



# B.C. INTER-PROFESSIONAL PALLIATIVE SYMPTOM MANAGEMENT GUIDELINES

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# NURTURING PSYCHOSOCIAL AND SPIRITUAL WELL-BEING

## INTRODUCTION

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Throughout the development process of the B.C. Inter-professional Palliative Symptom Management Guidelines<sup>1</sup>, the First Nations perspective on health and wellness was the lens through which health was viewed. This perspective takes a holistic view and considers wellness in all facets; physical, mental, spiritual and emotional. A person<sup>1</sup> and their family<sup>2</sup> can be well within one facet of life while being unwell in another facet. For example, one can be spiritually at peace while physically dying.<sup>1</sup>

The focus of the previous 15 symptom guidelines<sup>1</sup> was primarily on physical concerns, although they did include psychosocial interventions such as addressing anxiety associated with dyspnea. This current guideline focuses on the mental, spiritual and emotional facets of health and wellness.<sup>2,3</sup> Due to the uniqueness of each person and family, it does not address all issues and concerns that may arise. Instead, it concentrates on some key areas that were identified as important by practicing clinicians, people and families.

### Step 1 | Building a foundation of trust and dignity-conserving care<sup>2</sup>:

Health care providers (HCPs) have a responsibility to initiate and maintain therapeutic relationships with the people they care for.<sup>4</sup> However, it may be difficult for some people to trust HCPs and the health care system because of past traumatic or unpleasant experiences.<sup>5,6,7</sup> When people have repeated negative experiences, they may avoid seeking health care<sup>5,7</sup> or choose not to disclose vital information,<sup>8</sup> both of which may lead to further harm. HCPs may reinforce distrust by making assumptions and portraying bias in verbal, written, and non-verbal communication.<sup>9</sup>

#### **In order to move towards trusting, therapeutic relationships:**

##### **1. Practice regular self-reflection:**

- Recognize when you have an adverse emotional response to a person or group of people.<sup>8,9</sup>
- Identify assumptions behind the emotion.<sup>8,9</sup>
- Challenge your assumptions by recognizing that everyone has unique experiences, values and beliefs.<sup>3,4,10</sup>

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<sup>1</sup> Throughout this document, “people” and “person” refer to the recipients of care who have life-limiting condition(s); this includes terms such as “patient”, “client” or “resident”.

<sup>2</sup> “Family” is defined by the person and includes all who are identified by them as significant and involved.

## 2. In every interaction, communicate genuine respect for the person's humanity<sup>10</sup>:

- Ask: “What do I need to know about you as a person/family to give you the best care possible?”.<sup>2</sup>
- Be attentive to body language and other signs that indicate a person may be feeling vulnerable (e.g., becoming combative during personal care)<sup>5</sup> and make every effort to help them feel safe.
- Create a physical environment that is pleasant for the individual, as much as possible (e.g., managing desired noise level, maintaining privacy).<sup>3</sup>
- Promote times of “normalcy” with usual life activities they enjoy (e.g., social conversation).<sup>2</sup>
- Use polite, courteous language and tone<sup>10</sup> with acceptance, authenticity and compassion,<sup>4</sup> refraining from judgement. Show an equal partnering relationship through body language, such as sitting or rising to equal eye level.<sup>4, 10</sup> Convey attitudes of inherent worth of the person in written, spoken and non-verbal communication.<sup>3</sup>
- It may take time for the person to trust so be patient and sensitive to their readiness to engage with you. Ask what could be put in place to help them feel safe.
- Seek permission before engaging in difficult conversations and ensure the timing is right for the person (e.g., ask who they would like to be present or absent, if they are feeling well enough to talk, etc.).
- Ask and honour how much information they would like to give and receive, this may change over time.<sup>11</sup> Offer information in plain language, without medical terminology<sup>11</sup> at their level of health literacy.
- Describe what you will do with the information they share with you, who will have access to documentation with their consent, and the purpose of communicating with the inter-professional team.
- Advocate for the person and family to be active participants in care and decision-making.<sup>10</sup> Seek shared understanding of goals of care. Respect and honour choices based on their values and beliefs. Encourage independence and control whenever possible.<sup>3</sup>
- Throughout care, validate the person's and family's emotions and concerns and answer their questions. Promote ongoing, open dialogue with the person, family and health care team.

### 3. Respect gender identity and sexual orientation

- For people who self-identify as lesbian, gay, bisexual, transgender, two-spirit, queer or other (LGBT2Q+),<sup>12</sup> give opportunity for safe disclosure of their gender identity and/or sexual orientation that is received with acceptance and continued respect rather than judgement.<sup>8</sup> (**See Appendix A for a link to Trans-care BC**)
- To include those who identify as LGBT2Q+ and choose not to disclose, consider adopting a routine practice of using “they/them/their” as the singular pronoun for everyone rather than “he/she”.<sup>12</sup>
- With permission, document and communicate identified gender and preferred pronouns to the health care team. }

### 4. Respect chosen family and community caregivers

- Acknowledge and involve chosen family members<sup>7,8</sup> and community caregivers<sup>7</sup> during care and bereavement.
- With permission, document their chosen family members, using their preferred terminology to describe the relationship.<sup>7,8</sup>
- Ask if they have an identified spokesperson and provide information to legally appoint a Substitute Decision Maker (SDM)<sup>14</sup> if different than the B.C. Temporary Substitute Decision-Maker List (**Link in Appendix A**)
- With the person’s consent and if they desire, include community care providers (including friends, informal supports, volunteers, traditional, alternative and complementary treatment providers) in the circle of care by communicating and collaborating with them.<sup>6,7</sup>

### 5. Respect Culture

As with previous symptom guidelines, feedback was sought from people with personal and/or professional knowledge of indigenous culture. Some of the following items to consider may also be important for other cultures (recommend future guidelines revisions include input from other cultures as well).

