BCGuidelines.ca
Guidelines & Protocols Advisory Committee

Palliative Care for the Patient with Incurable Cancer or Advanced Disease
Part 1: Approach to Care

Effective Date: February 22, 2017

Scope

This guideline presents palliative care assessment and management strategies for primary care practitioners caring for adult patients aged ≥ 19 years with incurable cancer and end stage chronic disease of many types, and their families.

NOTE: Care gaps have been identified at important transitions for this group of patients:

- upon receiving a diagnosis of incurable cancer;
- when discharged from active treatment to the community;
- while still ambulatory but needing pain and symptom management; and
- at the transition when End-of-Life care may be needed.

Diagnostic code: 239 (neoplasm of unspecified nature)
Palliative care planning fee code: G14063

Key Recommendations

- Identify patients who would benefit from palliative care early in the illness trajectory: a palliative approach addresses the need for pain and symptom management, as well as psychosocial and spiritual support of patients and their families, beginning in disease management through to survivorship or End-of-Life care.
- Encourage patients to have an advance care planning discussion with family and/or caregivers.
- Establish goals of care with the patient and families/caregivers.
- Before ordering investigations, ensure that the results will change management to improve quality of life and/or prognostication, consistent with the patient's goals of care.
- Organize care coordination around key illness transitions.

Definition

The World Health Organization[1] defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial, and spiritual.

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor postpone death;
- integrates the psychological and spiritual aspects of patient;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;

British Columbia | Ministry of Health
doctors of bc
BC Cancer Agency
CARE + RESEARCH
An agency of the Provincial Health Services Authority
Family Practice Oncology Network

- will enhance quality of life, and may also positively influence the course of illness; and
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Background

The bow tie model of 21st century palliative care consists of two overlapping triangles resembling a bow tie, with an arrow pointing from left to right.[2] The first triangle represents disease management and the second triangle is palliative care. The base of the palliative care triangle (end of the model) includes both death and survival as possible outcomes. The arrow indicates that this is a dynamic process with a gradual switch in focus. The key difference between this and traditional models is that survivorship is included as a possible outcome.

Figure 1: The Bow Tie Model of 21st century palliative care[2]

Patients diagnosed with incurable cancer or advanced disease may not identify themselves as requiring palliative care. A palliative approach addresses the need for pain and symptom management, and the psychosocial and spiritual support of patients and their families, even if they choose to undergo life-prolonging treatments such as chemotherapy, radiotherapy, and/or surgery.

A proactive chronic disease management approach will help prevent care gaps that may occur during transitions in care and/or when the patient is not supported by a cancer agency or community hospice palliative care program.

Assessment

A palliative approach is needed for patients living with active, progressive, life-limiting illnesses who need pain and symptom management and support around practical or psychosocial issues, have care needs that would benefit from a coordinated or collaborative care approach, and/or have frequent emergency room visits. Assess where patients are in their illness trajectory, functional status, and symptom burden. Clarify goals of care in a culturally sensitive manner.

Estimating prognosis allows optimal use of limited time for patients and families. Rapid change in clinical condition is an understandable and helpful sign. Although prognoses can only be estimated, poor prognostic factors include:

- progressive weight loss (especially > 10% over 6 months);
- rapidly declining level on the Palliative Performance Scale (PPS) (refer to *Appendix A: Palliative Performance Scale (PPS)*);
- dyspnea;
- dysphagia; and
- cognitive impairment.

▸ **Investigations** (Refer to *Appendix B: Possible Investigations and Interventions*)

Before ordering investigations, ensure that the results will change management to improve quality of life and/or prognostication, consistent with the patient's goals of care. Investigations may be indicated to:

- better understand and manage distressing clinical complications;
- assist in determining prognosis;
- clarify appropriate goals of care; and
- determine whether all options have been considered before admission to hospice.

Management

Evaluate performance status and symptom burden in order to accurately assess a patient's need for added supports and symptom management. Assessment scales are commonly used to facilitate communication and collaboration among providers (e.g., *Appendix A: Palliative Performance Scale (PPS)*, *Associated Document: Supportive & Palliative Care Indicators Tool (SPICT™)*, and *Appendix C: Edmonton Symptom Assessment System (ESASr)*).

1. Monitor patient's functional capacity

Use the PPS (refer to *Appendix A: Palliative Performance Scale*) to base care on a patient's functional capacity and prognosis. "The single most important predictive factor in cancer is performance status and functional ability – if patients are spending more than 50% of their time in bed/lying down, prognosis is likely to be about three months or less".[3] The SPICT™ outlines general and disease-specific indicators and is used to assess patients for the BC Palliative Care benefits program (*Associated Document: Information about BC Palliative Care Benefits*).

2. Coordinate care with allied health care providers

Organize care coordination around key illness transitions.[4] To enhance coordination with allied health providers involved in the care of the patient, the following steps are recommended:

Transition 1: Disease advancement (would not be surprised if patient died in the next year)

- Identify and register patient in need of palliative care.
- Initiate advance care planning.
- Identify the patient's values and beliefs.
- Clarify illness trajectory, possible complications, prognosis, and expected outcomes to inform goals of care.
- Consider the need for referral/coordination with Home and Community Care.
- Consider referral to Home Care Nursing when patient's PPS is transitioning from 70% to 60% or lower.

Transition 2: Decompensation, experiencing life-limiting illness (prognosis approximately six months and PPS 50%)

- Discuss care coordination.
- Consider hospice palliative care referrals.
- Consider an application to BC Palliative Care Drug Plan (Plan P) when patient is in last six months of life and has a PPS of 50% or less (refer to *Associated Document: Information about BC Palliative Care Benefits*).

Transition 3: Dependency and symptom increase (concern about ability to support client at home given increasing care needs)

- Initiate End-of-Life care planning, including assessment of preferred location for care.

Transition 4: Decline and last days (anticipating death in the next few days or weeks)

- Discuss medications required in home with Home Care Nursing.
- Assess if patient and family are comfortable with their End-of-Life care plan.
- Support required changes to End-of-Life care plan.

Transition 5: Death and bereavement

- Perform follow-up bereavement visit or call.

Refer to *Associated Document: Practice Support Program (PSP) End-of-Life Care Algorithm*.

3. Evaluate symptom burden

Use a scale like the ESASr (refer to *Appendix C: Edmonton Symptom Assessment System*) to assess symptom management. Pain and other symptoms are assigned a numerical rating between 0 (none) and 10 (most severe imaginable). Record the level and range of symptom severity, aiming for ≤ 3 and thoroughly assess for values ≥ 4. For ESASr symptom scores, using pain as an example, a useful frame of reference is:[5]

- 0-1: no pain or minimal pain.
- 3: able to watch TV or read newspaper without paying much attention to pain.
- 5: pain is too distracting to find much pleasure in activities (e.g., TV, reading).
- > 5: on the verge of being or already overwhelmed by pain.
- 10: the worse pain that you could imagine.

4. Establish goals of care with patients and families

As the underlying condition progresses, a patient's goals of care often become less disease-specific and more palliative.

Discuss a patient's wishes before clinical deterioration, possibly over several visits. Start by determining how much the patient desires to know about their disease and how much they desire to participate in decision making. When translation is required, a professional interpreter (rather than a family member) is advisable.

- Enquire regarding cultural and individual preferences. Factors such as age, gender, religion, and culture can affect patient and caregiver approach to palliative care and conversations about end of life. The Canadian Virtual Hospice has resources supporting culturally-sensitive palliative care including the online resource livingmyculture.ca
- Well-established communication strategies such as "The Serious Illness Conversation Guide"[6] can be helpful for discussing goals of care. Refer to *Associated Document: The Serious Illness Conversation Guide*.
- Determine the patient's understanding of the disease and condition.
- Discuss the anticipated course of the illness, treatment choices, and options in relation to a patient's preferences, needs, and expectations.
- Document advance care planning discussions and the existence of any Advance Directive/Representation Agreement.
- In the absence of a representation agreement, identify a Temporary Substitute Decision Maker (TSDM) (see page 28 of the My Voice guide, available at: http://www2.gov.bc.ca/gov/content/family-social-supports/seniors/health-safety/advance-care-planning).
- Document whether the following forms have been completed (refer to *Associated Documents: Resource Guide for Patients and Caregivers* and *Resource Guide for Practitioners*):
  - *No CPR* (http://www.healthlinkbc.ca/healthfeatures/no_cpr.html),
  - *Notification of Expected Death in the Home* (http://www2.gov.bc.ca/assets/gov/health/forms/3987fil.pdf), and
  - Medical Orders for Scope of Treatment (MOST) (refer to your health authority for more information).
- Establish plans for key decisions for acute episodes, crisis events, and declining function in relation to life-sustaining therapies and hospitalizations, considering all comorbidities.
- Clarify the patient's preferred place of care.
- Establish the caregiver's ability to provide care at home, if that is the patient's preference.
- Review the goals of care regularly, and when there is a change in clinical status.

5. Management strategies: non-pharmacologic

Lifestyle management

- Exercise: Regular exercise and activity has been proven to improve quality of life and function in cancer survivors.[7]
- Nutrition: Nutritional needs are different for patients with cancer as their appetite is often reduced and forcing additional food may contribute to nausea or vomiting. When the goal is life prolongation, a consultation with a dietitian may be helpful.
- Rest: Fatigue is a common accompaniment of cancer or its treatment. Adequate rest and pacing of activities is important. Poor sleep will contribute to a lower quality of life for both the patient and caregiver.

Family and caregiver support (refer to *Associated Document: Resource Guide for Patients and Caregivers*).

- Caregivers who take time off work can apply for the Employment Insurance (EI) Compassionate Care Benefit (refer to *Associated Document: Resource Guide for Patients and Caregivers*).
- Registration can be made to the Palliative Benefits Program when a patient's life expectancy is estimated to be six months or less (refer to *Associated Documents: BC Palliative Care Benefits Registration Form*).
- Completing the "Notification of Expected Death in the Home" form means families can avoid waiting for a physician or nurse to pronounce death.

Patient self-management (refer to *Associated Document: Resource Guide for Patients and Caregivers*)

- Encourage patients to have an advance care planning discussion with family and/or caregivers (for an example see the "My Voice" booklet in the Resource Guide).
- Symptom reporting: Suggest that patients record symptoms using a numerical rating scale (0 = none to 10 = extreme) and report symptoms consistently ≥ 4.
- Medications: Suggest that patients keep up-to-date medication profiles to carry with them to appointments and ER visits, including flow sheets to record breakthrough medication. Ensure that treatment of incident pain is understood.
- Bowel protocol: Constipation, an opioid side effect, does not improve over time. Provide written instructions for a bowel protocol that patients may self-administer (refer to BCguidelines.ca – *Palliative Care Part 2: Pain and Symptom Management* and *Associated Document: BCCA Bowel Protocol*).
- Providing help 24/7: Includes contact numbers (and hours, where applicable) for the GP on call, home nursing, and HealthLinkBC (call 811).

6. Management strategies: pharmacotherapy

Refer to BCguidelines.ca – *Palliative Care Guideline Part 2: Pain and Symptom Management*.

7. Referral to a specialist

Refer to *Appendix D: Indications for Referral to a Specialist*

8. Indications for referral to a tertiary palliative care unit

- Referral is indicated for control of pain and other symptoms when these cannot be met in the community, and for support for severe psychological, spiritual, or social distress.

9. Ongoing care

Planned visits

- A shared care plan, complete with planned follow-up visits, helps patients and families feel supported.
- Planned visits proactively anticipate care transitions and care crises (refer to PSP End-of-Life Care Algorithm: http://www.gpscbc.ca/psp-learning/end-of-life/tools-resources).
- Recommended visit frequency depends on prognosis. For example, if the illness is stable (PPS ≥70%), quarterly visits are recommended, but if the illness is changing monthly, then visit monthly. More frequent planned visits are warranted in the face of more rapid decline.

Monitoring and documentation (refer to *Appendix E: Cancer Management Flow Sheet*)

- Prognostic factors: Monitor for impending transition or crisis (e.g., new or accelerated weight loss, dyspnea, cognitive impairment, or change in PPS).
- Signs and symptoms: Each visit, record pain scale for each pain type and location.
- Medications: In addition to slow release opioid, record use of breakthrough medications, antinauseants, and bowel protocol. Also consider adjuvant analgesics (refer to BCguidelines.ca – *Palliative Care Guideline Part 2: Pain and Symptom Management*).
- Care plan: Ensure that supports for patient and family are arranged through Home and Community Care and also document discussions regarding patient goals and advance directives.

Palliative care emergencies

Table 1: Palliative care emergencies: recognize and respond

Emergency	Investigation	Intervention
Spinal cord compression	Stat MRI (CT if MRI is not available)	Dexamethasone, surgical decompression and/or radiotherapy
Superior vena cava compression	CT chest	Dexamethasone, SVC stent or radiotherapy
Pathological fracture	X-ray, CT	Internal/external fixation, sufficient analgesia
Acute renal failure / obstructive nephropathy	Ultrasound	Ureteral stents or nephrostomies
Other: airway obstruction, hemorrhage, seizures	As required	Anticipate and provide crisis orders

Abbreviations: MRI – magnetic resonance imaging; **CT** – computed tomography; **SVC** – superior vena cava

10. Allied health care and referral to the local hospice palliative care program

- High quality palliative care is generally provided via a team approach and GPs are important team members as they often have good relationships with patients and families and the knowledge and expertise to coordinate and provide care for the whole patient. Team members may include medical specialists, advanced practice nurses, home care nurses, social workers, case managers, pharmacists, occupational therapists, physiotherapists, dietitians, spiritual care workers, hospice volunteers, and home support workers.
- Patients are often best educated by allied health providers when it comes to topics such as myths about opioids, proper use of breakthrough medications, managing side effects, accessing help after hours, how to plan a home death, etc.
- Refer to the local hospice palliative care program early in the illness trajectory so patients and their families can learn what supports are available before they are required.

11. Medical Assistance in Dying (MAiD)

It is likely that some conversations about end of life may result in patients or families wanting to discuss Medical Assistance in Dying (MAiD). A palliative approach to care is appropriate for all people living with chronic life-threatening illness, whether or not they choose MAiD, and specialist palliative care consultation is encouraged if MAiD is being considered. MAiD is intentionally beyond the scope of this guideline. However, practitioners seeking information about it are directed to the following resources:

- BC Ministry of Health: http://www2.gov.bc.ca/gov/content/health/accessing-health-care/home-community-care/care-options-and-cost/end-of-life-care/medical-assistance-in-dying/information-for-providers

12. Actively dying: the End-of-Life Care check list

There are several points to consider when patients enter the dying phase:

- Review a patient's goals of care, preferred place of care, and what to do in an emergency.
- Refer the patient to home nursing if not already arranged.
- Consider hospice palliative care referrals.
- Ensure that the required forms are completed (No CPR, MOST DNR M1, Notification of Expected Death in the Home).
- Discontinue non-essential medications.
- Arrange for subcutaneous (SC)/transdermal medication administration or a drug kit to be placed in the home when a patient is no longer able to take medications by mouth (refer to *Appendix F: Typical Home Drug Kit and Subcutaneous Medication List*).
- Arrange for a hospital bed +/- pressure relief mattress.
- Arrange for a Foley catheter, as needed.
- Leave an order for a SC anti-secretion medication (e.g., atropine, glycopyrrolate).

13. Death and bereavement (Refer to BCguidelines.ca – *Palliative Care Part 3: Grief and Bereavement*)

Recognition of and preparation for complex grieving optimally takes place before death occurs (refer to risk factors for prolonged grief disorder (complicated grief) in BCguidelines.ca – *Palliative Care Part 3: Grief and Bereavement*).

At time of death:

- Personally contact the bereaved caregiver/family.
- Provide information about grief and what to expect and refer to resources.
- Arrange follow-up contact.

Resources

References

1. World Health Organization. *WHO Definition of Palliative Care*. [Cited 2016 Oct] Available from http://www.who.int/cancer/palliative/definition/en/
2. Hawley PH . The bow tie model of 21st century palliative care. J Pain Symptom Manage. 2014; Jan 47(1):e2-5.
3. Royal College of General Practitioners. The gold standards framework. Prognostic indicator guidance. 4th Edition. Oct 2011 [Cited 2016 Oct]. Available from http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf
4. Practice Support Program. PSP End of Life Care Algorithm. c2016 [Cited 2016 Oct]. Available from http://www.gpscbc.ca/psp-learning/end-of-life/tools-resources
5. Lynn J, Schuster J, Wilkinson A, Simon LN. Improving care for the end of life: a sourcebook for health care managers and clinicians. 2nd ed. Oxford University Press; 2008.
6. Bernacki RE and Block SD. Communication about serious illness care goals a review and synthesis of best practices. JAMA Intern Med. 2014 Dec;174(12):1994-2003.
7. Cramp F, Daniel J. Exercise for the management of cancer-related fatigue in adults. Cochrane Database of Systematic Reviews 2008, Issue 2. Art. No.: CD006145.

Appendices

- Appendix A: Palliative Performance Scale (PPS)
- Appendix B: Possible Investigations and Interventions
- Appendix C: Edmonton Symptom Assessment System (ESASr)
- Appendix D: Indications for Referral to a Specialist
- Appendix E: Cancer Management Flow Sheet
- Appendix F: Typical Home Drug Kit and Subcutaneous Medication List

Associated Documents

- BCGuidelines.ca – Palliative Care: Resource Guide for Patients and Caregivers
- BCGuidelines.ca – Palliative Care: Resource Guide for Practitioners
- BCGuidelines.ca – Palliative Care: Information about BC Palliative Care Benefits
- Supportive & Palliative Care Indicators Tool (SPICT™)
  http://www2.gov.bc.ca/assets/gov/health/forms/349_spict_tool.pdf
- Associated Document: Practice Support Program (PSP) End-of-Life Care Algorithm
  http://www.gpscbc.ca/sites/default/files/uploads/EOL-Algorithm-v8.2.pdf
- The Serious Illness Guide, developed by Ariadne Labs[6,] is also available as a resource on the BC Cancer Agency's Advance Care Planning website.
  http://www.bccancer.bc.ca/new-patients-site/Documents/ACP-serious-illness-conversation-guide-card.pdf
- BC Cancer Agency Bowel Protocol
  http://www.bccancer.bc.ca/managing-symptoms-site/Documents/HowToTreatConstipationCausedByYourMedications.pdf
- Notification of Expected Death in the Home
  http://www2.gov.bc.ca/assets/gov/health/forms/3987fil.pdf
- Associated Document: No Cardiopulmonary Resuscitation – Medical Order
  http://www2.gov.bc.ca/assets/gov/health/forms/302fil.pdf

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.

THE GUIDELINES AND PROTOCOLS ADVISORY COMMITTEE

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

Email: hlth.guidelines@gov.bc.ca
Website: 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 problem. **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 A: Palliative Performance Scale (PPS)

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable normal job/work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Occasional assistance required	Normal or reduced	Full or confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or drowsy +/- confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or drowsy +/- confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or drowsy +/- confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or coma +/- confusion
0%	Death	—	—	—	—

Copyright 2001 © Victoria Hospice Society

1. PPS scores are determined by reading horizontally at each level to find a 'best fit' for the patient which is then assigned as the PPS% score.
2. Begin at the left column and read downwards until the appropriate ambulation level is reached, then read across to the next column and downwards again until the activity/evidence of disease is located. These steps are repeated until all five columns are covered before assigning the actual PPS for that patient. In this way, 'leftward' columns (columns to the left of any specific column) are 'stronger' determinants and generally take precedence over others.

   Example 1: A patient who spends the majority of the day sitting or lying down due to fatigue from advanced disease and requires considerable assistance to walk even for short distances but who is otherwise fully conscious level with good intake would be scored at PPS 50%.

   Example 2: A patient who has become paralyzed and quadriplegic requiring total care would be PPS 30%. Although this patient may be placed in a wheelchair (and perhaps seem initially to be at 50%), the score is 30% because he or she would be otherwise totally bed bound due to the disease or complication if it were not for caregivers providing total care including lift/transfer. The patient may have normal intake and full conscious level.

Example 3: However, if the patient in example 2 was paraplegic and bed bound but still able to do some self-care such as feed themselves, then the PPS would be higher at 40 or 50% since he or she is not 'total care.'

3. PPS scores are in 10% increments only. Sometimes, there are several columns easily placed at one level but one or two which seem better at a higher or lower level. One then needs to make a 'best fit' decision. Choosing a 'half-fit' value of PPS 45%, for example, is not correct. The combination of clinical judgment and 'leftward precedence' is used to determine whether 40% or 50% is the more accurate score for that patient.
4. PPS may be used for several purposes. First, it is an excellent communication tool for quickly describing a patient's current functional level. Second, it may have value in criteria for workload assessment or other measurements and comparisons. Finally, it appears to have prognostic value.

Definition of Terms for PPS

As noted below, some of the terms have similar meanings with the differences being more readily apparent as one reads horizontally across each row to find an overall 'best fit' using all five columns.

1. Ambulation

The items 'mainly sit/lie,' 'mainly in bed,' and 'totally bed bound' are clearly similar. The subtle differences are related to items in the self-care column. For example, 'totally bed bound' at PPS 30% is due to either profound weakness or paralysis such that the patient not only can't get out of bed but is also unable to do any self-care. The difference between 'sit/lie' and 'bed' is proportionate to the amount of time the patient is able to sit up vs need to lie down.

'Reduced ambulation' is located at the PPS 70% and PPS 60% level. By using the adjacent column, the reduction of ambulation is tied to inability to carry out their normal job, work occupation or some hobbies or housework activities. The person is still able to walk and transfer on their own but at PPS 60% needs occasional assistance.

2. Activity & Extent of Disease

'Some,' 'significant,' and 'extensive' disease refer to physical and investigative evidence which shows degrees of progression. For example in breast cancer, a local recurrence would imply 'some' disease, one or two metastases in the lung or bone would imply 'significant' disease, whereas multiple metastases in lung, bone, liver, brain, hypercalcemia or other major complications would be 'extensive' disease. The extent may also refer to progression of disease despite active treatments. Using PPS in AIDS, 'some' may mean the shift from HIV to AIDS, 'significant' implies progression in physical decline, new or difficult symptoms and laboratory findings with low counts. 'Extensive' refers to one or more serious complications with or without continuation of active antiretrovirals, antibiotics, etc.

The above extent of disease is also judged in context with the ability to maintain one's work and hobbies or activities. Decline in activity may mean the person still plays golf but reduces from playing 18 holes to 9 holes, or just a par 3, or to backyard putting. People who enjoy walking will gradually reduce the distance covered, although they may continue trying, sometimes even close to death (e.g., trying to walk the halls).

3. Self-Care

'Occasional assistance' means that most of the time patients are able to transfer out of bed, walk, wash, toilet and eat by their own means, but that on occasion (perhaps once daily or a few times weekly) they require minor assistance.

'Considerable assistance' means that regularly every day the patient needs help, usually by one person, to do some of the activities noted above. For example, the person needs help to get to the bathroom but is then able to brush his or her teeth or wash at least hands and face. Food will often need to be cut into edible sizes but the patient is then able to eat of his or her own accord.

'Mainly assistance' is a further extension of 'considerable.' Using the above example, the patient now needs help getting up but also needs assistance washing his face and shaving, but can usually eat with minimal or no help. This may fluctuate according to fatigue during the day.

'Total care' means that the patient is completely unable to eat without help, toilet or do any self-care. Depending on the clinical situation, the patient may or may not be able to chew and swallow food once prepared and fed to him or her.

4. Intake

Changes in intake are quite obvious with 'normal intake' referring to the person's usual eating habits while healthy. 'Reduced' means any reduction from that and is highly variable according to the unique individual circumstances. 'Minimal' refers to very small amounts, usually pureed or liquid, which are well below nutritional sustenance.

5. Conscious Level

'Full consciousness' implies full alertness and orientation with good cognitive abilities in various domains of thinking, memory, etc. 'Confusion' is used to denote presence of either delirium or dementia and is a reduced level of consciousness. It may be mild, moderate or severe with multiple possible etiologies. 'Drowsiness' implies either fatigue, drug side effects, delirium or closeness to death and is sometimes included in the term stupor. 'Coma' in this context is the absence of response to verbal or physical stimuli; some reflexes may or may not remain. The depth of coma may fluctuate throughout a 24 hour period.

© Copyright Notice. The Palliative Performance Scale version 2 (PPSv2) tool is copyright to Victoria Hospice Society and replaces the first PPS published in 1996 [J Pal Care. 9(4):26-32].

Appendix B: Possible Investigations and Interventions

Reason for Investigation	Investigation	Possible Interventions
Reversible causes of bone pain	Bone scan (for metastases)	Radiotherapy, bisphosphonates
	X-ray/CT spine (for compression fracture)	Cementoplasty
Reversible causes of dyspnea	Chest x-ray (for pleural effusion)	Thoracentesis, pleurodesis
	CT pulmonary angiogram or V/Q scan (for pulmonary embolism)	Anticoagulation
	Pulmonary function testing	Bronchodilators
	Pulse oximetry, Arterial blood gases	Supplemental O_2 if hypoxemic
	CBC & diff, BNP	Treat infection, anemia, CHF if present
Reversible causes of confusion	Calcium (ionized) (for hypercalcemia)	Hydration, bisphosphonates, calcitonin
	Electrolytes (for hyponatremia)	—
	eGFR (for renal failure)	Hydration, ureteric stents
	CBC & diff/cultures (for sepsis)	Treatment of sepsis or infection
	CT head (for cerebral metastases)	Dexamethasone, radiotherapy
	KUB x-ray (for fecal loading)	Aggressive bowel protocol
	Bladder scan or in/out catheterization	Urinary catheterization
Reversible causes of fatigue	Hemoglobin (for anemia)	RBC transfusion
	Potassium (for hypokalemia)	Potassium supplementation
	eGFR, liver function tests (for renal or hepatic dysfunction)	
Reversible causes of jaundice	CT abdomen (for common bile duct obstruction)	Common bile duct stent
Reversible causes of nausea and vomiting	eGFR (for pre-renal failure)	Hydration
	3 views of abdomen (bowel obstruction)	Stent, venting gastrostomy, medical treatment of small bowel obstruction, bowel protocol
Obvious or suspected malignant ascites	Ultrasound	Diagnostic/therapeutic paracentesis
	Albumin, eGFR, liver function tests	Spironolactone/furosemide

Appendix C: Edmonton Symptom Assessment System

Alberta Health Services | Covenant Health

Edmonton Symptom Assessment System:
(revised version) (ESAS-R)

Please circle the number that best describes how you feel NOW:

No Pain	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Pain
No Tiredness *(Tiredness = lack of energy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Tiredness
No Drowsiness *(Drowsiness = feeling sleepy)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Drowsiness
No Nausea	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Nausea
No Lack of Appetite	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Lack of Appetite
No Shortness of Breath	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Shortness of Breath
No Depression *(Depression = feeling sad)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Depression
No Anxiety *(Anxiety = feeling nervous)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Anxiety
Best Wellbeing *(Wellbeing = how you feel overall)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible Wellbeing
No _____ Other Problem *(for example constipation)*	0	1	2	3	4	5	6	7	8	9	10	Worst Possible _____

Patient's Name _____

Date _____ Time _____

Completed by (check one):
- ☐ Patient
- ☐ Family caregiver
- ☐ Health care professional caregiver
- ☐ Caregiver-assisted

ESAS-r
Revised: November 2010

BODY DIAGRAM ON REVERSE SIDE

Please mark on these pictures where it is that you hurt:

Appendix D: Indications for Referral to a Specialist

Indication	Procedure	Physician Specialty
OBSTRUCTED LUMEN		
Stenting		
Common bile duct (CBD)	CBD stent	Gastroenterologist
Esophagus	Esophageal stent	Thoracic/GI surgeon
	Brachytherapy	Radiation oncologist
Duodenum	Duodenal stent	Gastroenterologist, GI surgeon
Colon	Colonic stent	
Ureter	Ureteric stent	Urologist
Superior vena cava (SVC)	SVC stent	Interventional radiologist
Bronchus	Radiotherapy, brachytherapy	Radiation oncologist
Venting		
High small bowel obstruction	Venting gastrostomy	GI surgeon
Lower bowel obstruction	De-functioning colostomy	
Ureter	Nephrostomy	Urologist
HEMORRHAGE		
Hemoptysis	Radiotherapy	Radiation oncologist
	Laser therapy	Respirologist
Hematemesis	Upper GI endoscopy	Gastroenterologist
	Radiotherapy	Radiation oncologist
Vaginal/uterine	Radiotherapy	Radiation oncologist
Rectal	Laser coagulation	Gastroenterologist
Hematuria	Radiotherapy	Radiation oncologist
Skin surface of tumour	Radiotherapy	Radiation oncologist
EFFUSION		
Pleural effusion	Thoracentesis	GP, radiologist
	Pleurodesis	Respirologist
	Pleural catheter	Thoracic surgeon
	Chemotherapy, radiotherapy	Medical oncologist
Malignant ascites	Paracentesis	GP, radiologist
	Peritoneal catheter	Interventional radiologist
PAIN		
Bone pain/pathological fractures	Radiotherapy	Radiation oncologist
Cancer of the pancreas	Coeliac plexus block	Anesthetist, gastroenterologist (U/S)
Severe opioid resistant pain	Ketamine by continuous subcutaneous infusion (CSCI) or Lidocaine CSCI	Palliative care physician
	Neuroaxial block	Anesthetist
Vertebral compression fractures	Vertebroplasty	Interventional radiologist, neurosurgeon
> 50% of the cortex of femur or humerus involved	Intramedullary nailing	Orthopedic surgeon

Appendix E: Cancer Management Flow Sheet

Review: Enter Review Date: dd-mm-yy			Baseline:	Date:	Date:	Date:	Date:
Prognostic		WEIGHT	lbs kg	lbs kg	lbs kg	lbs kg	lbs kg
Prognostic		Performance Status – PPS (0–100%)	%	%	%	%	%
Prognostic		Dyspnea (0–10)					
Prognostic		Cognitive Impairment/Confusion					
Symptoms (VAS 0-10)		Pain 1: location: type: (0–10)					
Symptoms (VAS 0-10)		Pain 2: location: type: (0–10)					
Symptoms (VAS 0-10)		Pain 3: location: type: (0–10)					
Symptoms (VAS 0-10)		Nausea (0–10)					
Symptoms (VAS 0-10)		Constipation Bowel Performance Scale (BPS)*					
Symptoms (VAS 0-10)		Other 1 (i.e., fatigue)					
Symptoms (VAS 0-10)		Other 2 (i.e., disease specific Sx – dysphagia)					
Signs		Lungs/ BP (query Hypotension)					
Signs		Liver/Spleen/Abdomen					
Signs		Spine/Bone					
Signs		CNS (query Cord Compression)					
Signs		Nodes					
Signs		Skin/Edema					
Lab		Use for tumour marker, Hb, INR, Ca++, albumin etc.)					
Medications	Anticancer Rx	Systemic:					
Medications	Anticancer Rx	Biological:					
Medications	Anticancer Rx	Hormonal:					
Medications	Anticancer Rx	Radiation:					
Medications	Anticancer Rx	Other: (bisphonate, paracentesis, RBC transfusion, etc.)					
Medications	Symptom Control	Opioid SR:					
Medications	Symptom Control	Opioid IR:					
Medications	Symptom Control	Antiemetic: (e.g.: metoclopramide)					
Medications	Symptom Control	Bowel Protocol*:					
Medications	Symptom Control	Adjuvant 1: (query neuropathic pain)					
Medications	Symptom Control	Adjuvant 2: (query dexamethasone)					
Care Plan		Forms: ☐ No CPR ☐ Expected Death in the Home ☐ MOST DNR1**					
Care Plan		Palliative Care Program Referral: Discussion ☐ ☐ Benefits Form ☐ Home Care					
Care Plan		Representative Agreement: Discussion ☐ My Voice ☐ Preferred Place of Care:					
Care Plan		Temporary Substitute Decision Maker (TSDM): Name: Phone:					

Copyright© 2006 Family Practice Oncology Network. Created 2006, Revised 2017

* Bowel Performance Scale (BPS): Refer to http://www.bccancer.bc.ca/family-oncology-network-site/Documents/BPSConstipationScale.pdf
** MOST (Medical Orders for Scope of Treatment): Refer to your health authority for more information

Appendix F: Typical Home Drug Kit and Subcutaneous Medication List

Contents of typical home drug kit *[1]	
• Atropine 1% drops – 5 mL bottle • Dexamethasone 100 mg/10 mL – 1 vial • DimenhyDRINATE 50 mg/mL – 8 amps • Fentanyl 25 mcg/hr patch – 2 patches • Fentanyl 50 mcg/hr patch – 2 patches • Glycopyrrolate 0.4 mg/2 mL – 5 vials • Haloperidol 5 mg/mL – 4 amps • Hydromorphone 2 mg/mL – 10 vials • Hydromorphone 10 mg/mL – 10 vials	• Hydromorphone 50 mg/mL – 2 vials • Lorazepam 1 mg sublingual – 16 tablets • Methotrimeprazine 25 mg/mL – 12 amps • Metoclopramide 10 mg/2 mL – 8 vials • Midazolam 5 mg/mL– 5 vials • Morphine 10 mg/mL – 20 amps • Morphine 50 mg/mL – 10 vials • Phenobarbital 120 mg/mL – 8 amps * All injectables are 1 mL size unless otherwise noted

Availability, usage procedures, and contents of emergency drug kits vary throughout the province; contact your local Home Health Care Office or Palliative Care Team for information.

Medications that may be given by the subcutaneous (SC) route in the primary setting[2] (maximum volume per SC injection site = 2 ml)	
• Atropine (0.6 mg/mL) • Calcitonin • Chlorpromazine (25 mg/mL) • Clodronate (30, 60 mg/mL) • Dexamethasone (4 mg/mL) • Dimenhydrinate (Gravol® 50 mg/mL)* • Diphenhydramine (Benadryl® 50 mg/mL) • Epinephrine • Fentanyl (50 mcg/mL) • Furosemide (10 mg/mL – note max. 20 mg.SC/site) • Glycopyrrolate (0.2 mg/mL) • Haloperidol (5 mg/mL) • Heparin • Hydromorphone (2,10, 50 mg/mL) • Hyoscine butylbromide (20 mg/mL) • Ketamine (10 mg/mL)	• Ketorolac (30 mg/mL) • Lidocaine • Lorazepam (4 mg/mL) • Low molecular weight heparin • Loxapine (50 mg/mL) • Methylnaltrexone (Relistor®) (20 mg/mL) • Midazolam (5 mg/mL) • Methotrimeprazine (Nozinan®) (25 mg/mL) • Metoclopramide (5 mg/mL) • Morphine (10, 50 mg/mL)** • Naloxone (0.4 mg/mL) • Octreotide • Ondansetron (2 mg/mL) • Potassium Chloride (2 mEq/mL) • Phenobarbital (120 mg/mL) • Ranitidine (25 mg/mL) • Scopolamine (0.4, 0.6 mg/mL) • Sufentanil (50 mcg/mL)

** caution – sterile SC abscesses and skin necrosis*
*** caution – SC nodules if concentration > 50 mg/ml*

References

1. Fraser Health Hospice Palliative Care. Palliative Care Kit Package. Fraser Health, B.C. Revised 2009.
2. Cherny N, Fallon M, Kaasa S,et al. Oxford Textbook of Palliative Medicine: 5th ed. New York: Oxford University Press; 2015.
3. Twycross R, Wilcock A, Dean M, et al. Palliative care formulary (Canadian edition). Nottingham: Palliative drugs.com Ltd; 2010.