

GUIDELINES & PROTOCOLS

ADVISORY COMMITTEE

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

Effective Date: September 30, 2011

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)

Working 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

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.

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.

Grief

A. Assessment of grief

- Consider using the distress screening tool (refer Appendix A - Screening Tools for Measuring Distress) to ascertain the degree of psychosocial, spiritual, and physical distress. This is best given to the patient to be filled out while waiting to be seen. Scores of 5+ on the distress thermometer are significant and the problem checklist provides valuable assessment information.
- 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 Appendix B - Cultural Diversity and Individual Preferences) and be aware of age differences (refer Appendix C - Children and Death).

Palliative Care Part 1: Approach to Care is available at www.bcguidelines.ca/guideline_palliative1.html

Palliative Care Part 2: Pain and Symptom Management is available at www.bcguidelines.ca/guideline_palliative2.html

B. Management of grief

- a. **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 a scheduled follow-up visit as necessary. Within that context, the following aspects of management should be considered.

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. Patient handout: Normal Manifestations of Grief (refer Appendix D).
Education	<ul style="list-style-type: none">• Normalize responses to loss, e.g., “you are not going crazy”.• Discuss what to expect when grieving.
Lifestyle management	<ul style="list-style-type: none">• Explore what is personally helpful to the patient, e.g., rest, exercise, social connections, spiritual support, home support, compassionate care benefits program.
Resources	Patient handout: Normal Manifestations of Grief (refer Appendix D).

- b. **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.
- c. Other supports: Other support options are patient and caregiver support groups, on-line support groups, spiritual care and/or faith based communities, and hospice/palliative care programs including volunteer support. Refer for individual counselling when requested and appropriate.

Bereavement

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

A. Risk factors for complicated grief in bereavement

- Co-morbidities: mental illness; cognitive impairment; substance abuse.
- Concurrent stressors: multiple losses; significant other with life-threatening illness.
- Circumstances around the death: received as preventable; sudden, unexpected, traumatic or untimely.
- Lack of Supports: social isolation; disenfranchised grief; cultural or language barriers.
- Relationships: anger; ambivalence; resentment; insecurity.

B. Assessment of bereavement (Refer 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 Appendix C - Children and Death).
 - Bereavement Risk Assessment Tool (refer Appendix E).
 - Bereavement Algorithm (refer Appendix F).
 - Guide to Bereavement Assessment and Support (refer Appendix G).
 - Caregiver Questionnaire (refer Appendix H).
- Timing for assessment of caregivers for bereavement / grief
 - 2 – 8 weeks: assess for grief related depression (refer Appendix I – Distinguishing Grief and Depression) and other health issues (eg. sleep, nutrition)
 - 6 months: assess for complicated grief if not already identified and treated.
- Criteria for Diagnosing Complicated Grief
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 four of the following eight 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
- being on edge or agitated
- difficulty trusting others since the loss; social withdrawal

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

C. Management of bereavement (refer Appendix F - Bereavement Algorithm)

a. Non-pharmacological

TABLE 2: Non-pharmacological Management of Bereavement

At time of death (or ASAP there-after)	<ul style="list-style-type: none"> • 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	<ul style="list-style-type: none"> • Provide information about grief, i.e., what to expect and what is helpful (refer Appendix D - Normal Manifestations of Grief (Patient Handout). • Provide information about local resources (e.g., bereavement groups, spiritual / religious supports, grief counsellors) and online resources (refer Appendix J - Grief and Bereavement Guideline Resource Links (Patient Handout)). • Share Be Gentle with Yourself (Patient Handout - refer Appendix K).
	Ongoing care contact	<ul style="list-style-type: none"> • 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.

b. Pharmacological Management

85% of grief in bereavement is normal grief, not requiring pharmacological management.^{1,2}

TABLE 3: Pharmacological Management of Bereavement

Benzodiazepines	<ul style="list-style-type: none"> • Benzodiazepines have a very limited role in the management of acute grief.
Treating grief-related major depression: antidepressants	<ul style="list-style-type: none"> • 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 Depression – Diagnosis and Management at BCGuidelines.ca).
Treating complicated grief	<ul style="list-style-type: none"> • 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 (CGT), in addition to possible pharmacologic management.

Rationale

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.

Grief and bereavement services should be available to all patients and families based on assessed needs. 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 Aboriginal 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. In the case of complicated grief, assess early and refer, realizing that a primary care provider needs to continue to play a key role on the team.

