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Palliative Care for the Patient with Incurable Cancer or Advanced Disease
Part 3: Grief and Bereavement

Effective Date: February 22, 2017

Scope

This guideline addresses the needs of adult patients with incurable cancer or advanced disease (but can be useful for adults dying of any cause), as well as the needs of their caregivers or family, including children. Information and tools are provided to improve a primary care provider's comfort and skills in dealing with this type of loss.

Diagnostic Code: 309 (adjustment reaction)

Key Recommendations

- Everyone grieves losses, but it is important to recognize especially vulnerable groups such as the elderly, children, the socially isolated, the mentally ill, the disenfranchised, and culturally diverse groups such as new immigrants and the indigenous community.
- It is not necessary to alter normal grieving, but it is helpful to provide a listening ear, to be supportive, and to provide information.
- Distinguish grief from depression and treat grief-related major depression once you are confident it is pathological.
- In the case of Prolonged Grief Disorder (complicated grief), assess and take note of any risk factors or concerns.
- Primary care providers play a key role in the continued monitoring of patients' grief responses and may refer the patient to grief counselling and treatment options.

Definitions

Grief and bereavement are distinguished from each other, although bereavement includes many aspects of grief.

Grief: An expected response to loss.

Anticipatory grief: Response to anticipated losses.

Bereavement: The state where, following death, the family creates meaning and sense out of the new reality of life without their loved one/person who died.

Prolonged Grief Disorder (complicated grief): Occurs when there is a debilitating intensity or duration of "normal" grief responses that adversely affect the ability to cope with normal life events.[1, 2]

Background

Grief and bereavement services should be available to all patients and families based on assessed needs. Family physicians often feel unprepared and uncomfortable about knowing how to support those going through intense grief. They may both mourn the death of their patient and the patient's death may also trigger their own past grief. Physicians who find themselves significantly impacted by a patient's death should consider contacting the Physician Health Program. Refer to *Associated Document: Resource Guide for Patients and Caregivers*.

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Grief

Assessment of Grief

- Consider using the Adult Attitudes to Grief Scale[3] (*Appendix A: Adult Attitudes to Grief Scale – Patient Handout, Practitioner Score Sheet, and Protocol for Use*). The Adult Attitudes to Grief Scale is a brief, self-reported, evidence-based, practical tool. The questions are designed to promote an understanding of the patient's grief and vulnerability by identifying grief reactions (controlled or overwhelmed) and coping responses (vulnerable or resilient). By scoring responses to the Adult Attitudes to Grief Scale, practitioners can assess levels of vulnerability, and need for support. A score higher than 23 suggests severe vulnerability and a need for specialized grief support services.
- Be aware of the potential desire for hastened death. If present, assess for suicide risk.
- Focus on personal strengths and coping mechanisms: what has worked in the past?
- Protective factors / resiliency for a patient or caregiver:
  - Has an internalized belief in his / her own ability to cope effectively.
  - Perceives the need for AND is willing to access social support.
  - Is predisposed to a high level of optimism / positive state of mind.
  - Has spiritual / religious beliefs that assist in coping with the death.

All of us grieve differently due to age, gender, personal, religious, and cultural differences. Enquire regarding cultural and individual preferences (refer to *Appendix B: Cultural Diversity and Individual Preferences*) and be aware of age differences (refer to *Appendix C: Children and Death*).

Management of Grief

1. Non-pharmacological management

The relationship between the physician and the patient is one of the most potent therapeutic tools for assisting patients who are dealing with grief. Reassurance about the normal pattern of grief and a commitment to supporting the patient in an ongoing way is the mainstay of care. It may involve scheduled follow-up visits as necessary. Within that context, the following aspects of management should be considered (refer to Table 1).

Table 1: Non-pharmaceutical management of grief

Acknowledgement of loss(es)	• Use whatever words are appropriate in the context of the relationship with the patient and family.
Education	• Normalize responses to loss, e.g., "you are not going crazy". • Discuss what to expect when grieving.
Lifestyle management	• Explore what is personally helpful to the patient, e.g., rest, exercise, social connections, spiritual support, home support, compassionate care benefits program.
Resources	• Refer to patient handout: *Appendix D: The Grief Journey*.

2. Pharmacological management

In general, there is a limited place for pharmacological management in normal grief. The physician must be alert to the possibility of underlying disease and incipient pathologic grief and treat accordingly, but it is unwise to interrupt the normal constituents of grief such as depressed mood, anxiety, insomnia and anger.

3. Other support

Other support options are patient and caregiver support groups, online support groups, spiritual care and/or faith based communities, and hospice/palliative care programs, including volunteer support. Refer patients for individual counselling when requested and appropriate. Refer to *Associated Document: Resource Guide for Patients and Caregivers*.

Bereavement

Bereavement includes the period of adjustment following a person's death and it encompasses many elements of grief, including prolonged grief disorder (complicated grief). Anticipate / screen for prolonged grief disorder (complicated grief) reactions and also consider using *Appendix E: Bereavement Risk Assessment Tool* to assess risk.

1. Risk factors for Prolonged Grief Disorder (complicated grief)[4]:

- co-morbidities: mental illness; cognitive impairment; substance abuse;
- concurrent stressors: significant other with life-threatening illness;
- circumstances around the death: perceived as preventable, sudden, unexpected, violent, traumatic or untimely; suicide;found/saw/identified the body; issues with death notification;
- lack of supports: social isolation, disenfranchised grief; cultural or language barriers; relationships: anger, ambivalence, resentment, attachment insecurity; high marital dependency;
- low social support; and
- being a spouse or parent of the deceased.

2. Assessment of bereavement (Refer to *Appendix F: Bereavement Algorithm)*

- The following tools may be useful in support of the ongoing physician patient relationship:
    - Issues with different ages, especially children (refer to *Appendix C: Children and Death*)
    - *Appendix E: Bereavement Risk Assessment Tool*
    - *Appendix F: Bereavement Algorithm*
    - *Appendix G: Guide to Bereavement Assessment and Support*
    - *Appendix H: Caregiver Questionnaire*

- **Timing for assessment of caregivers for bereavement / grief**
    - 2 – 8 weeks: assess for grief related depression (refer to *Appendix I: Distinguishing Grief and Depression*) and other health issues (e.g., sleep, nutrition).
    - 6 months: assess for prolonged grief disorder (complicated grief) if not already identified and treated.

- **Diagnosis of Prolonged Grief Disorder (complicated grief)**
    - Consider using the Prolonged Grief Disorder PG-13 diagnostic tool. Refer to *Associated Documents: Prolonged Grief Disorder (PG-13)* available online at the Center for Research on End of Life Care at Weill Cornell Medical College http://endoflife.weill.cornell.edu/sites/default/files/file_uploads/pg-13_self-report_wcm.pdf

- **Criteria for diagnosing Prolonged Grief Disorder (Complicated Grief)[1, 5, 6]**
  Yearning for the deceased must be experienced at least daily over the past month or to a distressing and disruptive degree, (i.e., intense and intrusive thoughts, unusual sleep disturbance, suicidal ideation), and the persistence for at least six months of five of the following nine symptoms:
    - difficulty moving on or reengaging with life;
    - numbness / detachment;
    - excessive bitterness or anger about the death;
    - feeling that life is empty;
    - a sense that the future holds no meaning without the deceased;
    - trouble accepting the death;
    - feeling stunned, dazed, or shocked by the loss;
    - avoiding reminders of the loss; and
    - difficulty trusting others since the loss; social withdrawal.

  These symptoms can cause marked dysfunction in social, occupational, self-care, or other important domains.

▸ Management of Bereavement (Refer to *Appendix F: Bereavement Algorithm)*

1. Non-pharmacological management

Table 2: Non-pharmacological management of bereavement

At time of death (or ASAP there-after)		• Personally contact the bereaved person / family. • Acknowledge the death and reactions including feelings such as guilt, relief, or shock. • Ascertain and address immediate concerns about care, the death, or the funeral. • Arrange for follow-up contact.
After death	***Self-management***	• Provide information about grief, i.e., what to expect and what is helpful (refer to *Appendix D: The Grief Journey (Patient Handout)*. • Provide information about local resources (e.g., bereavement groups, spiritual / religious supports, grief counsellors) and online resources (refer to *Associated Document: Resource Guide for Patients and Caregivers*). • Share *Appendix J: Be Gentle with Yourself (Patient Handout)*.
	Ongoing care contact	• Within 2 weeks, acknowledge, or contact family. • Contact again at 1–2 months, 6 months, and 11–12 months (anniversary of the death). • Recognize that holidays, birthdays, and wedding anniversaries are tough. • Be aware that the second year can also be difficult.

2. Pharmacological management

85% of grief in bereavement is normal grief, not requiring pharmacological management.[6, 7]

Table 3: Pharmacological management of bereavement

Benzodiazepines	• Benzodiazepines have a very limited role in the management of acute grief. • Refer to sleep hygiene resources. For example, Associated Documents: BCguidelines.ca – *Sleep Hygiene: A guide for patients*. • Melatonin is non-addictive and may be a helpful sleep aid for some patients. Melatonin is prescribed at a wide range of doses (0.1-10 mg at hs). 3-10 mg hs is commonly used in palliative care and geriatric settings.
Treating grief-related major depression: antidepressants	• Treat grief-related major depression once you are confident it is pathological. • If depression is suspected while a person is acutely grieving, start by recommending regular exercise, counselling, and supports. If symptoms are worse or not improving by 8 weeks post-death, start antidepressant medication (refer to BCguidelines.ca – *Major Depressive Disorder in Adults - Diagnosis and Management*).
Treating Prolonged Grief Disorder (complicated grief)	• Assess in the context of the person's life, personality, culture, and the nature of the illness/death. • Refer to a bereavement counsellor, psychologist, or psychiatrist who will provide targeted psychotherapy, Complicated Grief Treatment, in addition to possible pharmacologic management.

Resources

References

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These references were chosen to be helpful and do not form an exhaustive list:

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Appendices

- Appendix A – Adult Assessment of Grief Scale – Handout, ScoreSheet and Protocol
- Appendix B – Cultural Diversity and Individual Preferences
- Appendix C – Children and Death
- Appendix D – The Grief Journey (Patient Handout)
- Appendix E – Bereavement Risk Assessment Tool
- Appendix F – Bereavement Algorithm
- Appendix G – Guide to Bereavement Assessment and Support
- Appendix H – Caregiver Questionnaire
- Appendix I – Distinguishing Grief and Depression
- Appendix J – Be Gentle with Yourself (Patient Handout)

Associated Documents

- BCguidelines.ca – Palliative Care: Resource Guide for Patients and Caregivers
- BCguidelines.ca – Palliative Care: Resource Guide for Practitioners
- BCguidelines.ca – Sleep Hygiene: A Guide for Patients
  http://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/sleepcomp-pg.pdf
- The Prolonged Grief Disorder (PG-13) is available online at the Center for Research on End of Life Care at Weill Cornell Medical College. http://endoflife.weill.cornell.edu/sites/default/files/file_uploads/pg-13_self-report_wcm.pdf
  Additional Resources: http://endoflife.weill.cornell.edu/

This guideline is based on scientific evidence current as of the effective date.

This guideline was developed by the Family Practice Oncology Network and the Guidelines and Protocols Advisory Committee, approved by the British Columbia Medical Association, and adopted by the Medical Services Commission.

A mobile version of this and other guidelines is also available at www.BCGuidelines.ca

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Disclaimer

Appendix A: Adult Attitude to Grief Scale – Patient Handout

Adult Attitude to Grief scale
Indicate (tick) your response to the attitudes expressed in the following statements:

Adult Attitude to Grief scale	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree
1. I feel able to face the pain which comes with loss.					
2. For me, it is difficult to switch off thoughts about the person I have lost.					
3. I feel very aware of my inner strength when faced with grief.					
4. I believe that I must be brave in the face of loss.					
5. I feel that I will always carry the pain of grief with me.					
6. For me, it is important to keep my grief under control.					
7. Life has less meaning for me after this loss.					
8. I think its best just to get on with life and not dwell on this loss.*					
9. It may not always feel like it but I do believe that I will come through this experience of grief.					

Appendix A: Adult Attitude to Grief Scale – For Practitioners – Score Sheet and Practice Protocol

Date completed:		Time:
Completed by:		

R = Resilient (items 1,3,9), **C** = Controlled (items 4,6, 8), **O** = Overwhelmed (items 2,5,7)

	Adult Attitude to Grief scale	Strongly agree	Agree	Neither agree nor disagree	Disagree	Strongly disagree	Additional responses/ comments
1.	**R.** (Resilient) I feel able to face the pain which comes with loss.	0	1	2	3	4	
2.	**O.** (Overwhelmed) For me, it is difficult to switch off thoughts about the person I have lost.	4	3	2	1	0	
3.	**R.** (Resilient) I feel very aware of my inner strength when faced with grief.	0	1	2	3	4	
4.	**C.** (Controlled) I believe that I must be brave in the face of loss.	4	3	2	1	0	
5.	**O.** (Overwhelmed) I feel that I will always carry the pain of grief with me.	4	3	2	1	0	
6.	**C.** (Controlled) For me, it is important to keep my grief under control.	4	3	2	1	0	
7.	**O.** (Overwhelmed) Life has less meaning for me after this loss.	4	3	2	1	0	
8.	**C.** (Controlled) I think its best just to get on with life and not dwell on this loss.*	4	3	2	1	0	
9.	**R.** (Resilient) It may not always feel like it but I do believe that I will come through this experience of grief	0	1	2	3	4	
	Vulnerability Score (AAG score) = _____ (total score for the 9 items) Level of vulnerability identified = _____	Levels of vulnerability identified by the AAG score: Severe vulnerability > 24 High vulnerability 21–23 Low vulnerability <20					

Adapted and used with permission from Dr. Linda Machin. © Linda Machin 2010 (*modified 2013) (N.B. resilient scores reversed to permit a simple addition)
Machin L, Bartlam B, Bartlam R. Identifying levels of vulnerability in grief using the Adult Attitude to Grief Scale: from theory to practice. Bereavement Care. 2015 34:2, 59-68.

Using the Adult Attitude to Grief scale (AAG) – a practice protocol (© Linda Machin)

- The AAG can be used as a **standard** form of assessment within a service or used **selectively** i.e. where it is seen to be appropriate (by the practitioner).
- **Information for clients:**
    i) **explain** how the AAG is used in the service/by the practitioner and gain informed consent (see ii, iii, iv below).
    ii) **explain the purpose of the scale** i.e. to help client and practitioner have a clear picture of a client's grief.
    iii) **give a copy of the scale to the client;** explain the 5 choices associated with each item on the scale (from strong agreement to strong disagreement) and decide who will read out each statement.
    iv) **assure** the client that there are no right or wrong answers.
    v) when the scale is used - in addition to identifying levels of agreement/disagreement with the 9 items in the scale **encourage** the client to say more about each of the 9 statements to increase an understanding of their individual experience and perspective on grief.
- **The Vulnerability Indicator score** is to help the practitioner have an overview of the client's need for support. It is important **NOT to use a score / numbers sheet with clients** as this can convey a sense of being tested and may prevent honest responses.
- When the AAG has been completed discuss the responses to the scale with the client:
    i) ask **how the client felt** using the scale.
    ii) ask whether there were particular themes in the scale which stood out as being **significant or troubling** to them.
    iii) give feedback on any **evident bias** i.e. an overview of the tendency towards being overwhelmed, controlled or resilient.
    iv) give more detailed feedback, reflecting on where there seems to be **tension/contradictions** between the overwhelmed, controlled and resilient responses suggesting possible vulnerability e.g. where the desire to be in control and get on with life is undermined by strong emotions (evident where there is agreement with both item 2 and 8).
- **Use the evidence from the AAG responses:**
    i) at an initial assessment to determine **what kind of support** service is most appropriate for the client.
    ii) to enable the practitioner and the client, jointly, **set goals** for support / intervention.
    iii) as part of the help process, **to review** the client's changing grief reactions and responses.
    iv) as a tool **in supervision** i.e. as a guide to determine appropriate and effective therapeutic/support strategies.
    v) to evaluate the **outcome** of the client's grief at the end of support.

N.B. for correspondence or copies of: the AAG for use with clients; the Vulnerability Indicator score sheets; practice record sheets – contact Dr Linda Machin – l.machin@keele.ac.uk

Appendix B: Cultural Diversity and Individual Preferences

Considerations for cultural and individual patient preferences in grief/bereavement discussions:

- When a patient and physician enter into grief and bereavement discussions, each brings individual cultural backgrounds and values that influence the discussions.
- Although understanding cultural norms is important, physicians must be careful to avoid stereotyping patients based on their cultures.
- An individual's culture is influenced by the culture of the family, religion, spirituality, education, occupation, social class, friends, and personal preferences.
- Asking open-ended questions can elicit a patient's preferences for physician frankness, decision making, and direct versus indirect communication.
- Physicians may prevent misunderstanding and promote trust by respectfully listening to a patient's beliefs and values.
- Assess individual preferences and tailor discussions appropriately.
- Consider a patient's sex, age, health literacy, health status, previous health care experiences, social status, culture, and race/ethnicity.
- Avoid assumptions about what the patient is likely to want and ask directly about values and preferences.

Useful Questions to Help Determine Preferences:

Factors	Useful questions	Rationale
Social, educational, and family factors	• "Tell me about your family" • "Have you or your family had significant experience with someone who has had a serious illness or who has died? If so, how did that experience affect you?"	• The physician may offend or stereotype the patient because of incorrect assumptions if he/she does not ask about the patient's background. • Misunderstandings between physician and patient may occur if social, educational, and family preferences are not assessed.
Cultural, religious, and spiritual factors	• "Is there anything I should know about your cultural, religious or spiritual views about illness or life and death?"	• The physician may be regarded as disrespectful if the patient's cultural, religious, and spiritual preferences are not addressed. • The patient may reject medical advice if the physician does not understand how the patient views the physician's role and advice in the context of culture, religion, or spirituality.

Adapted from: Ngo-Metzger Q, August KJ, Srinivasan M, et al. End-of-life care: Guidelines for patient-centered communication. Am Fam Physician. 2008;77(2):167-74.

Appendix C: Children and Death

Age	Developmental State/Task	Concept of Death	Grief Response	Signs of Distress	Possible Interventions
2–4	• Egocentric: believes world centres around them. • Narcissistic: No cognitive understanding. • Preconceptual: unable to grasp concepts.	• Seen as abandonment. • Seen as reversible, not permanent. • Common statements: "Did you know my daddy died – when will he be home?	• Intensive response, but brief. • Very present oriented. • Most aware of altered patterns of care.	• Regression: sleeping and eating disorders – bedwetting.	• Short interactions. • Frequent repetition. • Comforting. • Touching.
4–7	• Gaining sense of autonomy. Exploring world outside of self. • Gaining language. • Fantasy thinking/ wishing. Initiative stage seeing self as initiator. • Concerns of guilt.	• Death still seen as reversible. • Great personification of death. • Feelings of responsibility because of wishes, thoughts. • Common statements: "It's my fault; I was mad at her and wished she'd die."	• Verbalization. • Great concerns with process. • How? Why? • Repetitive questioning.	• Regression: nightmares, sleeping and eating disturbances, violent play. • Attempts to take on role of person who died.	• Symbolic play. • Drawing / stories. • Allow / encourage expression of energy / feelings about anger. • Talk about it.
7–11*	• Concrete – operational. • Industry versus inferiority. • Beginning of socialization. • Development of cognitive ability. • Beginning of logical thinking.	• Death as punishment. • Fear of bodily harm; mutilation. • This is a difficult transition period – still wants to see death as reversible but beginning to see it as final.	• Specific questioning. • Desire for complete detail. • Concerned with how others are responding. • What is the right way? • How should they be responding? • Starting to have ability to mourn and understand mourning.	• Regression: problems at school, withdrawn from friends. • Sleeping and eating disturbances. • Overwhelming concern with body. • Suicidal thoughts (desire to join the one who died). • Role confusion.	• Answer questions. • Encourage expression of range of feelings. • Encourage/allow control. • Be available but allow alone time. • Symbolic play. • Talk about it.
11–18*	• Formal operation problem solving. • Abstract thinking. • Integration of one's own personality.	• "Adult" approach. • Ability to abstract. • Beginning to truly conceptualize death. • Work at making sense of teachings.	• Depression. • Denial. • Regression: more often willing to talk to people outside of family. • Traditional mourning.	• Depression. • Anger. • Anger towards parents. • Non- compliance. • Rejection of former teaching. • Role confusion. • Acting out.	• Encourage verbalization. • Do not take control. • Encourage self-motivation. • Listen. • Be available. • Do not attempt to take away grief.

*it is during these 2 age / stages that most children / young adults struggle with their own body image issues, they also seem to struggle the most with changing body images of illness and death. It is important to prepare them in advance about what they may see and then allow them to verbalize their feelings about what they saw.

Appendix D: 'The Grief Journey' (Patient Handout)

The Grief Journey		
When a death occurs	**Adjusting to loss**	**As life goes on**
SOCIAL • Withdrawal from others • Unrealistic expectation of self and others • Poor judgment about relationships	**SOCIAL** • Rushing into new relationships • Wanting company but unable to ask • Continued withdrawal and isolation • Self-consciousness	**SOCIAL** • More interest in daily affairs of self / others • Ability to reach out and meet others • Energy for social visits and events
PHYSICAL • Shortness of breath and palpitations • Digestive upsets • Low energy, weakness, and restlessness	**PHYSICAL** • Changes in appetite and sleep patterns • Shortness of breath and palpitations • Digestive upsets	**PHYSICAL** • Physical symptoms subside • Sleep pattern and appetites are more settled • Gut-wrenching emptiness lightens
EMOTIONAL • Crying, sobbing, and wailing • Indifference and emptiness • Outrage and helplessness	**EMOTIONAL** • Intense and conflicting emotions • Magnified fear for self or others • Anger, sadness, guilt, depression	**EMOTIONAL** • Emotions are less intense • Feeling of coming out of the fog • More peace; less guilt
MENTAL • Confusion, forgetfulness, and poor concentration • Denial and daydreaming • Constant thoughts about the person who died and/or the death	**MENTAL** • Sense of going crazy • Memory problems • Difficulty concentrating/understanding • Wild dreams or nightmares	**MENTAL** • Increased perspective about the death • Ability to remember with less pain • Improved concentration and memory • Dreams and nightmares decrease
SPIRITUAL • Blaming God or life • Lack of meaning, direction, or hope • Wanting to die or join the person who died	**SPIRITUAL** • Trying to contact the person who died • Sensing the presence of the person who died; visitations • Continued lack of meaning	**SPIRITUAL** • Reconnection with religious / spiritual beliefs • Life has new meaning and purpose • Acceptance of death as part of life cycle
WHAT HELPS • Pace yourself moment to moment • Make no unnecessary changes • Talk about the person and the death • Identify and access practical and emotional supports	**WHAT HELPS** • Recognize and express emotions • Acknowledge changes • Understand grief and know that others • experience similar responses	**WHAT HELPS** • Reflect on progress since death • Begin envisioning a future • Engage in new activities • Establish new roles and relationships

Adapted from "The Grief Journey"; Victoria Hospice Society.

If you have ongoing concerns, please contact _____

Appendix E: Bereavement Risk Assessment Tool

Assessment Date	Assessed by	ID#	Patient / Deceased Name	Bereaved Name

Risk Indicators and Protective Factors

Comments

I. Kinship

- ☐ a) spouse/partner of patient or deceased
- ☐ b) parent/parental figure of patient or deceased

II Caregiver

- ☐ a) family member or friend who has taken primary responsibility for care

III. Mental Health

- ☐ a) significant mental illness (eg major depression, schizophrenia, anxiety disorder)
- ☐ b) significant mental disability (eg developmental, dementia, stroke, head injury)

IV. Coping

- ☐ a) substance abuse / addiction (specify)
- ☐ b) considered suicide (no plan, no previous attempt)
- ☐ c) has suicide plan and a means to carry it out OR has made previous attempt
- ☐ d) self-expressed concerns regarding own coping, now or in future
- ☐ e) heightened emotional states (anger, guilt, anxiety) as typical response to stressors
- ☐ f) yearning/pining for the deceased OR persistent disturbing thoughts/images > 3 months*
- ☐ g) declines available resources or support
- ☐ h) inability to experience grief feelings or acknowledge reality of the death > 3 months*

V. Spirituality / Religion

- ☐ significant challenge to fundamental beliefs / loss of meaning or faith / spiritual distress

VI. Concurrent Stressors

- ☐ a) two or more competing demands (eg single parenting, work, other caregiving)
- ☐ b) insufficient financial, practical or physical resources (eg ↓ income, no childcare, illness)
- ☐ c) recent non-death losses (eg divorce, unemployment, moving, retirement)
- ☐ d) significant other with life-threatening illness / injury (other than patient/deceased)

VII. Previous Bereavements

- ☐ a) unresolved previous bereavement(s)
- ☐ b) death of other significant person within 1 year (from time of patient's death)
- ☐ c) cumulative grief from > 2 OTHER deaths over past 3 years
- ☐ d) death or loss of parent/parental figure during own childhood (less than age 19)

VIII. Supports & Relationships

- ☐ a) lack of social support/social isolation (perceived or real - eg housebound)
- ☐ b) cultural or language barriers to support
- ☐ c) longstanding or current discordant relationship(s) within the family
- ☐ d) relationship with patient/deceased (eg abuse, dependency)

IX. Children & Youth

- ☐ a) death of parent, parental figure or sibling*
- ☐ b) demonstration of extreme, ongoing behaviours/symptoms (eg sep anxiety+, nightmares)
- ☐ c) parent expresses concern regarding his/her ability to support child's grief
- ☐ d) parent/parental figure significantly compromised by his/her own grief

X. Circumstances Involving the Patient, the Care or the Death

- ☐ a) patient/deceased less than age 35
- ☐ b) lack of preparedness for the death (as perceived or demonstrated by bereaved)*
- ☐ c) distress witnessing the death OR death perceived as preventable*
- ☐ d) violent, traumatic OR unexplained death (eg accident, suicide, unknown cause)*
- ☐ e) significant anger with OTHER health care providers (eg "my GP missed the diagnosis")
- ☐ f) significant anger with OUR hospice palliative care program (eg "you killed my wife")

XI. Protective Factors Supporting Positive Bereavement Outcome

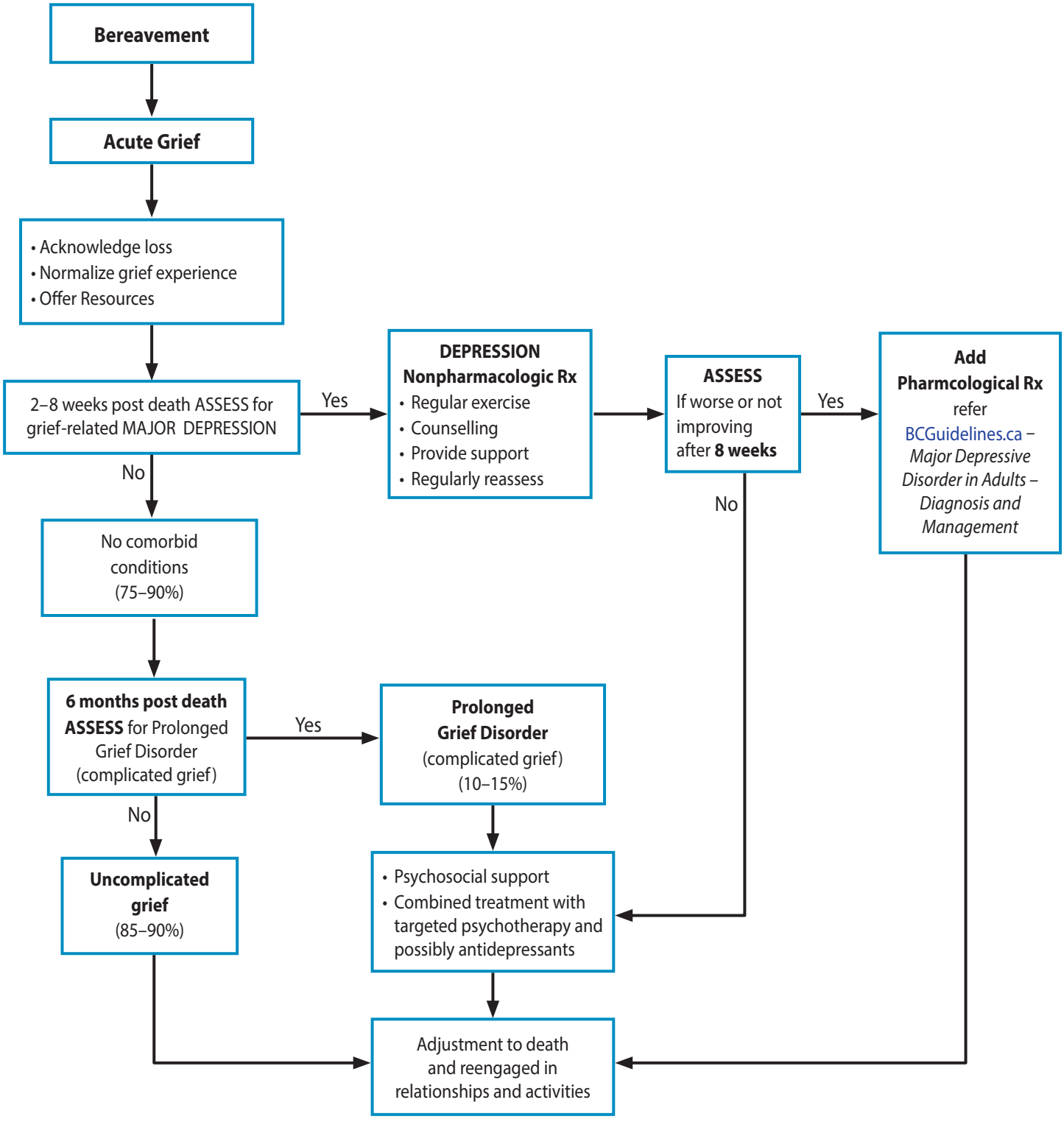
- ☐ a) internalized belief in own ability to cope effectively
- ☐ b) perceives AND is willing to access strong social support network
- ☐ c) predisposed to high level of optimism/positive state of mind
- ☐ d) spiritual/religious beliefs that assist in coping with the death

* this indicator can only be identified after the death

Aug-08

More information on this tool is available at: www.victoriahospice.org/health-professionals/clinical-tools

Appendix F: Bereavement Algorithm



Appendix G: Guide to Bereavement Assessment and Support

What you might hear/see	Risk Factors	What else helps
Ability to Cope		
Concerns re: identify, future	Partner, parent, or care provider of the deceased	Reframe/encourage, refer (hospice, seniors, support services), give homework: explore meaning of loss/what brings purpose to life. Review lifestyle factors.
Lack of comprehension or expected reactions	Mental illness/disability or depression	Mental health/depression protocol
Ongoing struggle with activities of daily living, concern about coping	History of unhelpful coping strategies (e.g., substance abuse, declines support/resources)	Explore history / context of coping and person's perspective, give homework: ask about sleep/ eating routines
A plan / the means to complete suicide, previous attempts	Suicidal ideation	Suicide protocol, refer to mental health/ community resources
Grief Reactions		
Ongoing heightened reaction(s) (e.g., pining, hopelessness, anger, guilt)	Inability > 6 months to address/work through emotional responses to death	Refer for counselling/therapy, give homework: identify triggers
Ongoing disbelief, denial of death or lack of reaction	Inability to experience grief or acknowledge reality of death	Explore cause(s), refer for bereavement counselling. Ask how death has impacted the person
Ongoing anger / disconnection with beliefs, God, meaning	Spiritual / religious angst	Encourage connection with faith community, spiritual advisor
Other Stressors		
Concerns about finances, children, work	Competing demands; limited practical resources	Explore options, recommend practical help, give homework: ask how person/ family are impacted financially
Loss of job, divorce, home	Other multiple losses	Explore impact of multiple griefs, normalize reactions
Confused, overwhelmed, loss of sense of 'self'	Cumulative grief, recent multiple/unresolved deaths; significant childhood death(s)	Normalize and acknowledge enormity/ impact of grief, refer for therapy/counselling
Supports		
Isolation, concern no one cares or understands them	Perceived lack of support including language/ cultural barriers; disenfranchised grief	Acknowledge perceptions; reframe, support social connections, give homework: explore what support feels helpful and who (might) provide this
Relationships		
Unresolved family tensions/issues re: care, death, estate or relationships (e.g., abuse)	Longstanding or current discordant relationships in family (including with deceased)	Explore possibility of resolution; support mediation/ advice, refer for family therapy/counselling
Anger, distrust of health care provider(s) (regarding diagnosis, care, system)	Negative perceptions/circumstances of care	Be open, non-defensive, support appropriate follow up.
The Death		
Concerns re: sudden, distressing, violent, untimely nature of death; extreme blame, fear, guilt, anger	Negative circumstances and trauma connected to the death	Invite the person to review the death/fill in any gaps or areas of misinformation, be factual, explore present/future issues and impact, refer for counselling
Listen & Be Present	**Explore & Acknowledge**	**Normalize & Follow Up**

Adapted from the Bereavement Risk Assessment Tool, © 2008 Victoria Hospice Society.
* Refer also to: Palliative Care Part 3, Table 2: Non-pharmacological Management of Bereavement"

Appendix H: Caregiver Questionnaire

Please CIRCLE a number from 1–5 to indicate your choice:

1. Do/did you feel overwhelmed by providing care?

Not at all	Somewhat	More often	Most often	All of the time
1	2	3	4	5

2. Do you feel isolated from family and friends?

Not at all	Somewhat	More often	Most often	All of the time
1	2	3	4	5

3. Are you worried about your ability to cope now or later?

Not at all	Somewhat	More often	Most often	All of the time
1	2	3	4	5

4. Are you feeling sad or depressed?

Not at all	Somewhat	More often	Most often	All of the time
1	2	3	4	5

5. Alcohol intake: _____ (drinks per day / week)

6. Exercise: _____ (sessions / week)

7. Sleep Change: Yes ☐ No ☐

8. Eating: More ☐ Less ☐

9. What changes have occurred in your life due to personal loss?

Source: Family Practice Oncology Network

Appendix I: Distinguishing Grief and Depression

Feeling	Grief	Depression
Mood states	• Greater range of moods and feelings • Quick shifts from sadness to normal state in the same day • Variability in mood, activity, communication, appetite, and sexual interest in the same week	• Moods and feelings are more static, little variability • Consistent sense of depletion, psychomotor retardation, anorexia, and/or decreased sexual interest or compulsive communication, eating, and/or sexual behavior
Expression of anger	• Open, externally directed	• Absence of externally directed anger, internally directed
Expression of sadness	• Weeping	• Difficulty weeping or controlling weeping
Self-concept	• Guilt associated with specific aspects of the loss • Experience the world as empty • Preoccupation with the loss	• The loss confirms the person is bad or worthless • Focus on punitive thoughts, guilt has global aspect • Preoccupation with self
Responsiveness	• Periodic • Want solitude but respond to warmth and involvement	• Static • Fear of being alone or unresponsiveness to others
Pleasure	• Periodic • Want solitude but respond to warmth and involvement	• Restrict all pleasure • Loss of sense of humour
Reaction to others	• Others want to offer support	• Others often feel irritated • Rarely feel like reaching out

Content adapted from the Victoria Hospice Society.

Appendix J: Be Gentle with Yourself (Patient Handout)

Thoughts on Coping with Loss

Grief is a process that takes time, patience, and understanding. There are, however, some things you can do to take some control during this painful time. Your physical health is often the easiest place to begin.

Start by:

- Reducing alcohol, caffeine and sugar intake.
- Drinking enough water each day.
- Eating a healthy diet.
- Getting as much rest as you can.
- Learning to say no to things you don't have energy to do.
- Believing in yourself and your ability to adjust to your loss.
- Participating in some form of physical activity each day.
- Allowing yourself time to mourn.
- Not isolating yourself, i.e., share your pain with a compassionate person or find a counsellor with experience in grief and loss.
- Nurturing yourself, i.e., use art, poetry, meditation, music, journaling, massage, or anything that makes you feel good.
- Talking about your grief, i.e., try to give your sorrow words or write them in a journal. It is healthy to share your memories both happy and sad with people who care.

Additional thoughts

- We have tears for a purpose. Some scientists believe that crying is important to our bodies to relieve the toxins that build up from stress and emotional pain. When we repress our tears it can lead to illness. However it works, experience tells us that crying is healing. If you don't feel comfortable crying in the presence of others, allow time to cry alone. It will relieve the pressure and help you to control your grief in social settings.
- You are the best authority on your grief. Well meaning friends may try to help by keeping you busy or making sure you are never alone. It is important for you to determine for yourself what is best.
- Spend time with people you trust. Try not to isolate yourself with your feelings. Friends who do not judge your behaviour, who allow you to talk about your grief, and who accept your feelings are invaluable.
- Recognize your physical and psychological limitations. Most people experience fatigue during grief. Don't hesitate to excuse yourself from commitments you feel too tired or sad to attend. Avoid situations you believe may cause you stress or anxiety, instead allow time for simple activities that sooth and relax and provide creative outlets of your own choosing. Allow yourself to just 'be'.
- Use all resources that are available to you. If you have a faith or religion that gives you comfort, this is a time to depend on it. Sharing feelings with others, even strangers, who have had similar experiences can give perspective and assure you that you will survive. Grief counselling in groups or individually can assist you in understanding your grief and help you to cope with its manifestations.

Above all, BE GENTLE WITH YOURSELF

Source: Living through Loss Counselling Society of BC, adapted May 10, 2010.