Never assume, but always **ASK** with a posture of humble curiosity if the following priorities at end of life are relevant for this person, family and community<sup>6,9</sup>:

- Preparing the spirit for transition into the next life (if they believe in an afterlife) by strengthening emotional, mental and spiritual wellness.<sup>11</sup>
- Connection with family, community, deceased relatives/ancestors, traditional territory/land, home,<sup>6, 11</sup> and spiritual beings.
- Protecting the spirit from negativity (they may be reluctant to discuss death or advance care planning).<sup>6, 11</sup> They may also worry that discussing death invites the spirits or death to come.
- Using traditional medicines and healers, ceremonies, rituals and practices (e.g., herbal remedies).

If desired by the person, family and community:

- Seek to understand where they come from: their story, history<sup>11</sup> and traditions.
- Ask if they would like to have a sacred object brought in from home (e.g., feather, rock).
- Adapt the physical environment and organizational policies as much as possible to accommodate large numbers of visitors at once.<sup>11</sup>
- Consider settings with windows that can open to allow for spirits to pass through.
- Partner with them to create opportunities for spiritual rituals<sup>11</sup> (e.g., smudging).
- Acknowledge their experience of the spirit world as real regardless of the HCP's beliefs.

**Using flexible, co-operative problem-solving** to address personal, physical, financial, jurisdictional and geographical barriers to support the person to receive palliative care services in their community and/or chosen safe place whenever possible.<sup>6, 7</sup>

## Step 2 | Screening and assessment

### Screening for distress<sup>15</sup>

1. Using a screening tool such as the Edmonton Symptom Assessment System-Revised (ESAS-r),<sup>16</sup> Hospital Anxiety and Depression Scale (HADS) (links in Appendix B.1), a screening tool used in your organization and/or endorsed by your profession to identify areas of potential psychosocial and/or spiritual distress.
2. Ask further screening questions such as:
  - Do you feel depressed<sup>17</sup> or extremely sad?
  - Do you feel anxious or worried?
  - Are there any issues you would like to resolve before your death?
  - Are there other things that are a concern to you and/or your family?
3. When areas of psychosocial and/or spiritual distress are identified through initial screening, further assessment is required.<sup>15, 18</sup>

Often, emotional distress is linked to physical distress.<sup>19</sup> Provide best practice symptom management<sup>20</sup> including assessment and treatment of total pain (Pain symptom management guidelines<sup>3</sup>).

The recommended assessment and interventions in the following sections are within the scope of practice for many health professions. Always practice within the boundaries of your profession, experience and organizational policies. Refer to social workers, counsellors and/or spiritual health practitioners as appropriate for specialized assessment and intervention.

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3 BC Centre for Palliative Care (2017). B.C. Inter-professional Palliative Symptom Management Guidelines. (Pain Section)

## Spiritual wellness screening and assessment

**Spirituality:** “a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose, and transcendence, and experience relationship to self, family, others, community, society, nature, and the significant or sacred. Spirituality is expressed through beliefs, values, traditions, and practices.”<sup>21</sup>

- May use spiritual screening tools such as FICA and HOPE. (See links in Appendix B.1)
- May use a “gentle querying”<sup>22</sup> approach. (Appendix B.1)
- Ask, “Do you, your family and/or your community have cultural/spiritual/religious beliefs, practices or values you’d like us to be aware of? If so, how can we support you as best as possible to meet these needs?”
- Ask, “What has given you meaning through your life? What brings meaning in this time in life?”
- What has given you strength in your life and throughout your illness?”
- Identify when the person’s needs may require the clinical training of a spiritual health practitioner (e.g., spiritual/existential distress, past spiritual hurts, rituals, sacraments, and/or wrestling with the impact of beliefs on decision-making).

## Recognizing existential distress

**Spiritual or existential distress:** there are many definitions but common themes are: personal anguish<sup>23</sup> loss of meaning<sup>24</sup> feeling irrelevant<sup>24</sup> questioning the purpose of one’s life and death<sup>23</sup> loss of connectedness<sup>23, 24</sup> intense fear of dying<sup>23, 24</sup> hopelessness<sup>24</sup> guilt, and a sense of isolation.<sup>23, 24</sup>

**Health care providers can recognize distress when the person, their families and/or caregivers are:**

- Struggling with hopelessness or a loss of faith.
- Feeling lonely, forgotten, isolated, guilty or misunderstood.
- Experiencing anger at others or a Higher Power.
- Questioning the purpose of their life or the meaning of suffering.
- Needing forgiveness or reconciliation.



## Psychosocial assessment

At the initial inter-professional assessments and throughout ongoing interactions, assess how the illness progression is impacting all domains for the person and family: spiritual, social, emotional, relational, practical, and financial.<sup>25, 26</sup>

- Self-reflective practice: acknowledge your own responses to the person's emotions as sometimes our clinical assessments can be influenced by our own perceptions of what is "emotionally normal" as well as our own discomfort with a person's expression of pain.<sup>27</sup>
- Assess the impact of caregiving on the family in all domains.<sup>26</sup> Sometimes families feel pressured to provide care. Assess their ability and willingness to continue to provide care, especially as the person's illness progresses.
- Ask questions about previous experiences with loss and grief and look for effective coping strategies used in the past, specifically identifying strengths to build on during this journey.
- Assess the frequency and persistence of feelings of distress (e.g, anxiety or depression).

## Differentiating between grief and depression

- 20%-25% of people with terminal illness experience depression but it is often not diagnosed.<sup>28, 29</sup> Thus, people may not receive appropriate care for their psychosocial needs.<sup>28, 29</sup> It is imperative for health care providers to have a basic understanding of the range of grief and depression symptoms so as to not intervene in a normal grieving process and possibly disrupt it<sup>30</sup> but also not underdiagnose this serious issue. Grief can be difficult to distinguish from depression and they can co-exist together. (See Appendix B.2 for a comparison table )
- The usual screening and assessment tools for depression include indicators such as: sadness, fatigue, weight loss, withdrawal from social relationships, anorexia, and unrelieved pain,<sup>19, 28</sup> which could all be due to illness progression, and/or grieving, rather than clinical depression.<sup>19</sup> These tools have been shown to screen out those who are not depressed. However, if a person identifies as possibly depressed using these screening tools, further assessment is required.<sup>16, 18</sup>