"There's no way around grief and loss: you can dodge all you want, but sooner or later you just have to go through it, and, hopefully come out the other side. The world you find there will never be the same as the world you left." – Johnny Cash

Useful References

1. Zhang B, El-Jawahri A, Prigerson H. Update on bereavement research: Evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *J Palliat Med.* 2006;9(5):1188-1203.
2. Zisook S, Shear K. Grief and bereavement: what psychiatrists need to know. *World Psychiatry.* 2009;8:67-74.
3. National Consensus Project for Quality Palliative Care. Clinical practice guidelines for quality palliative care, 2nd edition [homepage on the Internet]. c2009. Available from: <http://www.nationalconsensusproject.org/guideline.pdf>
4. Victoria Hospice Society, Cairns M, Thompson M, Wainwright W. Transitions in dying and bereavement: A psychosocial guide for hospice and palliative care. Baltimore: Health Professions Press; 2003.
5. Downing GM, Wainwright W, editors. Medical care of the dying. 4th Edition. Victoria: Victoria Hospice Society, 2006; p. 641-668.
6. Dyson T, Statton MA, Sutherland L. Psychosocial care. Hospice Palliative Care symptom guidelines. Fraser Health [homepage on the Internet]. c2009. Available from: www.fraserhealth.ca/media/psychosocial%20care.pdf
7. Holland JC, Andersen B, Breitbart BS, et al. Distress management. *J Natl Compr Canc Netw* 2010;8:448-85. Available from: www.jnccn.org/content/8/4/448.full
8. Kearney MK, Weininger RB, Vachon ML, et al. Self-care of physicians caring for patients at the end of life: "Being connected... a key to my survival". *JAMA.* 2009;301(11):1156-64, E1.
9. Prigerson HG, Jacobs SC. Perspectives on care at the close of life. Caring for bereaved patients: "all the doctors just suddenly go". *JAMA.* 2001;286(11):1369-76.
10. 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.
11. Zhang B, El-Jawahri BS, Prigerson H. Update on bereavement research: evidence-based guidelines for the diagnosis and treatment of complicated bereavement. *J of Palliat Med.* 2006;9(5):1188-1203.
12. Shear K, Frank E, Houck PR, et al. Treatment of complicated grief: a randomized controlled trial. *JAMA.* 2005; 293(21):2601-2608.
13. Stroebe MS, Hansson RO, Stoebe W, et al (Editors). *Handbook of Bereavement Research and Practice: Advances in Theory and Intervention.* Washington DC: American Psychological Association; 2008.

Resources

- BC Association of Clinical Counsellors (BCACC): www.bc-counsellors.org
(Toll free) 1-800-909-6303, (Victoria) 250-595-4448
- BC Bereavement Helpline (BCBH): www.bcbereavementhelpline.com/
(Toll free) 1-877-779-2223, (Lower Mainland) 604-738-9950
- British Columbia Hospice Palliative Care Association: www.hospicebc.org
(Toll free) 1-877-410-6279, (Lower Mainland) 604-267-7024
- Community Healthcare and Resource Directory (CHARD): <http://info.chardbc.ca/faq.asp>
(Toll free) 1-877-330-7322, (Lower Mainland) 604-215-7109
- General Practice Services Committee (GPSC) – Palliative Care Initiative:
www.gpsc.bc.ca/family-practice-incentive/palliative-care-initiative
- Employment Insurance Compassionate Care Benefits program:
www.servicecanada.gc.ca/eng/sc/ei/benefits/compassionate.shtml
- Lower Mainland Grief Recovery Society: www.lmgr.ca/index.htm
(Lower Mainland) 604-643-9637
- Victoria Hospice: www.victoriahospice.org
250-370-8715 (24 hours)
- Physician Health Program British Columbia: www.physicianhealth.com/
1-800-663-6729 (24/7)

Appendices

- Appendix A – Screening Tools for Measuring Distress
- Appendix B – Cultural Diversity and Individual Preferences
- Appendix C – Children and Death
- Appendix D – Normal Manifestations of Grief (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 – Grief and Bereavement Guideline Resource Links (Patient Handout)
- Appendix K – Be Gentle with Yourself (Patient Handout)

Associated Documents

Family Practice Oncology Network

The FPON has developed additional appendices including sections on communicating bad news and evidenced based recommendations regarding preserving patient hope. These appendices can be found at www.bccancer.bc.ca/HPI/FPON/Guidelines+and+Protocols.htm

This guideline is based on scientific evidence current as of the Effective Date.

