



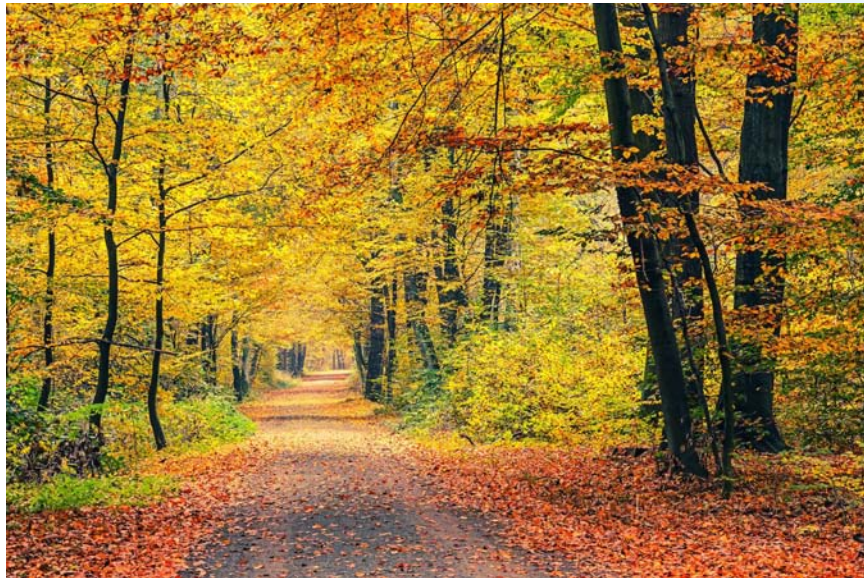
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Clinical Resource

Palliative Care Program Symptom Guidelines **3rd Edition**

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Author(s): Endorsed by NH Medical Advisory Committee
Revised by: Northern Health Palliative Care Consultation Team



November 2017

IMPORTANT NOTICE

In Northern Health there is an interdisciplinary consult team available for support in the management of palliative patients.

For support and education surrounding:

- Patient Assessment
- Pain and Symptom Management
- End-of-Life Decision Making

Nurse Consultants are available Monday through Friday (excluding statutory holidays) and can be reached at:

Northeast: 250-795-6134

Northwest: 250-631-4191

Northern Interior/Prince George: 250-565-7318

In the event the Nurse Consultants are unavailable, and there is urgent advice needed, physicians can:

1. Contact the Northern Health Palliative Care Physician on-call at 250-565-0000. Palliative on-call physicians are available 24hrs a day to assist physicians across Northern Health manage their palliative patients.
2. Provincial Palliative Care Consultation line at **1-877-711-5757**

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INTRODUCTION

Palliative care requires an interdisciplinary, total person approach with a goal to allow one an opportunity to achieve physical, emotional and spiritual comfort. The following definitions help us to understand Northern Health's vision and commitment to providing high quality services that are competent, compassionate and respectful of all people who are dying and their families.

Good palliative care is a continuum of services provided in accordance with a care plan developed collaboratively between the person with a life limiting illness, the person's primary care provider and members of the person's care team.⁽¹⁾

Palliative Care: "Palliative care" means the specialized care of people who are dying - care aimed at alleviating suffering (physical, emotional, psychosocial or spiritual), rather than curing. The term "palliative care" is generally used in association with people who have an active, progressive and advanced disease, with little or no prospect of cure".^(1,2)

Hospice Palliative Care: "Hospice palliative care" is a philosophy of care that stresses the relief of suffering and improvement of the quality of living and dying. It helps patients and families to:

- Address physical, psychological, social, spiritual and practical issues and their associated expectations, needs, hopes and fears;
- Prepare for and manage self-determined life closure and the dying process; and
- Cope with loss and grief during illness and bereavement^(1,2)

End of Life Care: "End of life care" is associated with advanced, life-limiting illnesses, and focuses on comfort, quality of life, respect for personal health care treatment decisions, support for the family, psychological and spiritual concerns".^(1,3)

Population Needs-Based Approach to Palliative Care: "Recognizes that individuals facing a serious illness have different needs, based on their unique health conditions, stage of disease and complexity of symptoms. Health care services and supports should therefore vary in type and intensity to most effectively meet the needs of the individual".⁽³⁾

Palliative Care Approach: Makes certain aspects of palliative care available to patients and families at appropriate times throughout the illness trajectory. After diagnosis and in the early stages of the illness the palliative care approach focuses primarily on:

- Open and sensitive communication about prognosis and illness trajectory;

- Advanced care planning;
- Psychosocial and spiritual support; and
- Pain and symptom management as required.