- The intent of this section is to aid the generalist HCP to identify when a person may be clinically depressed and then to refer to other members of the inter-professional team such as social workers, counsellors and physicians (including psychiatry if appropriate) for further assessment and management of depression. (See Appendix A for Link to Fraser Health guideline Depression in the terminally ill)

## Suggested questions for a preliminary assessment of depression

<p><b>Using Mnemonic O, P, Q, R, S, T, U and V<sup>31, 32</sup></b></p>	<p><b>Assessment questions</b> for depression.<sup>31</sup> This framework is based on the familiar O-V assessment questions for physical symptoms. The intention is not that the HCP will ask all of these; instead, chose a few questions that are most relevant for the person and situation. Questions should be asked within a therapeutic relationship and at a pace that is comfortable for the person. <b>The anticipated outcome is a greater understanding of the person’s experience and identification of internal resources and strengths that can be drawn on.</b></p>
<p><b>Onset</b></p>	<p>When did you notice changes in your mood? Did it happen gradually or was there a significant event that started it? Have there been times in your life prior to your illness when you have struggled with a low mood? If so, what has helped you in the past?</p>
<p><b>Provoking / Palliating</b></p>	<p>What have you noticed that makes your feelings of depression or sadness either better or worse?</p>
<p><b>Quality</b></p>	<p>Can you describe how you feel? Are there things you still enjoy doing, or have you lost pleasure in things you used to do before you became ill? How does the future look to you? Are you having feelings of hopelessness or worthlessness?</p>
<p><b>Region/ Radiation</b></p>	<p>Are your feelings constant or does your mood change, at times being better, and sometimes worse?</p>
<p><b>Severity</b></p>	<p>How severe are your feelings of depression/sadness? What would you rate it on a scale of 0-10 (0 being none and 10 being the worst possible)? How do you feel right now? At its worst? On average? Are there any other symptom(s) that accompany this feeling?</p>

<b>Treatment</b>	<p>What have you tried or have found helpful to manage feelings of depression? What medications and treatments are you currently using? Are you using any non-prescription treatments, herbal remedies, or traditional healing practices? Do you find spiritual practices such as meditation or mindfulness helpful? There are different ways of managing depression. These may involve medications, counselling, support groups, or resources to help manage some of the stressors that can contribute to depression. What are your thoughts about this? How do you feel about accessing support to help manage your feelings of depression?</p>
<b>Understanding</b>	<p>What do you believe is causing these feelings? Do you have other symptoms that you think are related? How is this impacting you and/or your family?</p>
<b>Values</b>	<p>What overall goals do we need to keep in mind as we support you? Would you like to share any beliefs, views or feelings about depression that are important to you, your family, or community?</p>

## Guiding principles

- Use approaches and language that are inclusive of gender identity and sexual orientation<sup>12</sup>, chosen family<sup>7, 12</sup> community caregivers<sup>7</sup> and culture.<sup>8,9</sup>
- With the inter-professional team, assess and address physical symptoms and emotional, mental and/or spiritual distress concurrently.<sup>18</sup>
- Encourage people, families and communities to identify and lean on their strengths and areas of wellness.
- Openness, active listening, silence and a therapeutic presence are interventions within the scope of any clinician.
- Refer on to palliative social workers, counsellors and spiritual health practitioners when the person's and/or family's needs are beyond your scope of practice or expertise to assess and/or intervene.
- When a person expresses a wish to hasten their death, explore their experience before taking any action.
- Work together with families to support children when someone they love is dying.
- Support people and families in their unique experiences of grief from diagnosis and into bereavement.

## Step 3 | Supporting spiritual and psychosocial wellness

### Supporting spiritual wellness

The aim of spiritual care is to support all people whether spiritual, religious, atheist or agnostic as they connect with their own inner spiritual resources (e.g., cultural, personal or religious beliefs/perspectives; practices or rituals; connection with others; connection to a transcendent Higher Power; meditation/prayer; sacred objects; scripture/text).

Spiritual well-being improves quality of life and positive coping<sup>33</sup> when approaching death and may have been a source of strength throughout their life as well. Spiritual care has been shown to relieve physical symptoms as well as increase the ability to cope with existing symptoms.<sup>34</sup>

## To support the person and family's spiritual wellness:

- Convey openness to discuss spirituality and integrate it into care, regardless of the HCP role (i.e., all HCP can integrate spiritual care into practice, not just spiritual health practitioners).<sup>33, 35, 36</sup>
- Allow the person to guide conversations.<sup>36</sup> Provide active listening to stories,<sup>33</sup> convey empathy, respect<sup>2</sup> and willingness to explore spiritual topics.<sup>37</sup>
- Offer times of silence. “As a caregiving practice, silence is perceived as particularly relevant in spiritual and existential dimensions of care when words may fail.”<sup>38</sup>
- Provide “sacred space”<sup>36, 39</sup> which includes time and privacy for spiritual practices the person and family find helpful<sup>33</sup> (e.g., post a sign on the door to prevent interruptions).

Refer to spiritual health practitioners who are responsible to offer respectful, person/family-centered care that supports any expression of spirituality/meaning-making. Spiritual health practitioners have the clinical training and scope to attend to the full range of spiritual and emotional needs of those facing existential/spiritual crisis or difficulties.<sup>40</sup>

If spiritual health practitioners are not available in your organization, social workers or counsellors may be able to provide limited support. The person and family may choose to contact specific spiritual support providers with whom they have an established trusting relationship. Be mindful if referring to religious leaders or other community resources that they may not have clinical training or expertise in health care.

## Supporting psychosocial wellness

Focus on strengths and areas of wellness rather than only on illness or problems. Help the person and family identify past and current problem solving abilities, courage, skills, resilience and resources that they can draw on.<sup>41</sup>

## Emotional supports

- Utilize active listening skills: being fully present, calm<sup>42</sup> and engaged, offer silence without seeming rushed.<sup>10</sup> Focus on their needs rather than the HCP task to be performed.
- Model and promote a team and organizational culture that values the importance of providing emotional and social support, which may require time to sit and listen to people and their families.<sup>42</sup>
- Convey compassion and empathy when they express emotions in a variety of ways, including those that may be uncomfortable for the HCP (e.g., wailing).<sup>10</sup>
- The life review that often happens near end-of-life may cause memories of past trauma to re-surface.<sup>5</sup> Offer the person support from social workers, counsellors and spiritual health practitioners to do a life review if desired.<sup>43</sup>
- Person and family education about signs and symptoms of worsening anxiety or depression.<sup>15</sup>
- Provide information on stress reduction strategies such as mindfulness, yoga, relaxation breathing and music.<sup>15, 43</sup>

## Social supports

- Assert the person's wishes for desired visitors, including "gatekeeping" those they do not wish to see or when they prefer to not have visitors at all. As much as possible, create a welcoming physical space for visiting.
- Recognize some people may be estranged from family and/or feel disconnected from their spirituality. Offer referral to social workers, counsellors and spiritual health practitioners for support in healing estranged social and spiritual relationships, if desired.<sup>8</sup>
- Offer information about on-line and in-person peer support groups<sup>15, 44, 45</sup> and group therapy.<sup>44</sup>
- Support family caregivers who may be extremely fatigued, encouraging them to acknowledge their own needs and to say "no" if they are not able to continue to provide care. Provide information about caregiver supports such as respite services<sup>20, 46</sup> and support groups. **(See Appendix A for a link to Family Caregivers of B.C.)**

## Financial and practical supports

- Anticipate possible needs and offer support to families who may be too weary to ask.
- Provide information about practical supports such as transportation, financial assistance, BC Palliative Care Benefits program<sup>15</sup> and palliative day care programs, where available.<sup>44</sup>
- When appropriate, refer to social work for significant financial concerns.

Refer to qualified social workers or counsellors for psychosocial interventions which may be brief and effective to increase quality of life and reduce emotional distress.<sup>43</sup>

<sup>46</sup> Examples are: music therapy,<sup>43</sup> dignity therapy,<sup>43</sup> and meaning-making therapy.<sup>47</sup>

## Expressed wish to hasten death

**The wish to hasten death:** is “a reaction to suffering”,<sup>48, 49, 50</sup> “in the context of an advancing life-limiting illness from which the person can see no way out other than to accelerate his or her death. This wish may be expressed spontaneously or after being asked about it, but it must be distinguished from the acceptance of impending death or wish to die naturally”.<sup>48</sup>

Expression of wanting to end one’s life in the presence of an advanced life-limiting illness is not uncommon.<sup>51, 52, 53</sup> It does not necessarily indicate a request for Medical Assistance in Dying (MAiD) or presence of depression.<sup>54</sup> To understand the person’s perspective, a critical and reflective analysis about what underlines their suffering is pivotal.<sup>50</sup> Statements made by persons with a life-limiting illness that either explicitly or implicitly suggest a desire to die can have a variety of meanings. The very fact that there is communication and expression of wanting to die may signify the expectation of an interaction with the physician or health care team.<sup>55</sup>

**An expression of a wish to hasten death is an invitation for a health care provider to lean in with curiosity, seeking to understand the meaning behind a person’s expression of desire to die.**

***Many reasons commonly associated with a person’s desire to die can be addressed by a palliative inter-professional care team.*** They include the following<sup>48, 56, 51</sup>:

- Existential distress (e.g., loss of meaning in life).
- Psychological distress (e.g., hopelessness, guilt, depression).
- Feeling a burden to others.
- Loss of autonomy and control.
- Uncontrolled physical symptoms presently or anticipated in the future.
- Fear of the future or other fears.
- Readiness -- feeling it is time to die.<sup>57</sup>
- Emotional and/or physical exhaustion.
- A desire to end suffering.

## Assessment and interventions<sup>48</sup>

It is imperative to distinguish between:

- an expression of a desire for a hastened death,
- a request for Medical Assistance in Dying (MAiD), or
- a plan for suicide.

Approaches when responding to an expressed wish to hasten death:

- Do not stigmatize or label the person as a “MAiD person” or “suicidal”.
- Ask about the person’s emotional state, conveying a willingness to talk about the reasons behind their statements.
- Listen and be present in the face of suffering, portray a commitment to respond.
- Engage with the person to identify and address the source of their distress and motivations for desiring hastened death.
- Assess for possible depression (See ["Psychosocial Topic Index" on page 31 for sections on depression](#) ).
- Referral to appropriate members of the inter-professional team including social workers, counsellors and spiritual health practitioners.



- If it is determined that there is an imminent threat of suicide, contact an emergency response team (911 or local Mental Health Unit/Hospital) or the person's family physician for direction. (**Appendix A for suicide prevention resources**)

## Suggested questions and phrases for responding to desire to die statements:

1. Exploring their current feelings and/or fears: *I am hearing you have a readiness to die. What is contributing to that readiness? Can you share your feelings with me? Are you concerned about something in particular?*
2. Assessing their state of suffering and distress (physical, emotional, spiritual): *What, if anything, do you feel could be improved in your care and treatment? If we could relieve this, would you still wish for a hastened death?* If the reason is refractory symptoms/suffering, refer to the [guideline for refractory symptoms and palliative sedation](#)<sup>4</sup>.
3. When they are seeking further information on MAiD:
  - *Have you talked with your loved ones about this request? Would you like assistance in talking further with them?* (Note: having families' agreement and acceptance of the person's request for MAiD is not required to proceed.)
  - *It sounds like you have given this a lot of thought. Would you like me to provide you with additional information about MAiD?*<sup>53</sup>
  - Provide information on MAiD if desired by the person in accordance with your organization's and professional governing body's policies and procedures. To ignore, dismiss or diminish a person's request for MAiD can lead to further isolation and suffering and a lack of trust in the health care system. (**See Appendix A for MAiD resources in each health authority**)

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4 BC Centre for Palliative Care (2019). B.C. Inter-professional Palliative Symptom Management Guidelines. (Refractory Symptoms and Palliative Sedation Chapter)

## Supporting people and their families who are grieving

### Definitions

**Grief** includes a range of emotions and processes in response to loss.<sup>58</sup> “Grief is a normal part of life<sup>20</sup> and a natural response to loss. It is the consequence of living and loving, and meaningful connections with others”<sup>27</sup> It is a complex process that involves the entire body, spirit and mind, an experience unique to each individual, family and community.<sup>27</sup>

- The person and their family may experience grief from the time of diagnosis of a life-limiting condition; family members’ grief continues through to bereavement.
- Positive emotions can be experienced alongside painful ones<sup>30</sup> and may fluctuate (e.g., when caregiving has been intense, grief may be combined with relief after death).
- Most people can cope with the support of family, friends and community groups.<sup>20</sup> Sometimes, they feel they have grown and become more resilient as a result of their grief.<sup>27, 59</sup> However, some individuals may be at risk for experiencing complicated grief and may need additional professional support.

**Preparatory grief** is experienced by people living with a life-limiting condition as they work through current and anticipated losses such as: ongoing changes in function, identity, future plans, purpose, role in the family, privacy, unresolved issues, and eventually their death.<sup>60, 61, 62</sup> The intensity of grief may increase as death draws closer<sup>61</sup> or symptoms escalate. The person may withdraw from family and caregivers in preparation for their death.<sup>61</sup>

**Anticipatory grief** is experienced by those grieving the loss of the person while they are still physically present.<sup>63</sup> They encounter a number of losses before death occurs, such as their previous relationship with the dying person, their own autonomy, the ability to participate in activities unrelated to caregiving<sup>63</sup> and plans for the future.

- Families may experience feelings of ambivalence which fluctuate between uncertainty, guilt, frustration, acceptance, desire for relief of suffering, and hope.
- HCPs may also experience anticipatory grief. In order to facilitate resilience to cope with the anticipatory grieving process, practice self-reflection and self-care, attending to your own individual grief and that of other team members.

**Bereavement** is the process of loss and grieving after the person has died.<sup>64</sup> It is a journey of healing that has no timeline<sup>27</sup> and may involve: acceptance of the death, adjusting to life without the person, creating a new relationship with the person, and re-connection with the world.<sup>27</sup>

**Complicated grief** occurs after the death, when the person has clinically relevant and disabling distress due to “difficulty accepting the painful reality of the death or imagining a future with purpose and meaning”<sup>65</sup> for an extended period of time<sup>65</sup> (length of time varies in the literature). It is characterized by intense and prolonged yearning<sup>65</sup> emotional pain, or preoccupation with the deceased.<sup>65,66</sup> The person may show symptoms of insomnia, hypertension, more frequent access of the medical system, and substance misuse.<sup>20</sup>

Caution should be taken not to over-diagnose complicated grief as a psychiatric disorder due to the individualized nature of the grieving process.<sup>66</sup> Risk for complicated grief/bereavement can be assessed during care and at the time of death.<sup>20</sup> See [Appendix B.1](#) for a link to the **Bereavement Risk Assessment Tool (BRAT)**.

## Supportive interventions for the grieving person and family during illness

- Preparation for the caregiving role decreases distress during bereavement, so answer questions honestly about what will be involved and support the family to plan for care at various stages.<sup>20</sup>
- Ensure the family is aware of and knows what physical changes to expect when death is near<sup>20, 67</sup> while being sensitive to their readiness to hear this information.
- Inform the person and family that they may wish to have important conversations before the person becomes less responsive as their dying time draws near or before administering a possibly sedating medication.
- Normalize the person’s and family’s experiences of grief including: shock, relief, gratitude, ambivalence, and guilt. Support internal family communication within your scope of practice.<sup>63</sup>
- Name and validate common expressions of grief including: cognitive (focus, memory), emotional (irritability, anger, anxiety), physical sensations (somatic symptoms, fatigue, and other stress responses), and behaviour (difficulty with managing strong emotions).<sup>68</sup>

## Supportive interventions at the time of death

- Allow privacy time with the body if desired. Ask if the family would like you to stay with them or if they prefer to be alone.
- Partner with the family to support religious, cultural or spiritual rituals and customs.

## Bereavement follow-up at key time points

- Ask questions about how specific family members perceived the death (e.g., do they see it as unexpected, traumatic, etc.) which may greatly impact bereavement.<sup>20</sup>
- Key time points are: immediately following death, 3 months after, 6 months after, and 1 year after.<sup>20</sup> If your organization is not resourced to support bereavement, ensure the family has information on community resources<sup>25</sup> including those provided by hospice societies.
- Referral to bereavement specialist services if desired by the family<sup>66</sup> especially if any members are at risk for complicated grief. ([Appendix A – BRAT](#))

## Supporting children and youth when someone close to them is dying

During a serious illness, families have the opportunity to adapt to changes, to model honest emotions<sup>69</sup> and grieve together.<sup>70</sup> Often families are anxious about how to support children and youth and desire educational, social, practical, and emotional support.<sup>71, 72, 73</sup> Many HCPs find supporting children one of the most difficult aspects of caring for people who are dying<sup>69</sup> and are unclear of their role. Be self-reflective and person/family-centred without allowing your own biases to impact the family's choices (e.g., thinking children shouldn't be around death).

**While families often do want guidance, they also want to have control over the content and timing of what is said.<sup>71</sup> Remember families know their child best and will support them in ways that are congruent with their values, beliefs and parenting style. Seek support from social workers and counsellors.**

Generally, the role of HCPs is to:

- Provide emotional support/validation to all members of the family.
- Assist families to identify needs of children, strategies to adapt to changes, and enhance coping throughout illness trajectory from a strengths-based approach.<sup>71, 72, 74</sup>
- Help family members to identify their own stress levels and coping strategies.
- Seek mental health and/or counselling services if: significant changes in behaviours at home or school, child unable to function with day-to-day tasks, destructive or self-harming behaviours, suicidal ideation<sup>75</sup> and/or decreased attention to hygiene in older children. Youth may exhibit high risk substance use and/or sexual behaviours.

Below are some principles to guide both families and professionals **as they work together** to support children and youth.

## Consider how decisions about end-of-life plans affect child:

- How will location of care (home, hospice, hospital) impact child? How will space, logistics, emotional support, and caregiving demands be managed?<sup>75</sup>
- Attend to practical needs such as advance care planning, guardianship, financial affairs, estate planning. This is particularly important for single parents.<sup>75</sup>

## Communication (See Appendix B.3 – Tips for families communicating with children about serious illness)

Families tend to disclose information related to serious illness using their usual relational patterns and styles of communication.<sup>76</sup> They may benefit from professional support if they usually avoid difficult subjects or have problematic relationships. Encourage adult family members to seek emotional support if needed and model self-care.<sup>75</sup> Ensure adults have a safe place to grieve and can honestly express emotions.

Refer to individual and group counselling services as desired, including community resources. Encourage peer social support such as support groups and camps with other grieving children and youth to decrease the feeling of isolation.<sup>77, 78</sup>

## Information sharing

Ask families if they would like to bring the child or youth to meet a health professional as this can increase the child's trust in medical care and help them to feel part of the process.<sup>78</sup> Ask what the child/youth has been told and how much the family wants them to know. Plan with the family ahead of time how the conversation will go. Discuss the suggestions below and ask if they would like you to address them, or if they would prefer to lead the conversation. Seek permission from the family before disclosing any health information to the child or youth.

Consider the child's developmental stage ([Appendix A](#) for a link to developmental considerations in the BC Guidelines). Families may prefer to share information themselves and could benefit from the suggestions below as they communicate directly with the child/youth.

- Engage with knowledgeable professionals such as child and youth counsellors or social workers to assess and support the child/youth with permission from the family.
- Validate how difficult and life-changing the illness is for the child.<sup>75</sup>
- Ask how much information they want and from whom, and tell them they can change their minds later.<sup>70</sup> Take cues from the child in how much they want to know, consider their individual preferences and developmental age.<sup>78</sup>
- Start with what a child can observe. You may have noticed... Ask what they know so far and clarify misunderstandings.<sup>13</sup> Provide current understanding of what may happen in future<sup>71</sup>.
- Offer assurances to the common fears children have<sup>69, 13</sup>:
  - They can't catch the illness.
  - It's not their fault, i.e., they didn't cause the illness.
  - They will be taken care of.
  - There are still medicine and treatments that can help their loved one be comfortable.
- Be open and honest, using concrete simple language. Don't use euphemisms such as "pass away". Use correct terms for the illness, such as "cancer",<sup>69, 70, 78, 13,</sup><sup>79</sup> and specific ways it affects the body.<sup>71</sup>

- Watch how the child or youth reacts to what you say; attend to the non-verbal, ask them how they're feeling.<sup>13</sup> Give them the opportunity to ask questions.
- Information may need to be repeated many times<sup>78, 79</sup> and there may be many smaller conversations along the way rather than "THE" talk. The child may persist in "magical thinking" as they take time to process the information.
- Encourage the family to check in often and keep discussion open<sup>13</sup> by asking child if they are getting "too much information, too little, or just right?"<sup>75</sup>

Managing visits to the hospital, hospice or bedside of a dying person.<sup>75</sup> Again, the recommendations below could be suggested to families rather than done by the HCP themselves.

- Ask the dying person for permission for the child to visit.
- Be responsive to the child's desire to be present with a dying person or not; never assume their desires or make them feel guilty if they don't want to visit.<sup>74</sup>
- Is there a place the child can go if they need to leave? If possible, have a caring adult who can help with breaks.<sup>75</sup>
- Prepare the child/youth for what to expect<sup>74</sup>:
  - How will the person look and act and what is the reason? Explain the reason for behaviours that may be scary for children (e.g., agitation in progressive dementia).<sup>75</sup>
  - What is the equipment in the room? What is it for?
  - What may they hear and see? Explain things that may be upsetting such as rattling breathing.
  - Give them age-appropriate tasks to help them feel involved (e.g., telling a story, painting the person's nails, fetching water<sup>13</sup>).
  - Help them understand how to interact safely and to communicate with the person.<sup>75</sup>

## APPENDIX A - ADDITIONAL RESOURCES

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- Fraser Health Hospice Palliative Care: Depression in the Terminally Ill
  - [https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Professionals-Resources/Hospice-palliative-care/Sections-PDFs-for-FH-Aug31/9524-15-FH---Sym\\_Guide-Depression.pdf](https://www.fraserhealth.ca/-/media/Project/FraserHealth/FraserHealth/Health-Professionals/Professionals-Resources/Hospice-palliative-care/Sections-PDFs-for-FH-Aug31/9524-15-FH---Sym_Guide-Depression.pdf)
- CAPO & CPAC: Pan Canadian Practice Guideline: Screening, Assessment and Care of Psychosocial Distress, Depression, and Anxiety in Adults with Cancer - Algorithms
  - <https://www.capo.ca/resources/Documents/Guidelines/4.%20Algorithms%20for%20Cancer-related%20Distress,%20Depression%20and%20Global%20Anxiety.pdf>
- BC Guidelines Palliative Care Part 3 - Appendix C: table with developmental ages and considerations for grief in children and youth
  - [https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative3\\_appendix\\_c.pdf](https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative3_appendix_c.pdf)
- Family Caregivers of B.C.
  - <https://www.familycaregiversbc.ca/>
- Trans-care BC. Glossary of terms and other resources
  - <http://www.phsa.ca/transcarebc/health-professionals>
- B.C. Temporary Substitute Decision-Maker List
  - <http://www.bc-cpc.ca/cpc/sdm/>
- BC Bereavement hotline
  - <http://www.bcbh.ca/>
- BC Cancer Sexuality and Partner Support pathfinder
  - [http://www.bccancer.bc.ca/library-site/Documents/pathfinder\\_Sexuality-General.pdf](http://www.bccancer.bc.ca/library-site/Documents/pathfinder_Sexuality-General.pdf)
- BC Cancer Symptom Management Guideline for intimacy and sexuality
  - <http://www.bccancer.bc.ca/nursing-site/Documents/8.%20Intimacy%20and%20Sexuality.pdf>



- Canadian Virtual Hospice
  - My grief.ca <http://www.mygrief.ca/>
  - Kidsgrief.ca <https://kidsgrief.ca/>
  - Living my culture.ca <http://livingmyculture.ca/culture/>
  - Programs and services for children and youth in B.C.  
[http://virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/British+Columbia/Programs+services+and+hospice+for+children.aspx#id\\_a4b3ed4308902e5eb0b17e4675f90f73](http://virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/British+Columbia/Programs+services+and+hospice+for+children.aspx#id_a4b3ed4308902e5eb0b17e4675f90f73)
  - Bereavement services in BC  
[http://virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/British+Columbia/Bereavement+services.aspx#id\\_e7c07bc97b7d5ccd50139a8255eda1c1](http://virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Resources/Programs+and+Services/Provincial/British+Columbia/Bereavement+services.aspx#id_e7c07bc97b7d5ccd50139a8255eda1c1)
- Crisis Intervention & Suicide Prevention Centre of BC
  - <https://crisiscentre.bc.ca/contact-us/>

## Resources regarding MAiD:

Article and case studies on request for hastened death: [http://www.virtualhospice.ca/en\\_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/Assessing+and+Managing+a+Request+for+Hastened+Death.aspx](http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/For+Professionals/For+Professionals/The+Exchange/Current/Assessing+and+Managing+a+Request+for+Hastened+Death.aspx)

Every Health Authority in BC has a Coordination Service or Program to provide specific information on MAiD and how to access. They can assist health care professionals to provide accurate and timely support and information to persons and families who request more information.

- Vancouver Island Health Authority:
  - <https://www.islandhealth.ca/index.php/learn-about-health/medical-assistance-dying/medical-assistance-dying>
- Northern Health Authority:
  - <https://www.northernhealth.ca/health-topics/medical-assistance-dying-maid>

- Interior Health:
  - <https://www.interiorhealth.ca/YourCare/MAiD/Pages/default.aspx>
- Vancouver Coastal Health:
  - <http://www.vch.ca/public-health/health-topics-a-z/topics/medical-assistance-in-dying>
- Fraser Health:
  - <https://www.fraserhealth.ca/health-topics-a-to-z/end-of-life-care/medical-assistance-in-dying#.W-UTbB9KjX4>

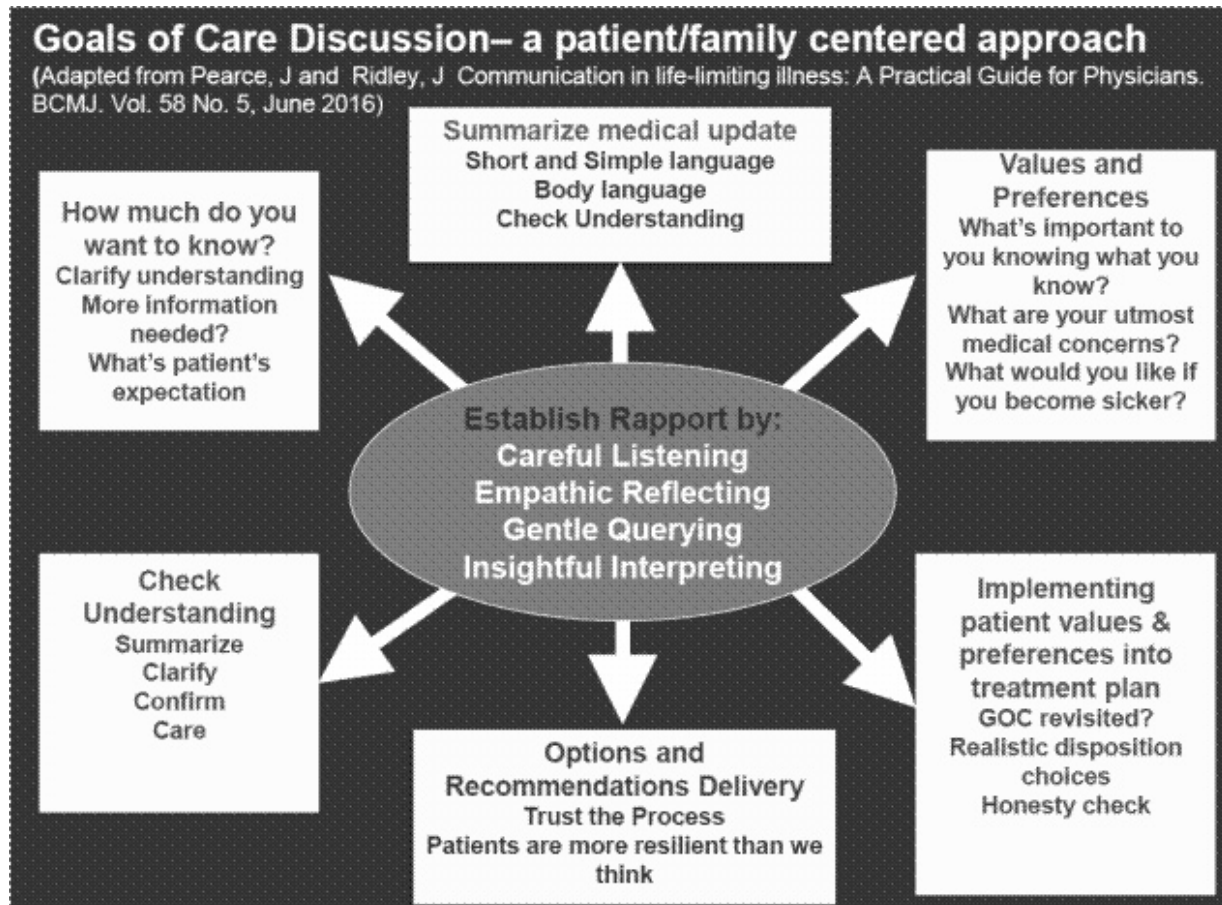
## APPENDIX B – EXTRA TOOLS

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### Appendix B.1 - Screening and assessment tools

- ESAS-r
  - [http://palliative.org/NewPC/\\_pdfs/tools/ESAS-r.pdf](http://palliative.org/NewPC/_pdfs/tools/ESAS-r.pdf)
- HADS
  - [https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/hads\\_mood.pdf](https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/hads_mood.pdf)
- Bereavement Risk Assessment Tool
  - [https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative3\\_appendix\\_e.pdf](https://www2.gov.bc.ca/assets/gov/health/practitioner-pro/bc-guidelines/palliative3_appendix_e.pdf)
- FICA and HOPE printable cards
  - <https://meds.queensu.ca/source/spiritassesstool%20FICA.pdf>
- Waterloo spiritual screening form<sup>80</sup>
  - <http://www.palliativecare.ca/Uploads/ContentDocuments/Spiritual%20Care%201-Pager-%20DRAFT%202D.pdf>

- “Gentle Querying” Image re-produced with permission<sup>22</sup>



## Appendix B.2 - Comparison of grief and depression<sup>27, 28, 29, 30, 31, 81, 82, 83</sup>

Unique to Grief	Shared by Both	Unique to Depression
<ul style="list-style-type: none"> <li>• Variable mood, activity, communication, appetite</li> <li>• Preoccupied with loss</li> <li>• Weeping</li> <li>• Stays connected to and is comforted by others</li> <li>• May enjoy simple pleasures</li> <li>• May re-define hope</li> <li>• Specific anxiety about dying process and leaving others behind</li> </ul>	<ul style="list-style-type: none"> <li>• Sadness</li> <li>• Fatigue</li> <li>• Loss of energy</li> <li>• Inability to focus</li> <li>• Not interested in the rest of the world</li> <li>• Anxiety</li> <li>• Physical symptoms</li> <li>• Anger</li> <li>• Fear of losing one's mind</li> <li>• Spiritual estrangement</li> <li>• Alteration in relationships</li> <li>• Impaired function</li> <li>• Longing for an end to the pain</li> <li>• Disturbed sleep patterns</li> <li>• Weight loss, anorexia</li> </ul>	<ul style="list-style-type: none"> <li>• Moods and feelings are more static and have little variability</li> <li>• Persistent low mood (for 2 weeks or more)</li> <li>• Difficulty weeping and/or controlling weeping</li> <li>• Loss confirms they are bad or worthless</li> <li>• Preoccupation with distorted, negative self-view, feel worthless</li> <li>• Feeling immobilized or stuck</li> <li>• Withdrawal, loss of connection with self and others</li> <li>• hopelessness</li> <li>• Loss of pleasure</li> <li>• Unable to be comforted by others</li> <li>• Guilt</li> <li>• Suicidal ideation</li> <li>• Thoughts and feelings of hopelessness</li> </ul>

## Appendix B.3 - Tips for families to support children and youth with a dying family member

Also refer to section within the body of the guideline: [page <?>](#)

In times of loss, children and youth learn how to grieve from the modelling of important adults in their life. When children see adults expressing emotion, it teaches them that this is okay to do. If adults hide their tears and repress emotions using alcohol or other substances, children will learn this too. Modelling grief is teaching children important life lessons.

The intensity of adult emotions can also be distressing to children. That is when it is important to pull in close family supports to help with parenting and the importance of the temporary time of “right now”.

Using conversation that reflects how you honestly feel is helpful and allows the child to see that their emotions are valid. For example, say: *I really miss Dad so much, and I feel so sad right now. I’m crying a lot and that may be hard to see, but it is okay to cry when we need to. This time is a really hard time for all of us, but it won’t always feel this way.*

### Other ways to offer support

- Normalize and expect a wide range of emotion, including times when the child acts like they aren’t affected at all.<sup>69, 79, 13</sup>
- Encourage safe ways to express emotion such as play, creativity and physical activity.<sup>79</sup>
- Differentiate between emotions and behaviour, (e.g., acknowledging feelings of anger while addressing undesired behaviour such as hitting).<sup>79, 13</sup>
- Serious illness requires families to reprioritize time/commitments and reorganize family life.<sup>72</sup> Encourage routines and predictability. Support from family and friends can be critical to support a sense of “normalcy”.<sup>72</sup>
- Give choices to maintain a bit of control.<sup>70, 72, 79</sup>

### Strengthen social supports for children

- Consider needs at school and how to best engage. Choose a point-person for information sharing and any needed social and emotional support.<sup>75</sup>

## Understand how changes in the person with the illness may affect children

- Acknowledge changes, new limitations, and behaviours. Explain how specific symptoms impact the person's body and their life.
- Focus on what the person can do and adapt interactions to optimize time together.
- Remind child that disturbing behaviours are not their fault, but a result of the illness<sup>75</sup> (e.g., agitation).
- Discuss ways to make special memories, keep memories alive, and continue to honour the loved one<sup>13</sup> (videos, recordings, letters, rituals). Encourage them to say good-bye in their own way.

## 7 Communication tips for families:

1. Find windows of opportunity to have conversations throughout illness, especially at times of new information or changes in health condition<sup>70, 71</sup> because:
  - They may hear from someone else or overhear family conversations.
  - They see changes in parent and family life, feel the emotional climate in family, and sense something is wrong. They often imagine incorrect scenarios if they don't know what's happening.<sup>76</sup> They often already know more than you think they do<sup>69, 70</sup>
  - Knowing the truth lowers anxiety.<sup>69, 13, 79</sup>
- Gives time to access supports available at school and in the community and allows the chance to say goodbye.<sup>70</sup>
2. Before any communication with a child, attend to your own feelings so you can balance modeling honest expression of emotion with self-care and regulation.<sup>75</sup>
3. Think about timing. Within a normal routine or driving in the car can be less intense.<sup>75</sup> Consider avoiding bedtime due to potential nightmares.
4. Be consistent as mixed messages can be harmful. Make sure loved ones and special people know messages children have received.<sup>75</sup> Never lie about what is happening.<sup>76</sup>
5. Ask if they're worried or have questions as they often try to protect adults by not upsetting them.<sup>13</sup> Let it be okay if they don't want to talk.<sup>75</sup>

6. Listen carefully to make sure you are answering what they're really asking (e.g., "where will Grandma go?" may be related to the body or to the afterlife).
7. Share your family's values and beliefs about spirituality and/or what happens after death. It's okay to say you don't know. <sup>13, 79</sup>

## TOPIC INDEX

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## Trauma-informed care

- ["Building a foundation of trust and dignity-conserving care<sup>2</sup>:" on page 3](#)

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