The guideline was developed by the Family Practice Oncology Network and the Guidelines and Protocols Advisory Committee. The guideline was 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

The principles of the Guidelines and Protocols Advisory Committee are to:

- encourage appropriate responses to common medical situations
- recommend actions that are sufficient and efficient, neither excessive nor deficient
- permit exceptions when justified by clinical circumstances

Contact Information

Guidelines and Protocols Advisory Committee
PO Box 9642 STN PROV GOVT
Victoria BC V8W 9P1
E-mail: hlth.guidelines@gov.bc.ca
Web site: www.BCGuidelines.ca

DISCLAIMER

The Clinical Practice Guidelines (the "Guidelines") have been developed by the Guidelines and Protocols Advisory Committee on behalf of the Medical Services Commission. The Guidelines are intended to give an understanding of a clinical problem and outline one or more preferred approaches to the investigation and management of the problem. The Guidelines are not intended as a substitute for the advice or professional judgment of a health care professional, nor are they intended to be the only approach to the management of clinical problems. **We cannot respond to patients or patient advocates requesting advice on issues related to medical conditions. If you need medical advice, please contact a health care professional.**

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?”	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 centers 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.

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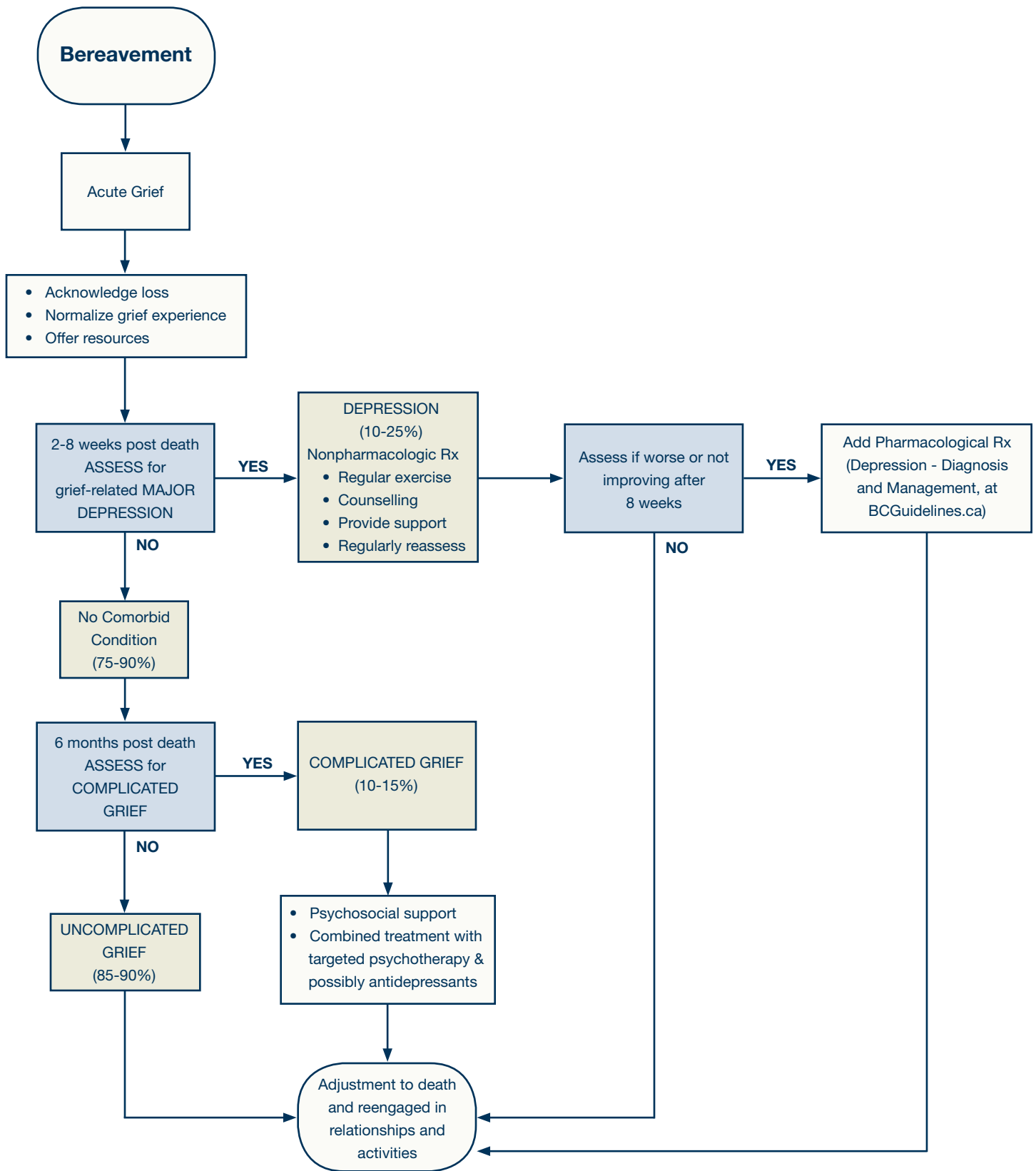
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Appendix D: Normal Manifestations of Grief (Patient Handout)