Later in the illness focuses on:

- Review of goals of care, and adjusting care strategies to reflect changes;
- On-going psychosocial support;
- Pain and symptom management; and
- Engagement of specialized palliative care providers as needed to address complex physical, psychosocial or spiritual symptoms.^(1,3)

Palliative approach requires upstream orientation to care delivery, adapts specialized palliative care knowledge and expertise and embeds it in care delivery, care processes and necessitates integration of care delivery.^(1,4)

What is Evidence-Based Palliative Care?⁽⁶⁾

Four important points are:

- “Evidence-based practice is the conscious, explicit and judicious use of current evidence in making decisions about the care of individual patients.
- It is more difficult to measure quality of life and altered outcomes in patients and families whose illness or frailty make it difficult to collect data.
- Outcome and quality of life measures need to be sensitive to the wider aspects of palliative care, not merely mortality, function, or absence of symptoms.
- Those working in palliative care must use existing research through appropriate systematic reviews to maximize the value of data yielded in caring for patients and families”.

What is a Clinical Practice Guideline (CPG)?

Clinical Practice Guidelines are “systematically developed statements to assist practitioner and patient decisions about appropriate healthcare for specific clinical circumstances”.⁽⁵⁾ “Their purpose is to make explicit recommendations with a definite intent to influence what clinicians do.”^(6, 7)

Why do we need to use Evidence-Based Clinical Practice Guidelines in Hospice Palliative Care?

We need to use Clinical Practice Guidelines in Hospice Palliative Care to help us provide the best care possible. Hospice Palliative Care Clinical Practice Guidelines will help us to:

- Inform healthcare providers, patients and families.

- Educate healthcare providers and the public.
- Include all members of the healthcare team.
- Improve clinical decision-making.
- Reduce variation in professional practice.
- Ensure equitable allocation of resources.
- Measure the quality of our care.
- Identify opportunities for improvement.
- Improve management of the healthcare system.
- Provide a foundation for the future.

What are the Palliative Care Symptom Guidelines?

These guidelines are an addition to the Provincial Symptom Guidelines developed in 2017; the provincial guidelines include 15 symptoms and the remainder are covered under the Northern Health Guidelines. These guidelines provide recommendations based on scientific evidence and expert clinical opinion. They provide practical and easy-to-follow advice to healthcare providers for effective patient care.

The NH Guidelines are intended to be a resource for the more common symptoms that are not covered under the Provincial Guidelines, and are experienced by adult patients (≥ 19 years of age) and their families who are living with advanced life threatening illness. As they are symptom guidelines only, they do not replace individual patient and family assessment and/or clinical judgment within the scope of professional practice. As these Hospice Palliative Care Symptom Guidelines are a work in progress and evidence changes, we encourage providers to be aware of this. We welcome and appreciate feedback.

What is the purpose of using the AGREE Instrument?

The purpose of using the Appraisal of Guidelines and Evaluation (AGREE) Instrument is to provide a framework for assessing the quality of clinical practice guidelines. The AGREE Instrument was used to ensure a structured and rigorous development process and as a self-assessment tool to ensure that the guidelines were sound before adopting the recommendations. It is suggested that the AGREE Instrument is perceived as reflecting the current state of knowledge in the field.⁽⁴⁾

The number of appraisers for each of the Northern Health Symptom Guidelines ranged between five and eight. All guidelines received two external reviews by a physician and pharmacist. Each guideline received an overall assessment based on four options:

1. 'strongly recommend'
2. 'recommend (with provisos and alterations)'
3. 'would not recommend'
4. 'unsure'

A summary of the quality of the Symptom Guidelines is currently under development.

