996; Shear et al. 2011) or prolonged grief disorder (Boelen & Prigerson 2007), this condition can be associated with severe mental and physical health problems such as insomnia, substance misuse, depression, depressed immune function, hypertension, cardiac problems, cancer, suicide, and work and social impairment. Bereaved people in this cohort report higher use of medical services and more frequent hospitalisation than people with similar losses whose grief is less intense and of shorter duration. These effects have been observed for between four and nine years after the death (Neimeyer & Burke 2012).

For all bereaved individuals, grief is experienced in the context of their ‘whole being’, including their physical, emotional, cognitive, behavioural and spiritual manifestations. When grief is complicated and prolonged, evidence suggests that intervention is both indicated and effective (Currier et al. 2008). However, the available evidence suggests that only a minority of people will require specialist bereavement interventions and that for the remainder, intervention is not effective. Therefore, targeting scarce resources for people who will benefit most from them is important. These bereavement support standards have been developed to assist palliative care services to do that.

These standards were developed using several methods:

- consultation with key Australian and international stakeholders using interviews, workshops, and via an expert advisory group
- a survey of all publicly funded Victorian palliative care services
- a review of international evidence on the impact of bereavement and bereavement interventions
- adaptation and/or reference to key Australian standards and guidelines such as *Standards for bereavement support programs* (Australian Centre for Grief and Bereavement 2001) and *Clinical practice guidelines for the psychosocial and bereavement support of family caregivers of palliative care patients* (Hudson et al. 2010).

Purpose and target audience

A range of Australian and Victorian Government policy drivers have led to recognising a need to develop bereavement support standards for specialist palliative care services. In addition, there is limited empirical evidence to support decision making regarding assessing risk for adverse bereavement-related outcomes or providing appropriate bereavement interventions. As a result there has not been a systematic guidance on assessing bereavement risk or on intervention responses for Victorian and Australian palliative care services.

The bereavement support standards have been developed for use in all Victorian government-funded, adult, specialist palliative care services including community, inpatient, acute and consultancy services. They have potential application to other Australian and international palliative care services. The standards are not specifically targeted at Aboriginal or culturally and linguistically diverse (CALD) populations or at children and other groups with special needs. Caring for the needs of these groups may require enhanced knowledge, skills and strategies that are not detailed in this document but are, none the less, critical for providing best practice bereavement care to members of these groups. The *Resources* section of this document contains additional resources for assisting providers to offer services to these groups.

These standards are a broad tool for all palliative care services staff to use. They are not a prescriptive tool for staff providing specialist interventions for people with complex grief issues.

The key principles underpinning the standards are that bereavement support is delivered:

- in a targeted way with those who would benefit most from specialist interventions being identified through structured screening and assessment
- with a focus on identifying the bereaved person's own resources and capacity that will enhance their resilience
- over a period from pre-death to several months post death and beyond where required
- within the policy context that there is no limitation on the time period for providing bereavement support by Victorian palliative care services
- with a focus on the palliative care client's primary carer and extending to other carers/family members where resources allow.

In addition to providing care for bereaved family members and carers, good bereavement support will involve caring for palliative care staff through processes such as death reviews, professional development and professional supervision.

These standards should be considered alongside other key palliative care documents and resources, some of which are listed in the *Resources* section. A glossary of key terms used in this document is also provided at the back of this document.

2. Factors impacting on grief reactions

It is important to maintain a holistic perspective when considering the context and factors that impact upon grief reactions. Given the distinctive nature of complicated bereavement, anxiety and depression it is important that any assessment be both comprehensive and broad in its character. Modern developments in grief theory recognise human diversity and 'suggest the need for an integrative approach to assessment which examines both risk factors and coping styles' (Agnew et al. 2010).

In the palliative care setting, the bereaved have frequently undertaken care-giving roles that can have both positive and negative features, with carers often prone to physical and psychological morbidity, financial disadvantage and social isolation (Hudson et al. 2011). Depression rates of between 12 and 59 per cent (Hudson et al. 2011) and anxiety rates of between 30 and 50 per cent (Grunfeld et al. 2004; Hudson et al. 2011) in carers have been reported.

2.1 Risk factors

Neimeyer and Burke (2012), in a summary of the clinical literature on pre-loss risk factors for the development of complicated grief, identified a range of key risk factors:

Background factors

- Close kinship to the dying person (especially spouse or child loss)
- Female gender (especially mothers)
- Minority ethnic status (in the United States)
- Insecure attachment style
- High pre-loss marital dependence
- Religion and spiritual beliefs and practices (for some, religious/spiritual belief results in lower levels of grief and, for others, a stronger faith can lead to more severe experiences of grief)

Treatment-related factors

- Aggressive medical intervention (for example, intensive care, ventilation, resuscitation)
- Ambivalence regarding treatment
- Family conflict regarding treatment
- Economic hardship created by treatment
- Caregiver burden

Death-related factors

- Bereavement overload (multiple losses in quick succession)
- Low acceptance of impending death
- Violent death (suicide, homicide, accident)
- Finding or viewing the loved one's body after a violent death
- Death in the hospital (rather than home)
- Dissatisfaction with death notification

2.2 Factors that enhance resilience

Adopting a strength or resilience perspective to providing bereavement services is important. Components of resilience include psychological, social, spiritual and 'meaning-making' (Davydov et al. 2010). Resilience can be viewed as a mechanism that enables people to thrive in the face of adversity and can be considered synonymous with reduced 'vulnerability', with the ability to adapt to adversity or to 'cope'.

The resilience approach is compatible with the World Health Organization's conceptualisation of mental health as a positive state of psychological wellbeing that goes beyond the absence of disease (World Health Organization 2005). Resilience includes factors and mechanisms that impact on a person's level of protection against adversities. Resilience is not only a result of an individual's personal attributes but can be impacted by a variety of community and cultural factors.

Resilient individuals tend to:

- draw upon past experiences of loss survival
- connect with their family and community of care
- draw upon religious and spiritual beliefs and practices
- identify internal and external strengths and resources
- reconstruct a world of meaning and personal identity following the loss
- draw upon the experience and support of other bereaved people
- have higher levels of practical support
- hold a belief in a just world and acceptance of death
- gain comfort from talking or thinking about the deceased (Boerner et al. 2013).

Best practice bereavement support for these individuals:

- identifies and reinforces their coping and positive achievements
- avoids interfering with their innate capacity for recovery
- avoids undermining or replacing their family and community as sources of social support.

3. The bereavement support standards for palliative care services

These standards are recommended as a minimum level of bereavement support to be provided to primary carers and bereaved people by specialist palliative care services. This section outlines each of the standards and the criteria for meeting the standards. More detail about factors to consider when implementing the standards at different points in the bereavement trajectory is contained in Table 1 (see section 5).

3.1 Standard 1: Access

All primary carers of clients cared for by a specialist palliative care service are eligible to access palliative care bereavement services regardless of age, gender, culture, sexual orientation, socioeconomic status, religious beliefs, physical or other disability, or ability to pay.

Criteria

- 3.1.1 At a minimum, bereavement support is available to all primary carers of the deceased. If resources allow, support is extended to additional family members and carers.
- 3.1.2 Services are delivered in a manner sensitive to social, cultural and spiritual beliefs, values and practices of the client.
- 3.1.3 The bereavement program employs staff or actively develops links with other service providers or organisations with relevant experience in providing support services to specific social and cultural groups represented in the catchment area.

3.2 Standard 2: Coordination of bereavement services

Bereavement programs in palliative care services provide coordinated services.

Criteria

- 3.2.1 The structure and processes of the palliative care bereavement support program ensure continuity of care.
- 3.2.2 The bereavement program reflects an interdisciplinary approach to planning, implementation and evaluation.
- 3.2.3 A person with demonstrated competency and experience in bereavement support is nominated as accountable for the bereavement support program across all settings, program elements and age groups.
- 3.2.4 The role, responsibilities and scope of practice of bereavement support staff are clearly described and documented in a position description and staff are aware of these.

3.3 Standard 3: Training and support

All staff in a palliative care service, including administrative staff, will come into contact with bereaved people and will therefore require training and support in dealing with those bereaved people.

Staff and volunteers who have contact with bereaved people are required to achieve appropriate competencies in delivering bereavement support.

Criteria

- 3.3.1 All administrative and non-clinical staff should have minimum training in basic principles of grief and bereavement support strategies.
- 3.3.2 All clinical staff in the palliative care service have:
 - a tertiary qualification in an appropriate clinical discipline
 - attained minimum competencies (to be developed) for delivering bereavement support services
 - regular access to continuing education and professional development that includes bereavement content
 - access to professional supervision and/or opportunities for consultation with experienced bereavement support staff for skill development and clinical support
 - if delivering group interventions, appropriate training and experience in facilitation and group work.

3.3.3 All staff providing specialist bereavement services (see standard 5 for definition):

- are specialist bereavement providers such as psychologists, psychiatrists, nurses, social workers, pastoral care workers or counsellors with postgraduate qualifications or equivalent in loss and grief
- have mandatory access to professional supervision.

3.3.4 All volunteers who have contact with bereaved people have:

- undertaken training equivalent to the Palliative Care Victoria volunteer training module on responding to loss and grief
- support from a bereavement coordinator (not only a coordinator of volunteers)
- access to professional supervision and opportunities for debriefing.

3.3.5 Volunteers responsible for delivering **specialist bereavement interventions** must have the same qualifications and access to clinical supervision as paid staff delivering those interventions.

3.3.6 All staff must be aware of the limits of their scope of practice and must be aware of internal and external referral pathways should a client require interventions that are outside their scope of practice or outside the scope of services the organisation they work for is able to provide.

3.4 Standard 4: Screening and assessment

Screening and assessing for psychosocial and spiritual distress and risk of complicated grief is a continuous process undertaken from the time the client enters the palliative care service to many months after the client's death (where pertinent). These assessments are a multidisciplinary and interdisciplinary undertaking because clients may disclose different information to different staff at different times.

Pre-death screening and assessment

A range of bereavement screening tools that aim to identify clients at risk of complicated bereavement are currently being used in Victorian palliative care services; however, there is insufficient empirical evidence to support the validity of one particular tool to screen for risk of complicated bereavement prior to the person's death.

For this reason, a structured assessment should be undertaken through a conversational exploration of risk factors and strength/resilience factors as outlined in section 2. It is important to note that adjusting to bereavement does not take place in clinical isolation and is frequently accompanied by other comorbid conditions such as major anxiety disorders, depression and post-traumatic stress disorder. Any assessment of bereavement must address these frequently co-occurring conditions as well as emotional, behavioural, social, spiritual and physical domains.

Several tools are recommended for screening for psychosocial distress including the distress thermometer (National Comprehensive Cancer Network 2012), the *General health questionnaire* 12 (MAPI Research Trust 1978) and the FICA spiritual history tool for assessing spiritual issues (The George Washington Institute for Spirituality & Health 2012). Where pertinent the screening should be followed up with a comprehensive holistic assessment and/or referral to a suitably qualified professional if required.

Further guidance for undertaking these structured assessments is provided in section 4.

Post-death screening and assessment

As there is such variability in the way people adapt to bereavement it is difficult to make safe predictions in terms of longer term functioning of bereaved people before a minimum of six months after a death. At this point, tools such as the PG-13 (Prigerson & Maciejewski 2012) have been found to have stronger predictive validity and reliability for identifying a prolonged and complicated grief disorder.

Table 1 in section 5 outlines how these screening and assessment standards might be implemented along the grief trajectory.

Criteria

- 3.4.1 It is recommended that, with their consent, a comprehensive bio-psychosocial, spiritual and bereavement risk assessment be undertaken with the primary carer (at a minimum) as soon as possible after the palliative care client is admitted to the palliative care service.
- 3.4.2 A structured risk assessment based on conversational exploration of the risk factors identified in section 2.1 is completed for the client's primary carer and, if resources allow, for other carers/family members identified as closely involved with the dying person. This assessment requires structured documentation, review in team meetings and the use of family assessment.
- 3.4.3 The risk assessment process begins on intake to the palliative care service and continues throughout the palliative care service's involvement with the client and beyond. It is a process requiring input from the client, the carer(s) and relevant professionals.
- 3.4.4 At death (or as soon as practicable after death), an assessment of the level of trauma the family has experienced as a result of the death is undertaken to inform risk assessment.
- 3.4.5 At 12 weeks after death a follow-up phone call to all primary carers is undertaken to determine whether further assessment or support is required.
- 3.4.6 At any stage, a finding of elevated risk of suicidal behaviour, self-harm or where the client may be a threat to the welfare of others should be immediately acted upon through urgent referral to a personal emergency service such as SuicideLine; Lifeline or MensLine or an emergency service such as an emergency mental health service or public hospital emergency department.
- 3.4.7 Clients with complex needs may be referred to appropriate supports within the palliative care service or through external agencies such as the Australian Centre for Grief and Bereavement Practitioner Consultancy Service, the Bereavement Information and Referral Service or local community health services. Further referral options can be located at the Department of Human Services *Human services directory* (see *Resources* section for contact details of these services).
- 3.4.8 At around six months following the client's death, people identified as being at elevated risk of developing prolonged or complicated grief are offered comprehensive bereavement assessment using a validated tool such as the PG-13 (Prigerson & Maciejewski 2012).

3.5 Standard 5: Bereavement support strategies

The recommended bereavement supports include two types of strategies:

- universal strategies that are targeted at all carers and bereaved people
- specialist bereavement support strategies targeted at those with an elevated risk of a developing prolonged or complicated grief or with current psychosocial and/or spiritual distress.

Universal strategies include:

- screening and risk assessment as detailed in standard 4
- best practice symptom management of the palliative care client to reduce the impact of traumatic death on carers as well as the client themselves
- providing structured information and support at various points along the grief trajectory including
 - at admission to the palliative care service
 - when death is imminent
 - immediately following the death
 - at regular intervals following the death such as three, six and around 12 months (and beyond if appropriate)

- providing access to support strategies such as
 - participation in a bereavement information session and opportunities to review and reflect on the experience of loss
 - activity-based programs such as walking, meditation, music and art groups.

Specialist bereavement support strategies may include:

- bereavement counselling and psychotherapy using evidence-informed specialist interventions for complicated grief such as
 - cognitive behavioural therapy (CBT) for complicated grief (Boelen et al. 2006)
 - focused family grief therapy (Kissane et al. 2002)
 - complicated grief treatment (Shear et al. 2005)
 - meaning reconstruction approaches to grief therapy (Neimeyer 2000)
- online support (Wagner et al. 2006)
- bereavement support groups.

In general, the more complicated the grief process, the greater the efficacy of specialist bereavement interventions.

Table 1 in section 5 outlines how these bereavement support strategies can be implemented along the grief trajectory.

Criteria

- 3.5.1 Bereavement support strategies are designed to promote accessibility by taking account of identified differences in need, particularly recognising that the majority of bereaved people will neither need nor necessarily benefit from specialist interventions.
- 3.5.2 Bereaved people have access to in-house or external specialist bereavement services appropriate to their needs and level of risk as assessed through structured bereavement risk assessment.
- 3.5.3 Bereaved people are informed about the services available to them.
- 3.5.4 A collection of literature and resource materials on the grief process and support services is made available to bereaved people in a sensitive and appropriate manner and at appropriate times throughout the grief trajectory.
- 3.5.5 There is a confidential system for documenting and regularly updating bereaved people's information. Information includes relevant history, assessment (including risk assessment), intervention and support services, date and type of contact, progress, other service provider involvement and outcomes.
- 3.5.6 Drawing upon the Dual Process Model of Coping, support and interventions address both the emotional (managing the feelings related to grief) and problem-focused (managing the demands of daily living) challenges of coping with loss (Stroebe & Schut 1999).
- 3.5.7 Universal bereavement support strategies are implemented at various points along the grief trajectory including:
 - between intake and the client's death, when information and psycho-educational materials/sessions are provided and at-risk carers are appropriately referred for specialist support
 - when death is imminent – appropriate information is provided and at-risk people are referred for specialist support
 - at death, or as soon as practicable following death – the level of family trauma resulting from the death is determined, information is provided and at-risk people are referred for specialist support
 - at 12 weeks after the death the bereavement service follows up all primary carers to provide information and assessment
 - at six months post-death, when a formal bereavement assessment is undertaken for people at risk of prolonged or complicated grief and referral for specialist support is made if appropriate
 - at around 12-months post-death, when palliative care services send an anniversary card or memorial service invitation that includes information regarding self-assessment and referral if needed.

3.5.8 Shortly after the client's death, the palliative care service undertakes a death review that will allow palliative care team members to reflect on the experience and impact of the client's death, and identify strengths and areas of improvement in bereavement care.

3.6 Standard 6: Clinical handover and referral to specialist services

Where providing bereavement support falls outside the skills and competencies of palliative care staff, referral to external specialist agencies or practitioners is undertaken. These include the Australian Centre for Grief and Bereavement Practitioner Consultancy Service, the Bereavement Information and Referral Service or local community health services. Further referral options can be located at the Department of Human Services, *Human services directory* (see the *Resources* section for contact details for these agencies).

Criteria

- 3.6.1 There is a clearly documented system for making a referral and actively supporting the client in accessing the specialist service.
- 3.6.2 Bereaved people have ready access to information about a range of specialist services.
- 3.6.3 There is a clearly documented protocol for prioritising referrals to specialist services according to the bereavement risk assessment.
- 3.6.4 Clinical handover is undertaken within the context of the Australian quality standards and using the service coordination tools developed by the Victorian Department of Health.

3.7 Standard 7: Community education and health promotion

The importance of promoting community awareness of bereavement issues and acceptance of the bereaved is recognised and acted upon.

Information regarding grief and bereavement is available for general practitioners, employers and other groups.

Criteria

- 3.7.1 Palliative care bereavement services participate in community education and health promotion activities on loss and grief. These activities may be initiated by the bereavement support program or conducted in collaboration with other relevant services.
- 3.7.2 Information and consultation on loss and grief is provided to community members and staff from other support services.

3.8 Standard 8: Privacy, confidentiality and consent

The palliative care bereavement program ensures the privacy and confidentiality of its bereaved clients.

Criteria

- 3.8.1 Bereavement staff comply with relevant legislation, regulations and instruments in relation to the privacy and confidentiality of clients.
- 3.8.2 The carer's or bereaved person's verbal permission is sought prior to screening, assessment, referral and bereavement interventions being offered. This verbal consent is documented in the palliative care client's notes.
- 3.8.3 The process of obtaining consent involves providing clear and direct information about the process, communicated in a language that the carer or bereaved person understands. Information should be provided about all steps in the process so that family members can choose whether to opt out of some or all of the process (for example, receiving follow-up letters and memorial service invitations).

- 3.8.4 Informed consent is obtained from bereaved people before information about them is collected and/or communicated to others.
- 3.8.5 Confidential information is stored in a way that ensures the privacy of bereaved people is protected. Only authorised staff have access to the information.
- 3.8.6 Bereaved people are made aware that bereavement program policies and procedures are available to them.
- 3.8.7 The physical environment for delivering support services provides for visual and sound privacy.
- 3.8.8 Confidential processes exist for client feedback on the palliative care service's bereavement program.
- 3.8.9 Confidentiality standards applicable to delivering all palliative care services within the organisation apply to delivering bereavement services.

3.9 Standard 9: Integration with the health and support system

The bereavement support program is part of a general health and support system working to promote the health and wellbeing of bereaved people and the wider community.

Criteria

- 3.9.1 Bereavement service staff are aware of the range of other support resources available to clients and can provide information on how to access them.
- 3.9.2 The bereavement program supports staff and clients in their involvement with other support service providers.
- 3.9.3 The bereavement program develops and maintains effective networks to promote interagency collaboration to:
- ensure coordinated client care and optimise service delivery
 - pursue coordinated strategies for community education and health promotion
 - pursue coordinated strategies for staff education and support.

3.10 Standard 10: Resource allocation

Resources are allocated in a systematic manner that allows the palliative care service's bereavement program to respond to the changing needs of clients and staff.

Criteria

- 3.10.1 A budget is allocated for the bereavement support program within each palliative care service.
- 3.10.2 There is a clearly documented system for appropriately allocating and utilising resources consistent with the level and type of client needs, particularly bereaved people at risk of adverse outcomes.
- 3.10.3 A clearly documented system exists for the appropriate allocation and utilisation of resources in order to provide appropriate education and support for its staff.

3.11 Standard 11: Program evaluation, quality improvement and research

Palliative care services are committed to improved outcomes for bereaved people through research, program evaluation and quality improvement.

There is an absence of well-validated and reliable prognostic bereavement tools that can be used in the pre-death and early post-death phases. This applies in particular to the availability of localised tools. As such, further rigorous research is essential in order for this area to be strengthened. It is important that research designs are methodologically sound.

Criteria

- 3.11.1 There is a clearly documented evaluation strategy that uses a combination of accepted qualitative and quantitative methods (see Appendix 1 for an example of an evaluation framework).
- 3.11.2 Services use existing or establish new datasets to enable information to be collected from clients, staff and other relevant services.
- 3.11.3 The bereavement support program demonstrates a regular and active interest in research outcomes as they relate to current practice and supports rigorous, methodologically sound research into the field of bereavement using empirical studies.
- 3.11.4 A process of continuous quality improvement can be demonstrated.
- 3.11.5 Performance is monitored regarding the minimum standards and data is used to improve performance as part of a quality improvement process.

4. Processes and protocols

The literature highlights a number of factors that have been found to be predictive of poor adjustment to bereavement. In the pre-death phase, information on background and treatment-related factors has been shown to be of critical importance. This section provides guidance on undertaking conversational exploration of risk factors and strength/resilience factors shown to be important factors impacting on people's grief responses.

4.1 Exploring background factors

- **Close kinship to the dying person (especially spouse or child loss)**

Kinship relationships can be readily identified through demographic information and self-report.

- **Female gender (especially mothers)**
- **Minority ethnic status**

Can be identified through demographic information and self-report.

- **Insecure attachment style**

May be explored through questions such as:

Did you experience the loss of a parent or other close loved one while you were a young child, for example, a sibling or a close family member?

Have you had any other experiences that you would regard as potentially traumatic?

How do you respond now, in terms of feelings, when you separate from people you care deeply about?

Further examples of items can be found in the Adult Attachment Scale (Hazan & Shaver 1987).

- **High pre-loss marital dependency**

This information can be elicited by discussing the nature of the dependency to the client by the carer. To what extent is your wellbeing reliant on your partner?

- **Religion and spirituality**

The FICA spiritual history tool has been developed by the George Washington Institute for Spirituality and Health as a guide for spiritual conversations in the clinical setting. The tool can be found at www.gwish.org.

4.2 Exploring treatment-related factors

- **Aggressive medical interventions (for example, intensive care unit, ventilation, resuscitation)**

This information can be elicited by a discussion on the nature of the medical intervention from the bereaved person's perspective.

- **Ambivalence regarding treatment**

This information can be elicited by discussing the nature of the medical treatment from the bereaved person's perspective.

- **Family conflict regarding treatment**

This information can be elicited by discussing how other family members perceive treatment and the degree of consensus of opinion held by family members.

- **Economic hardship created by treatment**

This information may be obtained through questions such as:

Have you experienced financial hardship or accrued debt, sold or refinanced your home, borrowed money from friends or family, or experienced a 20 per cent or greater decline in your annual income as a result of treatment-related expenses?

- **Caregiver burden**

In addition to questions of economic hardship this would also include questions on feelings of abandonment such as:

Is it very difficult to get help from your family in taking care of [client's name]?

How has [client's name]'s illness impacted on your daily life such as visiting friends or dealing with interruptions?

How has caring impacted upon your health?

Do you sometimes feel trapped or overwhelmed by the caring role?

The information obtained from these conversations is used to inform the palliative care team's clinical decision making regarding the level of risk of complicated grief for carers and bereaved people. Ideally these conversations are ongoing and conducted by more than one member of the palliative care team.

5. Bereavement support care pathway

Table 1 outlines recommendations for implementing the standards along the grief trajectory. While all of the standards apply at each point on the grief trajectory, the table highlights where a specific standard applies to different actions along the bereavement support pathway.

Table 1: Recommendations for implementing the standards

Point on grief trajectory	Actions	Relevant standards	Factors to consider
Between intake and the client's death	As part of a comprehensive bio-psychosocial spiritual assessment, the team assesses the carer's risk of complicated grief	Standard 4	Multidisciplinary/interdisciplinary process Ongoing conversational examination of risk and resilience factors (see section 4)
	If there is an elevated risk of self-harm or current high levels of psychosocial distress, refer for specialist intervention	Standard 5	Urgent referral may be required if risk assessed as high May need to refer to an external agency if expertise does not sit within the palliative care service
	If the carer meets the criteria (based on the multidisciplinary team assessment) for bereavement risk the team identifies the person as potentially vulnerable and monitors accordingly	Standard 5	With the person's consent, if risks are identified, an appropriate member of staff is notified to offer support The identified carer/family member is provided with support that addresses the assessed needs
	Provide information and psycho-educational materials	Standard 5	Psycho-education should be provided via a variety of means such as information sessions, books and DVDs, and focus on: <ul style="list-style-type: none"> preparing the primary carer for the typical role of supporting a relative/friend outlining the palliative care services and external services available assisting the primary carer to support their relative (such as symptom management and psychosocial support) self-care strategies for the primary carer (including respite services, if pertinent) Information on death and bereavement
Imminent death	Provide information	Standard 5	Ensure the family is aware that death is imminent (where possible) Assess family preparedness for death Provide practical information such as signs of imminent death, how to arrange a funeral and the role of the funeral director Provide information about wills, Centrelink, financial and banking matters
	Discussion regarding death decisions	Standard 5	Who do the client and family wish to be present? Where would the client and family like the death to occur? Who is to be notified? Funeral arrangements
	For those at risk of complicated grief, provide more comprehensive support	Standard 5	Assessment of separation distress and traumatic distress

Point on grief trajectory	Actions	Relevant standards	Factors to consider
At death (as soon as practicable following the death)	Assess the level of trauma the family experienced as a result of the death	Standard 4	<p>Bereavement overload (multiple losses in quick succession) – including non-death losses</p> <p>The level of trauma caused to the bereaved by the death, which may be influenced by the experience of suddenness (unexpectedness or trauma)</p> <p>Place of death such as hospital or home</p> <p>Who was present at the time of death?</p> <p>Any difficult aspects of the death for family and carers</p> <p>Dissatisfaction with death notification</p> <p>Incongruity between the client's/family's expressed pre-death wishes and actual death experience</p> <p>It is important to differentiate between the family's and the health professionals' perception of the death as these may differ markedly</p>
	Provide information	Standard 5	<p>Practical information</p> <p>Typical grief responses and ways of managing these</p> <p>Seeking assistance for distress including pertinent bereavement and emergency services</p> <p>The role of the palliative care team and other support services and how to access them</p>
	Specialist bereavement interventions	Standard 5	For people with high levels of psychosocial, spiritual distress or manifesting significant symptoms of separation distress and trauma
	Conduct a death review (multidisciplinary team members)	Standard 5	<p>Each palliative care team member is provided with an opportunity to reflect on the experience of the client's death and its impact on them</p> <p>Encourage the use of professional supervision and support</p>
	If there is an elevated risk of self-harm or current high levels of psychosocial distress, refer for specialist intervention	Standard 5	<p>Urgent referral to crisis mental health services may be required if the risk is assessed as high</p> <p>May need to refer to an external agency if the expertise does not sit within the palliative care service</p>
At 12 weeks after death	Provide information	Standard 5	Information includes supports available such as social/support groups
	Follow-up phone call (for all primary carers)	Standard 5	<p>Explore issues including insomnia, social support, return to work, contact with their GP, and exacerbation of previously existing psychological or physical conditions. How have things changed for the person over the previous three months?</p> <p>If symptoms related to bereavement are unremitting, this may be a sign that further assessment or support is required</p>

Point on grief trajectory	Actions	Relevant standards	Factors to consider
At 12 weeks after death	Specialist bereavement interventions	Standard 5	<p>May require referral for specialist bereavement interventions based on findings of follow-up phone call/home visit</p> <p>Consider a range of interventions including clinical options, counselling or GP referral</p>
Around six months after death	Undertake formal bereavement assessment of those who have previously been identified as being at high risk of prolonged or complicated grief	Standard 4	<p>Symptoms have been present for at least six months after the client's death</p> <p>Symptoms include a sense of disbelief regarding the death, persistent intense longing, yearning and preoccupation with the deceased, recurrent intrusive images of the dying person and avoidance of painful reminders of death (Prigerson et al. 2009)</p> <p>People identified as being at elevated risk of developing prolonged or complicated grief are offered a comprehensive bereavement assessment using a validated tool such as the PG-13 (see Appendix 3)</p>
	For those who meet the criteria for prolonged grief, refer to specialist bereavement services	Standard 5	Referral to an experienced bereavement worker within the organisation or to an external organisation
	For bereaved people assessed as having moderate psychosocial distress or a moderate risk of prolonged or complicated grief, more formal opportunities to review and reflect on their grief may be required	Standard 5	<p>May involve referral to support or social groups</p> <p>Support may be provided by unpaid staff such as trained volunteers</p> <p>The support of family and friends remains important throughout the grief trajectory</p>
Around 12 months after death	Send an anniversary card or memorial service invitation at around 12-months after the death that includes information regarding self-assessment and referral if needed	Standard 5	<p>There is no 'cut-off time' for providing bereavement support – a carer may present at any time for bereavement support</p> <p>Information provided may include useful contacts, and facts about grief and bereavement</p> <p>Hand-written bereavement cards may be considered more personal</p> <p>Ensure a single agency takes responsibility for follow-up to reduce duplication</p>

Glossary

Bereavement

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 (Christ et al. 2003).

Bereaved person

A bereaved person is any person who is experiencing grief following a loss. In the context of these standards, the bereaved person is experiencing grief following the death of a person who is close to them from a life-threatening illness.

Family caregiver

A relative, friend or partner who has a significant personal relationship and provides assistance (physical, social and/or psychological) to a person with a life-threatening illness. These people may be primary or secondary family caregivers or may not reside with the person receiving care (Canadian Hospice Palliative Care Association 2012).

Carer

Carers provide unpaid support to a family member or friend who needs assistance (Carers Victoria 2012).

Client

In line with Victoria's palliative care policy, the term 'client' is used to describe the primary recipient of palliative care (Department of Health 2011).

Complicated grief

State of chronic grieving characterised by intense separation distress, intrusive and troubling thoughts about the deceased, a sense of meaninglessness, trouble accepting the reality of the loss, and various difficulties 'moving on' with life following the loss (Holland et al. 2010).

Typical grief

Each person's grief trajectory will be unique. For the majority, grief will involve intense yearning, intrusive thoughts and images and emotional responses such as anxiety, unhappiness or uneasiness. These symptoms will not persist longer than a few months and eventually they will be able to integrate the loss into their lives and regain their interest and engagement with life (Shear & Shair 2005).

Palliative care

The World Health Organization defines palliative care as an approach that improves the quality of life for patients and their families facing the problems associated with life-threatening illness. It does this through preventing and relieving suffering by means of early identification and impeccable assessment and treatment of pain and other problems – physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms
- affirms life and regards dying as a normal process
- intends neither to hasten nor postpone death
- integrates the psychological and spiritual aspects of patient care
- offers a support system to help patients live as actively as possible until death
- offers a support system to help the family cope during the patient's illness and in their own bereavement
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated
- will enhance quality of life, and may also positively influence the course of illness
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Specialist palliative care

Consistent with Victoria's palliative care policy, in this document, palliative care refers to the specialist interdisciplinary practice of palliative care and the designated service system funded to deliver that care (Department of Health 2011).

Psycho-education

A specific form of education. It is aimed at helping those with a mental illness or anyone with an interest in mental illness to access the facts about a broad range of mental illnesses in a clear and concise manner. It is also a way of accessing and learning strategies to deal with mental illness and its effects (Queensland Government Inner North Brisbane Mental Health Service 2012).

Prolonged grief

The syndrome of prolonged grief, also called pathological, complex or traumatic grief, is chronic and debilitating, results in substantial distress and impairment, worsens quality of life and has been linked to excess medical morbidity and suicidality. As currently defined, prolonged grief consists of symptoms at least six months after the loss of a loved one that include a sense of disbelief regarding the death, persistent intense longing, yearning and preoccupation with the deceased, recurrent intrusive images of the dying person and avoidance of painful reminders of death (Prigerson et al. 2009).

Psychological distress

While there is a lack of consensus regarding what constitutes psychological distress, for the purposes of this document, psychological distress is an unpleasant experience of an emotional, psychological, social and spiritual nature. It may include a range of symptoms from sadness and fear to clinical depression, generalised anxiety, panic, feeling isolated or suffering spiritual distress (Holland 1999; Murillo & Holland 2004; Thekkumpurath et al. 2008).

Psychosocial

Of or relating to processes or factors that are both social and psychological in origin (HarperCollins 2003).

Bio-psychosocial

A bio-psychosocial model of health care refers to strategies that are inclusive of the biological, psychological and social aspects of health (Australian Psychological Society 2011).

Resources

Web-based resources

The Australian Centre for Grief and Bereavement (ACGB) is an independent, not-for-profit organisation and operates the Statewide Specialist Bereavement Service. ACGB provides a range of education, clinical and research and consultancy services including the:

- Practitioner Consultancy Service – 1300 858 113
- Bereavement Information and Referral Service – 1300 664 786.

www.grief.org.au

CanTeen is the Australian organisation for young people living with cancer.

www.canteen.org.au

The Childhood Bereavement Network is a UK based, multi-professional federation of organisations and individuals working with bereaved children and young people.

www.childhoodbereavementnetwork.org.uk

Department of Human Services *Human services directory* – for further referral options for crisis or bereavement services.

<http://humanservicesdirectory.vic.gov.au>

Kids Help Line offers support and resources to children.

1800 55 1800

www.kidshelp.com.au

Lifeline provides online support and suicide prevention services.

13 11 14

www.lifeline.org.au

MensLine Australia is a professional telephone and online support, information and referral service, helping men to deal with relationship problems in a practical and effective way.

1300 78 99 78

www.menslineaus.org.au

riprap is a website for kids coping with a parent who has cancer.

www.riprap.org.uk

SuicideLine offers free professional, anonymous support 24 hours a day, seven days a week across Victoria.

1300 651 251

Very Special Kids provides flexible family support programs, planned and emergency respite and end-of-life care for families caring for a child with a life-threatening illness.

www.vsk.org.au

Victorian Aboriginal Community Controlled Organisation Inc. is the peak Aboriginal health body representing Aboriginal community-controlled health organisations.

03 9411 9411

www.vaccho.org.au

Victorian Paediatric Palliative Care Program provides specialist paediatric palliative care consultation and liaison to health professionals caring for children with a life-threatening condition and their families, enabling them to receive optimal care in the setting of their choice.

(03) 9345 5374

www.rch.org.au/rch_palliative/contact/index.cfm?doc_id=1655

Winston's Wish is the leading childhood bereavement charity and the largest provider of services to bereaved children, young people and their families in the UK.

www.winstonswish.org.uk

Books

Relf M, Machin L, Archer N 2008, *Guidance for bereavement needs assessment in palliative care*, Help the Hospices, London.

Monroe B, Machin L, Archer N 2007, *Resilience in palliative care: achievements in adversity*, Oxford University Press, London.

Neimeyer RA, Harris DL, Winokuer HR, Thornton GF (eds) 2011, *Grief and bereavement in contemporary society: bridging research and practice*, Routledge, New York.

Stroebe M, Schut H, Van Den Bout J (eds) 2013, *Complicated grief: scientific foundations for health care professionals*, Routledge, London.

Appendix 1:

Framework for evaluating elements of bereavement support in Victorian palliative care services

The Victorian Department of Health has developed a framework for evaluating health promotion and disease prevention programs. It contains a number of key steps that could be used in a range of evaluation contexts and could be adapted to provide a framework for evaluating bereavement services in Victorian palliative care services.

The key steps in the framework are:

Step 1: Describe the program

Include the goals, objectives and target groups.

Step 2: Preview the evaluation

Define the purpose of the evaluation, outline stakeholder engagement strategies, identify the key questions and identify the evaluation resources.

Step 3: Focus the evaluation design

Specify the study design, data collection methods and data collection instruments.

Step 4: Collect the data

Nominate who is responsible for the data collection tasks and what resources will be required to undertake the data collection. Summarise the key findings, themes and information contained in the raw data.

Step 6: Disseminating the lessons learnt

Outline what worked and what didn't work including possible explanations for the program's successes and failures (Department of Health 2009).

Appendix 2: Bereavement support in Victorian palliative care services and the palliative care service delivery framework

The palliative care service delivery framework is an important element of implementing *Strengthening palliative care: Policy and strategic directions 2011–2015*. The service delivery framework identifies clear expectations of Victorian palliative care services.

The service capability framework, which is a component of the service delivery framework, comprises:

- three types of palliative care services (inpatient, community and consultancy)
- three levels of inpatient categories, two levels of community-based services and one level of consultancy across seven dimensions of measuring/describing capability.

Consultancy teams can be either hospital- or community-based and the designated level of capability of any service provider will be determined by the Victorian Department of Health in consultation with the sector.

Under the bereavement support standards, the client journey is expected to remain the same regardless of the capabilities of individual palliative care services; however, the type of input services will have with individual clients may vary. Example:

- A level one inpatient service provides or facilitates access to psychosocial and spiritual care, bereavement support and respite care (this may mean undertaking screening and/or assessment within the service but referring to an external mental health specialist for intervention).
- level two inpatient service provides a broad spectrum of care and has the capacity to manage most palliative care clients including their physical and psychosocial needs.
- level three inpatient service provides comprehensive care and has capacity to manage the full range of palliative care clients including those with clinically and/or psychosocially complex needs. A level three inpatient service offers liaison psychiatry and/or psycho-oncology and/or appropriate mental health services.
- level one community palliative care service provides or facilitates access to psychosocial and spiritual care, bereavement support and respite care for palliative care clients, carers and families.
- level two community service provides comprehensive clinical care (including complex symptom and pain management) and psychosocial and spiritual care, bereavement support and access to respite care.
- Consultancy palliative care services offer in-reach and outreach advice and support to hospitals, community-based health care professionals and community palliative care services (Aspex Consulting and Department of Human Services Victoria 2010).

Appendix 3: The PG-13

The PG-13 has been reproduced with the permission of its authors.

Center for Psychooncology & Palliative Care Research - Prolonged Grief Disorder (PG-13)[®]

Holly G Prigerson, PhD, Paul K Maciejewski, PhD

Prolonged grief disorder (PGD) is a newly defined syndrome that is a specific reaction to the loss of someone loved very much. There are a particular set of PGD symptoms – feelings, thoughts, actions – that must be elevated at six months after the loss and that must be associated with significant functional impairment in order for a person to meet criteria for PGD (Prigerson et al. 2008; Prigerson et al. 2009; Zhang et al. 2006).

PG-13 is a diagnostic tool. If a respondent meets the criteria for PGD, this would suggest that he or she should seek a more thorough evaluation from a mental health professional. Only an in-person assessment by a mental health professional can determine for certain the clinical significance of the reported symptoms, and provide recommendations or referrals for treatment.

Instructions

Below lie instructions for how to score (diagnose) PGD. Each of the requirements for criteria A–E must be met for an individual to be diagnosed with PGD.

A. Event criterion: In order to complete the PG-13, we assume the respondent has experienced bereavement (the loss of a loved person).

B. Separation distress: The respondent must experience PG-13 questions #1 or 2 at least daily.

C. Duration criterion: The symptoms of separation distress must be elevated at least six months after the loss. That is, PG-13 question #3 must be answered as ‘Yes’.

D. Cognitive, emotional and behavioural symptoms: The respondent must experience five of the PG-13 questions #4–12 at least ‘once a day’ or ‘quite a bit’.

E. Impairment criterion: The respondent must have significant impairment in social, occupational or other important areas of functioning (for example, domestic responsibilities). That is, PG-13 question #13 must be answered as ‘Yes’.

Part I instructions: For each item, place a check mark to indicate your answer.

1. In the past month, how often have you felt yourself longing or yearning for the person you lost?

- _____ 1 = Not at all
- _____ 2 = At least once
- _____ 3 = At least once a week
- _____ 4 = At least once a day
- _____ 5 = Several times a day

2. In the past month, how often have you had intense feelings of emotional pain, sorrow or pangs of grief related to the lost relationship?

- _____ 1 = Not at all
- _____ 2 = At least once
- _____ 3 = At least once a week
- _____ 4 = At least once a day
- _____ 5 = Several times a day

3. For questions 1 or 2 above, have you experienced either of these symptoms at least daily and after six months have elapsed since the loss?

- No
 Yes

4. In the past month, how often have you tried to avoid reminders that the person you lost is gone?

- 1 = Not at all
 2 = At least once
 3 = At least once a week
 4 = At least once a day
 5 = Several times a day

5. In the past month, how often have you felt stunned, shocked or dazed by your loss?

- 1 = Not at all
 2 = At least once
 3 = At least once a week
 4 = At least once a day
 5 = Several times a day

Part II instructions: For each item, please indicate how you currently feel. Circle the number to the right to indicate your answer.	Not at all	Slightly	Somewhat	Quite a bit	Overwhelmingly
6. Do you feel confused about your role in life or feel like you don't know who you are (feeling that a part of yourself has died)?	1	2	3	4	5
7. Have you had trouble accepting the loss?	1	2	3	4	5
8. Has it been hard for you to trust others since your loss?	1	2	3	4	5
9. Do you feel bitter over your loss?	1	2	3	4	5
10. Do you feel that moving on (for example, making new friends, pursuing new interests) would be difficult for you now?	1	2	3	4	5
11. Do you feel emotionally numb since your loss?	1	2	3	4	5
12. Do you feel that life is unfulfilling, empty or meaningless since your loss?	1	2	3	4	5

Part III instructions: For each item, place a check mark to indicate your answer.

13. Have you experienced a significant reduction in social, occupational or other important areas of functioning (for example, domestic responsibilities)?

- No
 Yes

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