THE GRIEF JOURNEY		
<i>When a death occurs</i>	<i>Adjusting to loss</i>	<i>As life goes on</i>
<p>SOCIAL</p> <ul style="list-style-type: none"> Withdrawal from others Unrealistic expectations of self and others Poor judgment about relationships 	<p>SOCIAL</p> <ul style="list-style-type: none"> Rushing into new relationships Wanting company but unable to ask Continued withdrawal and isolation Self-consciousness 	<p>SOCIAL</p> <ul style="list-style-type: none"> More interest in daily affairs of self / others Ability to reach out and meet others Energy for social visits and events
<p>PHYSICAL</p> <ul style="list-style-type: none"> Shortness of breath and palpitations Digestive upsets Low energy, weakness, and restlessness 	<p>PHYSICAL</p> <ul style="list-style-type: none"> Changes in appetite and sleep patterns Shortness of breath and palpitations Digestive upsets 	<p>PHYSICAL</p> <ul style="list-style-type: none"> Physical symptoms subside Sleep pattern and appetites are more settled Gut-wrenching emptiness lightens
<p>EMOTIONAL</p> <ul style="list-style-type: none"> Crying, sobbing, and wailing Indifference and emptiness Outrage and helplessness 	<p>EMOTIONAL</p> <ul style="list-style-type: none"> Intense and conflicting emotions Magnified fear for self or others Anger, sadness, guilt, depression 	<p>EMOTIONAL</p> <ul style="list-style-type: none"> Emotions are less intense Feeling of coming out of the fog More peace; less guilt
<p>MENTAL</p> <ul style="list-style-type: none"> Confusion, forgetfulness, and poor concentration Denial and daydreaming Constant thoughts about the person who died and/or the death 	<p>MENTAL</p> <ul style="list-style-type: none"> Sense of going crazy Memory problems Difficulty concentrating/understanding Wild dreams or nightmares 	<p>MENTAL</p> <ul style="list-style-type: none"> Increased perspective about the death Ability to remember with less pain Improved concentration and memory Dreams and nightmares decrease
<p>SPIRITUAL</p> <ul style="list-style-type: none"> Blaming God or life Lack of meaning, direction, or hope Wanting to die or join the person who died 	<p>SPIRITUAL</p> <ul style="list-style-type: none"> Trying to contact the person who died Sensing the presence of the person who died; visitations Continued lack of meaning 	<p>SPIRITUAL</p> <ul style="list-style-type: none"> Reconnection with religious / spiritual beliefs Life has new meaning and purpose Acceptance of death as part of life cycle
<p>WHAT HELPS</p> <ul style="list-style-type: none"> Pace yourself moment to moment Make no unnecessary changes Talk about the person and the death Use practical and emotional supports 	<p>WHAT HELPS</p> <ul style="list-style-type: none"> Recognize and express emotions Acknowledge changes Understand grief and know that others experience similar responses 	<p>WHAT HELPS</p> <ul style="list-style-type: none"> 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.

Appendix F: Bereavement Algorithm



Source: Family Practice Oncology Network

Appendix G: Guide to Bereavement Assessment and Support

WHAT YOU MIGHT HEAR / SEE	RISK FACTORS	WHAT ELSE HELPS
Ability to Cope		
Concerns re: identity, future	Partner, parent, or care provider of deceased	Reframe / encourage, refer (hospice, seniors, support services)
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*
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	Explore cause(s), expression and impact, refer for counselling / therapy, give homework*
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
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*
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)	Identify 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*
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, give homework*
The Death		
Concerns re: sudden, distressing, violent, untimely nature of death; extreme blame, fear, guilt, anger	Negative circumstances and trauma connected to the death	Review the death, 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 to examples of homework in grieving: Palliative Care Part 3, Section B, Table 1: Non-pharmaceutical Management of Grief

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 changes: 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	<ul style="list-style-type: none"> 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 	<ul style="list-style-type: none"> 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 behaviour
Expression of anger	<ul style="list-style-type: none"> Open, externally directed 	<ul style="list-style-type: none"> Absence of externally directed anger, internally directed
Expression of sadness	<ul style="list-style-type: none"> Weeping 	<ul style="list-style-type: none"> Difficulty weeping or controlling weeping
Self-concept	<ul style="list-style-type: none"> Guilt associated with specific aspects of the loss Experience the world as empty Preoccupation with the loss 	<ul style="list-style-type: none"> The loss confirms the person is bad or worthless Focus on punitive thoughts, guilt has global aspect Preoccupation with self
Responsiveness	<ul style="list-style-type: none"> Periodic Want solitude but respond to warmth and involvement 	<ul style="list-style-type: none"> Static Fear of being alone or unresponsiveness to others
Pleasure	<ul style="list-style-type: none"> Periodic Want solitude but respond to warmth and involvement 	<ul style="list-style-type: none"> Restrict all pleasure Loss of sense of humour
Reaction to others	<ul style="list-style-type: none"> Others want to offer support 	<ul style="list-style-type: none"> Others often feel irritated Rarely feel like reaching out

Content adapted from the Victoria Hospice Society.

Appendix J: Grief and Bereavement Guideline Resource Links (Patient Handout)

- **BC Bereavement Helpline:** www.bcbereavementhelpline.com
Dial: 604-738-9950, (Toll Free) 1-877-779-2223
The BC Bereavement Helpline (BCBH) is a non-profit free, and confidential service that connects the public to grief support services within the province of BC. Services include: helpline for referral and support, community network of support and information, brochures of available support in BC, e.g., “Ten Things to Know about Grief” (available in many different languages) and “5 Tips to Help the Grieving”.
- **BC Cancer Agency:** www.bccancer.bc.ca
Multiple experiences of loss and grief happen throughout the cancer experience, from diagnosis to treatment to post-treatment. The loss may be temporary or permanent, life-altering, or a minor inconvenience. The following pages provide some information on grief and loss in the context of cancer, as well as support services available: www.bccancer.bc.ca/PPI/copingwithcancer/emotional/dealingemotions/lossgrief.htm
- **BC Children’s Hospital:** www.bcchildrens.ca
For those who may be grieving the loss of a child, a brother or sister, another family member, or a friend who are looking for grief support resources and information: www.bcchildrens.ca/YourVisit/Familyservices/GriefAndLoss/default.htm
- **BC Hospice Palliative Care Association (BCHPCA):** www.hospicebc.org
Dial: 604-267-7024, (Toll Free) 1-877-410-6297
BCHPCA’s vision is that all people in BC and the Yukon have access to quality end-of-life care. Their mission is to build capacity in communities to support this vision. The following link leads you to a directory of hospices and hospice societies: www.hospicebc.org/membership/our-program-members . There are also many excellent books that cover a wide range of topics related to dying, death and bereavement: www.hospicebc.org/research-education/books . Check with your local library or book store.
- **Canadian Virtual Hospice:** www.virtualhospice.ca
The Canadian Virtual Hospice provides support and personalized information about palliative and end-of-life care to patients, family members, health care providers, researchers, and educators:
www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Emotional+Health/Grief+Work.aspx
- **Suicide Attempt Follow-up, Education and Research (SAFER):** <http://youthinbc.com/safer/>
Dial: 604-675-3985
Works to reduce suicide risk among those in crisis, to assist family and friends who care about them, and to promote healing among those bereaved by suicide. Also available for family physicians to consult.
- **Victoria Hospice:** www.victoriahospice.org
Victoria Hospice’s commitment to care continues through bereavement education, resource materials, and services, including several excellent brochures: www.victoriahospice.org/about-us/publications#bereave

Appendix K: 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.*