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SYMPTOM ASSESSMENT ACRONYM

The Symptom Assessment Acronym is a tool to aid in a systematic assessment approach to whatever hospice palliative care symptom you are reviewing. Other aids are available however; in Northern Health we found this Symptom Assessment Acronym helpful. We recommend this tool for our Northern Healthcare providers to guide a consistent and comprehensive symptom assessment in hospice palliative care.

Assessment using Acronym O, P, Q, R, S, T, U, and V ^(1, 2, 3, 4, 5, 6, 7, 8, 9) *

O Onset	When did it begin? How long does it last? How often does it occur?
P Provoking/ Palliating	What brings it on? What makes it better? What makes it worse?
Q Quality	What does it feel like? Can you describe it?
R Region/ Radiation	Where is it? Does it spread anywhere?
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* also include a Physical Assessment (as appropriate for symptom)

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**Approved by: Northern Health Hospice Palliative Care Consult Team,
October 2008**

ASCITES

Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice setting in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for the assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing the symptom of ascites. This guideline does not address disease specific approaches in the management of ascites. Ascites may develop in 15% to 50% of patients with malignancies^(1, 2) but most cases (80%) of ascites will be related to cirrhosis.⁽³⁾

Definition of Terms

Ascites is the accumulation of fluid within the peritoneal cavity.⁽²⁾

Standard of Care

1. Assessment
2. Diagnosis
3. Education
4. Treatment: Non-pharmacological
5. Treatment: Pharmacological

RECOMMENDATION 1 - ASSESSMENT OF ASCITES

Ongoing comprehensive assessment is the foundation of effective management of ascites, including interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and appropriate diagnostics. Assessment must determine the cause, effectiveness and impact on quality of life for the patient and their family (see *Table 1*).

Table 1: Ascites Assessment using Acronym O, P, Q, R, S, T, U, and V*

O Onset	When did it begin? How often does it occur?
P Provoking/ Palliating	What brings it on? What makes it better? What makes it worse?
Q Quality	What does it feel like? Can you describe it? Have you noticed weight gain?
R Region/ Radiation	Where is the pressure? Is it spreading?
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom – nausea, loss of appetite, pain?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* also include a Physical Assessment (as appropriate for symptom)

Diagnostic Tests:

- Using abdominal radiography, ascites may demonstrate a ‘ground glass appearance’.⁽¹⁾
- Ultrasound or CT scan may be required to demonstrate small volumes of free peritoneal fluid.⁽¹⁾
- Diagnostic paracentesis may be required to elucidate the type of ascites and should be done on newly diagnosed cases of ascites.⁽¹⁾

Clinical Signs and Symptoms:

- Abdominal pressure, pain.^(1, 3, 4)
- Anorexia, early satiety, nausea, vomiting.⁽¹⁻⁴⁾
- Dyspnea and/or orthopnea.⁽¹⁻³⁾
- Increased abdominal girth.⁽²⁾
- Peripheral edema.^(1, 2)
- Reduced mobility.⁽⁴⁾
- Reflux esophagitis.⁽¹⁻³⁾
- Shifting dullness to percussion and a fluid thrill.^(2,5)

RECOMMENDATION 2 - DIAGNOSIS

Management should include treating reversible causes where possible and desirable according to the goals of care. The most significant intervention in the management of ascites is identifying underlying cause(s) and treating as appropriate (*See Causes of Ascites*). While underlying cause(s) may be evident, treatment may not be indicated, depending on the stage of the disease.

Identifying the underlying etiology of ascites is essential in determining the interventions required.

Causes of ascites:^(1, 3)

- Cirrhosis – is the predominant cause in 80% of cases. It presents as transudative ascites (ascitic fluid protein concentration of less than 2.5g/dl).
- Malignancy – causes 10% of cases. They are mostly (80%) epithelial related ovarian, uterus, breast, colon, gastric and pancreatic however the remaining 20% have tumours of primary unknown origin. The fluid produced in malignancy is exudative (ascitic fluid protein concentration of greater than 2.5g/dl).
- Heart failure – is responsible for 3% of cases. The fluid produced is transudative.
- Renal related – 3%, tuberculosis – 2%, pancreatitis – 2% and miscellaneous – 1% or absent.^(5, 9)

Types of ascites:⁽⁶⁾

- Raised hydrostatic pressure – caused by cirrhosis, congestive heart failure, inferior vena cava obstruction and hepatic vein occlusion.
- Decreased osmotic pressure – caused by protein depletion (nephrotic syndrome, protein-losing enteropathy), reduced protein intake (malnutrition) or reduced protein production (cirrhosis).

- Fluid production exceeding resorptive capacity – caused by infection or neoplasms.
- Chylous – due to obstruction and leakage of the lymphatics draining the gut.

RECOMMENDATION 3 - EDUCATION

Education of patient and their family should comprise discussion of treatment methods of ascites and the value of paracentesis when the patient becomes symptomatic.⁽³⁾

RECOMMENDATION 4 - TREATMENT: NON-PHARMACOLOGICAL

- Observation is appropriate when the condition is asymptomatic.⁽³⁾ Observation would include measuring the abdominal girth at a marked site each week⁽⁶⁾ as well as appropriately scheduled weight measurement.
- Paracentesis is the draining of ascitic fluid via a catheter inserted through the abdominal wall. This may be achieved under ultrasound guidance or in an outpatient setting for quick relief of symptoms. Generally, upwards of 5 litres of fluid may be removed with little risk of hypotension or hypovolemic shock when patient screening is applied.⁽⁶⁾ Intravenous hydration should be considered if the patient is hypotensive, dehydrated or known to have severe renal impairment and paracentesis is still indicated.⁽⁴⁾ If there is leakage over the paracentesis site an ostomy bag can be applied.^(2, 6) Single or repeated paracentesis in patients with advanced cancer does not significantly lower serum protein.⁽²⁾
- Peritoneal catheters (smaller bore catheter) may be useful when ascites is rapidly accumulating and requiring frequent paracentesis for symptom control. This significantly exposes the patient to the risk of peritonitis and is usually reserved for patients in the terminal phase of their illness, with a prognosis of weeks.^(3, 5, 7, 8)
- Radiation therapy and chemotherapy may be useful in cases where a meaningful response to tumour growth may be expected, such as lymphoma.⁽¹⁾
- Salt restriction plays an important role where fluid is transudative, but may also provide relief in patients with cancer and hepatic metastases.^(1, 3)
- A low fat diet and increase in medium-chain triglyceride intake may be useful in patients with chylous ascites.⁽¹⁾

RECOMMENDATION 5 - PHARMACOLOGICAL

Diuretics:

- Diuretics should be considered in all patients, but has to be evaluated individually. Patients with malignant ascites due to massive hepatic metastases seem to respond better to diuretics than those with malignant ascites due to peritoneal carcinomatosis or chylous ascites.⁽⁴⁾
- Diuretics may help with portal hypertension (hepatic metastases, heart failure and cirrhosis)⁽³⁾ and should be tried in most patients after their first abdominal paracentesis as approximately one-third of patients are shown to benefit.⁽⁹⁾
- Goal of diuretic therapy would be to achieve a weight loss of 0.5 to 1 kg per day.⁽⁶⁾
- Spironolactone 100 mg daily⁽²⁾ titrated slowly to 400 mg daily – titrated to remove enough fluid for comfort.^(1, 3, 6)
- Furosemide 40 to 120 mg daily may be added to spironolactone to improve the effect^(2, 3, 6) and prevent hyperkalemia. Furosemide given by continuous infusion is reported to produce significant diuresis and marked relief of ascites.⁽²⁾
- When utilizing diuretics monitor electrolytes, renal function, drug interactions and blood pressure weekly.⁽⁶⁾

Octreotide:

- Octreotide in doses of 200 to 600 mcg S.C. per day has shown promise in cases of ascites refractory to paracentesis.^(2, 10) Dosing frequency should be in two to three divided doses per day.

References

Information was compiled using the CINAHL, Medline (1996 to April 2006) and Cochrane DSR, ACP Journal Club, DARE and CCTR databases, limiting to reviews/systematic reviews, clinical trials, case studies and guidelines/protocols using ascites terms in conjunction with palliative/hospice/end of life/dying. Palliative care textbooks mentioned in generated articles were hand searched. Articles not written in English were excluded.

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**Approved by: Northern Health Hospice Palliative Care Consult Team,
October 2008**

DEPRESSION IN THE TERMINALLY ILL

Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice setting in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for the assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing the symptom of depression. This guideline does not address disease specific approaches in the management of depression.⁽¹⁻¹²⁾

Definition of Terms

Depression is a primary mood disorder, which, according to the DSM-IV-TR includes:

- a depressed mood and/or;
- an inability to experience pleasure in normally pleasurable acts (anhedonia).⁽¹³⁾

For major depression, the DSM-IV-TR states that one of the above symptoms must be present for a period of at least two weeks in combination with four or *more* of the following symptoms:⁽¹³⁾

- Feelings of overwhelming sadness and/or fear, or the seeming inability to feel emotion (emptiness).
- A decrease in the amount of interest or pleasure in all, or almost all, daily activities.
- Changing appetite and marked weight gain or loss. Note: ensure not related to disease process.
- Disturbed sleep patterns, such as insomnia, loss of rapid eye movement (REM) sleep, or excessive sleep (hypersomnia).
- Psychomotor agitation or retardation nearly every day.
- Fatigue, mental or physical, also loss of energy.
- Intense feelings of guilt, helplessness, hopelessness, worthlessness, isolation/loneliness and/or anxiety.
- Trouble concentrating, keeping focus or making decisions or a generalized slowing and obtunding (to dull or blunt, especially sensation or pain) of cognition, including memory.

- Recurrent thoughts of death (not just fear of dying), desire to just “lay down and die” or “stop breathing”, recurrent suicidal ideation without a specific plan, or a suicide attempt or a specific plan for committing suicide.
- Feeling and/or fear of being abandoned by those close to one.

Minor depression is a less-used term for a subclinical depression that does not meet criteria for major depression but where there are at least two symptoms present for two weeks.

Note: do not include symptoms that are clearly due to a general medical condition, or mood-incongruent delusions or hallucinations.

Standard of Care

1. Incidence and Risk Factors
2. Assessment
3. Diagnosis
4. Education
5. Treatment: Non-pharmacological
6. Treatment: Pharmacological

RECOMMENDATION 1 - INCIDENCE AND RISK FACTORS

Incidence and Risk Factors

People with advanced illness have a higher incidence of clinical depression than the general population. The prevalence of depression in the general population is 6 to 10%.⁽⁹⁾ Terminally ill patients have been found to have a higher level of both physical and emotional distress with 24% having depression.⁽¹⁴⁾ Clinical depression occurs in 15 to 30 % of cancer patients.

The diagnosis of depression in people with cancer is often under-diagnosed and under-treated.⁽⁹⁾

Risk factors include:

Non-cancer related risk factors:

- History of depression or family history of depression.^(3, 4, 9, 10)
- Two or more episodes in a lifetime.
- First episode early or late in life.
- Lack of family or social support.^(8, 10)
- Previous suicide attempts.^(3, 4, 9)
- Concurrent chronic illnesses such as: stroke or myocardial infarction.⁽¹⁵⁾

- Intercurrent substance abuse

Cancer-related risk factors:

- Depression at time of cancer diagnosis.^(3, 4)
- Advanced stage of cancer.^(4, 9, 10)
- Additional concurrent life stressors.^(3, 4, 9)
- Increased physical impairment or discomfort.^(4, 5, 8-10, 12)
- Being unmarried and having head and neck cancer.⁽¹⁰⁾
- Pancreatic and primary or metastatic brain cancers.^(4, 8, 10)
- Medications may contribute to depression (benzodiazepines, corticosteroids, anticonvulsants, methyldopa, propranolol, chemotherapeutic agents).^(4, 7, 8, 10)
- Chronic pain.^(3,4,8,9,10,12)

RECOMMENDATION 2 - ASSESSMENT OF DEPRESSION

Ongoing comprehensive assessment is the foundation of effective management of depression, including interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and appropriate diagnostics. Assessment must determine the cause, effectiveness and impact on quality of life for the patient and their family.^(1, 2, 5, 16)

Recognition and diagnosis of depression is variable depending on the clinical setting and the diagnostic acumen of those delivering end of life care.⁽⁹⁾

Suggested Questions for the Assessment of Depressive Symptoms in Adults with Terminal Illness^(15, 17)

How well are you coping with your illness. Well? Poor?	Well being
How are your spirits since diagnosis? During treatment? Down? Blue?	Mood
Do you cry sometimes? How often? Only alone?	Mood
Are there things your still enjoy doing, or have you lost pleasure in things you used to do before you became ill?	Anhedonia
How does the future look to you? Bright? Black?	Hopelessness
Do you feel you can influence your care, or is your care totally under others' control?	Helplessness
Do you worry about being a burden to family and friends during the treatment?	Worthlessness
Physical symptoms (Evaluate in the context of disease related symptoms)	

Author(s): Endorsed by NH Medical Advisory Committee

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Do you have pain that is not controlled?	Pain
How much time do you spend in bed?	Fatigue
Do you feel weak? Fatigue easily? Rested after sleep?	
Any relationship between how you feel and a change in treatment or how you otherwise feel physically?	Fatigue
How is your sleeping? Trouble going to sleep? Awake early? Often?	Insomnia
How is your appetite? Food tastes good? Weight loss or gain?	Appetite
How is your interest in sex? Extent of sexual activity?	Libido
Do you think or move more slowly than usual?	Psychomotor slowing

Adapted from Roth, AJ, Holland JC: Psychiatric complications in cancer patient. In: Brain MC, Carbone PP, eds.: Current Therapy in Hematology-Oncology. 5th ed. St Louis, Mo: Mosby-Year Book, Inc., 1995, pp 609-618.

Mnemonics commonly used to remember the DSM-IV criteria are:

- **SIGECAPS** (sleep, interest (anhedonia), **g**uilt, **e**nergy, **c**oncentration, appetite, **p**sychomotor, **s**uicidality)⁽¹⁷⁾ and;
- **DEAD SWAMP** (depressed mood, **e**nergy, **a**nhedonia, **d**eath (thoughts of), sleep, **w**orthlessness/guilt, **a**ppetite, **m**entation, **p**sychomotor).⁽¹⁷⁾

RECOMMENDATION 3 - DIAGNOSIS

Identifying the underlying etiology of depression is helpful in determining the interventions required.

The usual somatic symptoms of depressed patients (fatigue, loss of appetite, sleep disturbance, poor concentration, etc.) are often present in advanced cancer and terminal illness and cannot always be relied upon for diagnosis.^(4, 10)

Psychological symptoms of depression that are persistent, out of character and severe are of greater diagnostic value in patients with advanced illness.^(5, 18) In particular, watch for pervasive dysphoria, feelings of helplessness, hopelessness and worthlessness, guilt, loss of self-esteem, loss of interest and wishes to die. Even very mild or passive suicidal ideation is indicative of significant depression in terminally ill patients.^(1, 4-6)

If the diagnosis of depression is uncertain, consider psychiatric referral and a trial of antidepressant medication or therapy. When in doubt, treat.^(1, 6)

RECOMMENDATION 4 - EDUCATION

Depression is a distressing symptom to experience and witness. It is commonly under reported as many of the signs and symptoms are a feature of terminal illness.^(1, 5)

Reinforce to patient and family the importance of reporting symptoms that are causing distress, physical or psychological, as both may influence psychological well being.^(1, 5, 9)

Reinforce that if depression is diagnosed it can be managed. Treatment can be effective even when life expectancy is short.^(1, 5, 9)

Teach the purpose of Non-pharmacological and pharmacological measures and the goal of each.⁽⁵⁾

Teach that many antidepressant medications take time to become effective.⁽⁵⁾

RECOMMENDATION 5 - TREATMENT: NON-PHARMACOLOGICAL

Depression in patients with advanced disease is optimally managed by utilizing a combination of supportive psychotherapy, cognitive-behavioural techniques, and antidepressant medications.^(8, 12)

Always ensure that pain is well treated or alleviated. Uncontrolled pain is a major risk factor for depression and suicide among patients with cancer.^(1, 2, 4)

For patient and family consider psychosocial therapies, relaxation techniques, massage therapy and therapeutic touch.^(1, 4-6, 8, 12, 15)

RECOMMENDATION 6 - TREATMENT: PHARMACOLOGICAL

“Medication without ongoing contact is often seen as abandonment and never acceptable.”⁽¹⁹⁾

- Start with low doses and increase slowly.^(1, 5, 6, 8, 15)
- When anticipated survival time is short, consider psychostimulants due to their more immediate onset of effect.^(1, 5, 6, 8, 15)
- Consider side effects and additional therapeutic benefit (tricyclic antidepressants may benefit neuropathic pain but worsen constipation; avoid tricyclics in patients with cardiac conduction delays, etc.).^(1, 2, 5, 6, 8, 15)
- Withdrawal symptoms may be of significant importance in palliative patients who are unable to continue with oral medications.
- There are similar response rates when comparing antidepressant medications.⁽²⁰⁾

Selective Serotonin Re-uptake Inhibitors (SSRIs)^(1, 2, 5, 8, 10, 15)

Example: **Citalopram**,⁽⁶⁾ **Paroxetine**, **Fluoxetine**, **Sertraline**⁽¹⁵⁾

Initial and maintenance doses are specific for each of the SSRI's.

Initial dose for Citalopram: 10 to 20 mg per day to start, increasing at intervals of no less than one week. Maximum daily dose is 60 mg, although doses above 40 mg are not ordinarily recommended.⁽²⁰⁾ Usual maintenance dose is 20 to 30 mg per day.

- Have fewer side effects than tricyclic antidepressants (TCAs).
- Start SSRI at half the usual dose for the general population.
- Paroxetine and fluoxetine are active inhibitors of the enzyme responsible for metabolizing oxycodone and codeine to its active analgesic form. Concurrent use of these opioids and SSRIs can therefore result in decreased pain control.
- The sudden cessation of SSRI therapy when a patient is unable to swallow can produce a withdrawal syndrome. Withdrawal risk is greater with short-half life drugs such as paroxetine, lowest with long-half life drugs such as fluoxetine, and are of intermediate risk for other SSRI's.⁽²⁰⁾

Fluoxetine has less selective receptor sites and a much longer half-life than the other SSRIs and should not be the drug of choice. Switching to other antidepressants after having been on fluoxetine can be complicated due to the extended half life.⁽⁵⁾

Serotonin-Norepinephrine Reuptake Inhibitors (SNRIs)

Example: **Venlafaxine**⁽¹⁰⁾

Initial dose: Venlafaxine XR – 37.5 to 75 mg per day then maintenance dose: 150 to 375 mg per day.

Atypical Antidepressants

Example: **Bupropion**^(1, 2, 8, 15)

- Initial activating dose-related seizure-inducing potential. Contraindicated in patients with a history of seizure, in those with concomitant conditions predisposing to seizure, and in patients taking other drugs that lower seizure threshold.
- Low incidence of sedative, hypotension and anticholinergic side effects.
- Can cause over stimulation.
- Generally considered third line treatment.
- Initial: 100 mg per day then maintenance: 200 to 300 mg per day.

Example: Trazodone^(1, 10)

- Trazodone may cause hypotension including orthostatic hypotension and syncope; caution is required if it is given to patients receiving antihypertensive drugs and an adjustment in the dose of the antihypertensive medication may be required
- Increased serum digoxin and phenytoin levels have been reported with concurrent trazodone use.^(1,10)
- Treatment should be started with low initial doses of 25 to 50 mg daily in divided doses or in an evening single dose. The dose may be increased slowly to a maximum of 300 to 400 mg daily in ambulatory patients and to 600 mg daily in hospitalized patients.

Example: Mirtazapine^(10, 21)

- A tetracyclic antidepressant. Mirtazapine elimination is decreased in elderly persons.
- When used concomitantly with drugs that reduce the seizure threshold (e.g., phenothiazines), mirtazapine may increase the risk of seizure.
- Initial dose: 7.5 to 15 mg daily, maintenance dose: 15 to 45 mg daily.

Psychostimulants^(1, 2, 5, 10, 12)**Examples: Methylphenidate and Dextroamphetamine.**

- