Gippsland Region Palliative Care Consortium

Bereavement Risk Screening and Management Guidelines

Gippsland Region Palliative Care Consortium
Clinical Practice Group

Title	Grief and Loss Screening Guidelines
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Ratified	GRPCC Clinical Practice Group
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Purpose	The intent of this document is to assist nurses and other health professionals in gathering relevant and up to date clinical information to provide best practice bereavement support. Enquiries can be directed to GRPCC by email enquiries@grpcc.com.au or phone 03 5623 0684.
Acknowledgements	Some of the information contained in this document is based on the: Melbourne City Mission Grief and Loss Screening Guidelines; La Trobe Community Health Service Ambulatory Care, Bereavement Risk Assessment tool; Central Gippsland Health Service Bereavement Assessment Tool and Peninsula Health Spiritual Assessment Bereavement Risk Assessment and Referral.
Pages	12

1. Background

Bereavement Support Standards for Specialists Palliative Care Services were published by the Department of Health, Victoria (2012).[1] The standards are intended for use by all Victorian government funded, adult, specialist palliative care services including community, inpatient, acute and consultancy services. Providing bereavement support is an essential component of palliative care delivery, but there is little evidence-based guidance for health professionals and others providing this support.

The philosophy of palliative care emphasises support for the client during illness and support for family carers before and after the client's death. Palliative care services, by and large provide the most comprehensive strategy for bereavement support in our community. However, most Australian palliative care services offer bereavement support services, often regardless of risk or need[2]. The majority of bereaved people manage their grief with the support of family, friends and neighbours and only a small proportion (10-20 percent) will experience persistent psychosocial difficulties, including Prolonged Grief Disorder (PGD) (previously known as Complicated Grief) and who will benefit from professional intervention[3],[4].

While loss and grief are fundamental to human life the cause and consequences of bereavement will vary for each individual:

1. For highly resilient individuals, significant grief may be limited to a few weeks. For most people the acute experience of grief subsides over time;
2. For a subgroup of people, around 10-20 percent, the symptoms of distress following the death of a family member or friend are more intense and persistent.

2. Policy

The Gippsland Region Palliative Care Consortium Clinical Practice Advisory membership recognises that grief is a normal response to loss and that most people are resilient and supported in their grief by family, friends and community. A small percentage of people will require specialist intervention.

Key principles for bereavement support delivery:

- Identify need through structured screening and assessment in order to target resources to those most in need
- Identify bereaved person's own coping resources and capacity:
    - The clinician conducting the bereavement assessment can obtained meaningful information regarding carer and family coping mechanisms when significant events happened if the right questions are asked.

[1] Bereavement support standards for specialists palliative care services. Department of Health, Victoria 2012.

[2] Aoun S. M. , Breen L. J., O'Connor M., Rumbold B., & Nordstrom C. A public health approach to bereavement support services in palliative care. Australian and New Zealand Journal of Public Health 2012 Vol.36 No. 1

[3] Lobb Leonard R, Horsfall D, Noonan K. Identifying changes in the support networks of end-of-life carers using social network
analysis. BMJ Support Palliat Care 2013. doi:10.1136/ bmjspcare-2012-000257.

[4] Rumbold B. Health promoting palliative care and dying in old age. In: Gott M, Ingleton C (eds.) Living with ageing and dying: palliative and end of life care for older people. Oxford University Press; 2012. p. 75–89.

- Potential questions for use in a bereavement risk assessment meeting may include the following:

    - How have the caregiver and family members coped with illnesses and previous death?
    - How supported by family and friends do you feel?
    - Will you explore the possibility of counselling?
    - Is there any practical support we can offer and provide?[5]

- Bereavement support covers pre death to several months after death
- There is no time limit to providing bereavement support
- Focus on the primary carer, but can include other carers/family if resources allow.

3. Purpose

The purpose of this document is to:

- provide practical guidelines to clinicians in the region for assessing and documenting bereavement for those who may be at risk from admission; and
- provide timely and appropriate support in a sensitive manner.

It must be noted that this guideline is for use by health professionals working with adults.

This document includes two recommended tools;

1. Complicated Bereavement Risk Assessment Tool (CBRAT); and
2. Genogram

4. Screening, assessment and documenting of bereavement risk

Screening and assessment for risk of PGD is a continuous process that commences from the time the client enters the palliative care service to many months after the client's death[6].

1. Initial assessment
    a. A bereavement risk assessment should be included as a mandatory item in the client's care plan under the heading CBRAT;
    b. It must be completed by the assessing nurse or allied health team member if available and appropriate;
    c. Additions are documented as required through subsequent visits;

[5] Aranda, S& Milne D. (2000) Guidelines for the assessment of bereavement risk in family members of people receiving palliative care. Melbourne: Centre for Palliative Care, page 18

[6] Standard 4, Bereavement support standards for palliative care services

d. The CBRAT care plan identifies potential risks and proposed strategies to manage risks; and
e. If no bereavement risk factors are identified; this is also clearly documented.

2. Assessment and follow up procedure- ***key nursing/allied health considerations***
    a. Observe the following from a psychosocial and spiritual context:
        i. characteristics of the dying person;
        ii. characteristics of the main carer and other family members pre and post death;
        iii. interpersonal; relationships dynamics and cultural context;
        iv. burden and/or stigma of illness and nature of the death; and
        v. history of loss.

    b. Other elements to be considered when conducting a bereavement risk assessment:
        i. family cohesion or lack of; and
        ii. communication pattern e.g. open/closed communication within the family that includes expression of cultural beliefs and attitudes.

    c. ***When risk is assessed as moderate or high,*** during assessment process ar at any time through the client's episode of care, at timely referral is required *(or at least a conversation with a grief and loss counsellor)*;
        i. may also require discussion with GP (*for access to a mental health plan)* and referral to an external health agency if expertise not available within the palliative care service

3. Once a bereavement risk is identified this must be included as a mandatory item in the care plan under "*Bereavement Risk" heading* noting the presence of any of the listed factors *:*
    a. It must be completed by the health professional involved following the initial assessment
    b. Add to the care plan and progress notes, as appropriate, as issues may emerge after subsequent visits and/or throughout the episode of care;
    c. If needed make succinct notes in the progress notes under the same heading;
    d. If a carer is identified as at a medium-high risk of complicated bereavement or issues of concern, discuss with the appropriate MDT member and at the MDT meeting; and
    e. Remember that protective factors and resilience may outweigh apparent risk factors.[7],[8],[9]

[7] Melbourne Citymission Palliative Care *Complicated Risk Assessment Tool (CBRAT)-Procedure CC108*
[8] Aranda, S& Milne D. (2000) Guidelines for the assessment of bereavement risk in family members of people receiving palliative care. Melbourne: Centre for Palliative Care
[9] Hudson, P., Remedios, C., et al. Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. Centre for Palliative Care, St Vincent's Hospital: Melbourne, Australia 2010.

4. If the caregiver and/or family are identified to benefit from Bereavement Risk resources either at initial assessment or through subsequent visits. These resources can be accessed for downloading and viewing through the GRPCC website: www.grpcc.com.au

5. Important elements for nursing staff and other health professionals to consider

Typical grief

Each person's grief trajectory will be unique. For the majority, grief will involve intense longing, intrusive thoughts and images and emotional responses such as anxiety, unhappiness, uneasiness and unexpected desire to cry. These symptoms subside in a few months and eventually the person will be able to integrate the loss into their lives and regain interest and engagement with life.[10] People experiencing typical grief begin to understand that bereavement can be an experience to be engaged in rather than a problem to be solved.[11]

Complicated grief

State of chronic grieving , outside the period expected in "acute grief" (4 to 6 months post death), is characterised by intense separation distress, intrusive and unwelcome thoughts about the deceased, a sense of meaningless, trouble accepting the reality of the loss, and various difficulties "moving on" with life following the loss.[12]

Low Bereavement Risk 58.4% (60%)
The majority of individuals deal with grief with support of family and friends.
No risk of complicated grief identified by CBRAT

Moderate Bereavement Risk 35.2% (30%)
Individuals in need of some additional support e.g. peer support/trained volunteer led group.
Minimal risk of complicated grief identified by CBRAT

High Bereavement Risk 6.4% (10%)
Individuals at multiple risks of complicated grief identified by CBRAT.
May need referral to specialist health professionals[13]

[10] Bass Coast Health: District Nursing and Palliative Care Bereavement. Final Draft June 2015
[11] Rumbold B. & Aoun S. Bereavement and palliative care: A public health perspective. Progress in Palliative Care 2014 Vol. No3
[12] Bass Coast Health: District Nursing and Palliative Care Bereavement. Final Draft June 2015
[13] Aoun SM, Breen LJ, Howting DA, Rumbold B, McNamara B, Hegney D (2015) Who needs bereavement support? A population based survey of Bereavement Risk and Support Need. PLoS ONE 10(3):e121101,doi: 10.137/journal.pone.0121101

Appendix 1

AT A GLANCE BEREAVEMENT RISK SCREENING GUIDELINES

Factors Enhancing Resilience in Bereavement

- Drawing upon past losses – i.e. how I survived
- Connecting with family & community of care
- Drawing on spiritual/religious beliefs and practices
- Identifying internal & external strengths and resources
- Reconstructing meaning and identity after the loss
- Drawing on experience and support of other bereaved people
- Having higher levels of practical support
- Holding a belief in a just world, and acceptance of death
- Gaining comfort from talking or thinking about the deceased

Evidence Based Practice Bereavement Support

- Identify and reinforce their coping and positive achievements
- Reinforce the importance of family and community as sources of social support
- Build on strengths and encourage their innate capacity to recover and cope with grief
- Intervention should be minimal

COMPLICATED BEREAVEMENT RISK ASSESSMENT TOOL (CBRAT)

(**it is acknowledged that protective factors and resilience may outweigh apparent risk factors)

Client Characteristics (Bereaved client)

- ☐ Under 18
- ☐ Was a twin
- ☐ Young Spouse
- ☐ Elderly Spouse
- ☐ Isolated
- ☐ Lacks Meaningful Social Support
- ☐ Dissatisfied with help available during illness
- ☐ New to Financial Independence
- ☐ New to Decision Making

Deceased Illness

- ☐ Inherited Disorder
- ☐ Stigmatised Disease in the Family/Community
- ☐ Lengthy and Burdensome

Death

- ☐ Sudden or Unexpected
- ☐ Traumatic Circumstances Associated with Death
- ☐ Significant Cultural/Social Burdens as a result of Death

History of Loss (Bereaved Client)

- ☐ Cumulative Multiple Losses
- ☐ Previous Mental Health Illness
- ☐ Current Mental Health Illness
- ☐ Other Significant Health Issues
- ☐ Migrant/Refugee

Relationship with Deceased

- ☐ Profound Lifelong Partner
- ☐ Highly Dependant
- ☐ Antagonistic
- ☐ Ambivalent
- ☐ Deeply Connected
- ☐ Culturally Defined

Risk factors scores

0-2 Low
3-5 Moderate
5+ High

*All persons scoring moderate to high presume to be at risk***

Appendix 2

The genogram

One method of pictorially representing key findings of a family risk assessment is the genogram. A genogram provides a structure and conventional means of documenting the nature of relationships within and between generations, a history of loss events, grieving patterns and subsequent coping strategies, along with an indication of the nature of relationships and support systems[14].

A genogram is the starting point of family care and as such should be part of routine family assessment also useful to CBRAT.

The entire team should be skilled at developing and interpreting a genogram as it engenders confidence for the client and caregiver that the health professional conducting assessment:

- believes family factors influence health;
- understands that illness affects the family; and
- the clinician is open to discussions on family matters[15].

The genogram has been widely promoted as a useful tool for gathering, recording and displaying family information in order to provide client and family-centred care[16]. A genogram also:

- displays the emotional bonds among individuals composing a family or social unit. This type of information is invaluable for a counsellor/social worker;
- functions as an assessment tool to measure the cohesiveness of the family group in order to determine the care that is needed;
- provides nurses and allied health professionals such as family counsellors or therapists with a starting point to explain family dynamics to a client who is going through personal or family therapy; and
- can be used to examine interesting and/or complex family history such as, rivalry, facing adversity and/or other significant events[17].

[14] Aranda, S& Milne D. (2000) Guidelines for the assessment of bereavement risk in family members of people receiving palliative care. Melbourne: Centre for Palliative Care, *page* 19

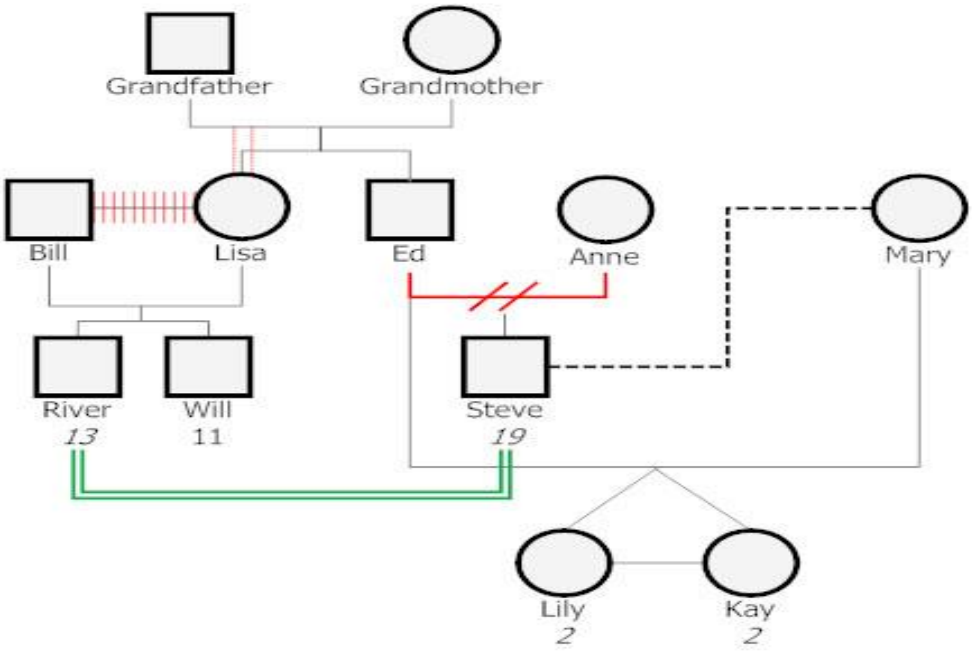
[15] John Clabby, PhD UMDNJ-Robert Wood Johnson Medical School, CentraState Family Medicine Residency and Geriatric Fellowship Program Freehold, New Jersey jclabby@centrastate.com (accessed March 2016)

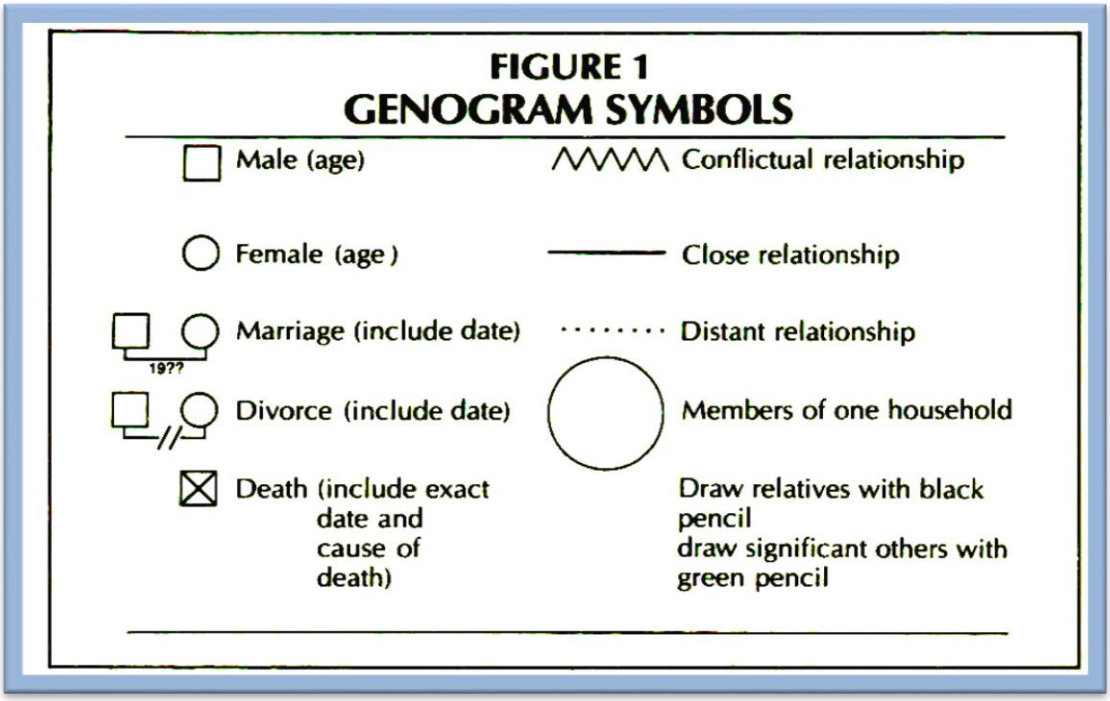
[16] Liossi, C., Hatira, P. and Mystakidou, K. (1997) The use of the genogram in palliative care. *Palliative Medicine*, 11, (6), 455-461

[17] https://www.smartdraw.com/genogram/ (accessed March 2016)

Insert Genogram

(sample genograms below)





Appendix 3

POST-DEATH SCREENING AND ASSESSMENT GUIDE

The bereavement experience will vary in intensity from person to person[18]. It is therefore difficult to make safe predictions in terms of longer term functioning [19] of bereaved people before a minimum of six months after a death[20].

BEREAVEMENT SUPPORT STRATEGIES

The recommended bereavement support include two types of strategies[21]:

1. Universal strategies targeted at all carers and bereaved people; and
2. Specialist bereavement support strategies directed at those at risk of developing complicated grief or currently experiencing psychosocial and/or spiritual distress

1. Universal strategies include:

- ≈ Conducting bereavement risk assessment either at admission or at any phase during the episode of care if bereavement risk factors start to emerge;
- ≈ Promoting effective symptom management of the palliative care client to reduce the impact of refractory symptoms and difficult death on carers and clients themselves;
- ≈ Provision of formal/structured written and verbal information and clinical support at various points of the grief trajectory such as:
    - following admission to the palliative care program that includes:
        - palliative care and external services available;
        - strategies that may assist the primary caregiver to support their relative i.e. symptom management and psychosocial support; and
        - self-care strategies and respite.

[18] Hudson, P., Remedios, C., et al. Clinical Practice Guidelines for the Psychosocial and Bereavement Support of Family Caregivers of Palliative Care Patients. Centre for Palliative Care, St Vincent's Hospital

[19] Rumbold B. Health promoting palliative care and dying in old age. In: Gott M, Ingleton C (eds.) Living with ageing and dying: palliative and end of life care for older people. Oxford University Press; 2012. p. 75–89.

[20] Standard 4, Bereavement support standards for palliative care services: Post death screening and assessment, pp 12

[21] *Ibid*

- **When death appears imminent:**
  - ensure the caregiver /family are aware that death is imminent;
  - assess their understanding and preparedness;
  - provide succinct and practical information such as:
    - signs and symptoms of imminent death
    - funeral arrangements
    - Centrelink, wills and financial matters
  - site of death decisions:
    - establish and/or corroborate *where the client and family would like death to occur***
    - who is to be notified
    - would a nursing visit be required for verification?
    - who is certifying the death?

- **Immediately following death:**
  - provide assessment of separation distress and degree of trauma to the bereaved if death experienced as sudden;
  - follow up with formalised psychosocial support for those identified to be at risk of complicated grief; and
  - conduct a multidisciplinary death review:
    - each team member involved in the death is provided with an opportunity to reflect on the experience of the client's death and its impact on the team individually and collectively.

- **12 weeks post death**:
  - follow up phone call for all primary carers:
    - explore/discuss issues such as:
      - degree of current social support;
      - plans to return to work;
      - any health relate issues i.e. insomnia, anxiety, exacerbation of previously existing psychological or physical conditions;
      - any dramatic changes for the person over the last three months that may require specialist bereavement interventions; and
      - ongoing contact with GP
  - provide information on supports available such as social/ loss and grief support groups

≈ **At six months after death:**
- conduct formal bereavement assessment, using a validated tool[22] for those previously identified as being at risk of prolonged or complicated grief
- identified established or emergence of symptoms which may include:
  - sense of disbelief regarding the death;
  - persistent intense longing and preoccupation with the deceased; and
  - recurrent images of the dying person; and avoidance of reminders of the death experience[23],[24].

≈ **Around 12 months after death**
- send an anniversary card that includes information regarding self-assessment- *hand- written bereavement cards are considered to be more personal*;
- information must be succinct and clear including useful contacts and facts about grief and bereavement
- and/or memorial service invitation.

≈ Provide access to evidence based supportive structures and strategies, which may include:
- participation in bereavement information session to provide caregiver/family opportunities to reflect and to share on the loss and grief experience; and
- activity-based structures such as walking, meditation, music therapy and art therapy groups.

2. Specialist bereavement support strategies:

a. *for those who met the criteria for prolonged grief:*
   i. refer to an experienced bereavement health professional within the organisation or to an external provider for bereavement

[22] Standard 4, Bereavement support standards for palliative care services: Post death screening and assessment, The PG-13 pp 28
[23] Prigerson H, Horowitz MJ et al. 2009, "Prolonged grief disorder: psychometric validatiopn of criteria proposed for DSM-V and ICD-!!, PLoS Medicine, no. 6, DOI: 10.1371/journal.pmed 1000121

[24] Guldin et al: Identifying bereaved subjects at risk of complicated grief: Predictive Value of questionnaire items in a cohort study. BMC Palliative Care 2011 10:9

counselling and psychotherapy using evidence-based specialist interventions for complicated grief

b. for those assessed as having moderate psychosocial distress or moderate risk of prolonged or complicated grief:

   i. referral to support or social groups;
   ii. support may be offered by unpaid staff such as trained volunteers;
   iii. introduce formal opportunities for caregivers/family to review and reflect on their grief; and
   iv. remember that family and friends network and support remains a significant supportive component throughout the grief trajectory.

There is no "cut off time" for providing bereavement support- a carer may present at any time for bereavement support. A single agency, particularly 12 months post death, must take full responsibility for follow- up to reduce duplication. [25]

[25] Standard 4, Bereavement support standards for palliative care services: Bereavement support care pathway pp 19.

Appendix 4

After bereavement phone call and/or visit

1. Record the phone call in deceased client's progress notes. Document potential risks
2. Complete the CBRAT tool check boxes if risks are identified
3. Assign a risk level in the care plan under care support or nominated bereavement field as per organisational requirements[26]

If LOW RISK

- No further follow-up required (but carer has or will receive cards, letter & brochure)

If MEDIUM & HIGH RISK

- Further follow up may be required
- Complete CBRAT
- If unsure about emerging issues, discussion may be then required with counseling staff if available face to face or by phone, stating: "further contact required, because ……." *(state reason, utilizing CBRAT and your own assessment – queries/doubts,etc)*
- Does the issue require urgent attention? If no counseling staff available: discuss timely with team and/or nurse coordinator

Clearly indicate a time frame for follow up;
e.g. within a week, fortnight, within a month.

[26] Melbourne Citymission Palliative Care. Grief and Loss Screening Guidelines and End of Life: Preparation and Planning 2014-2015.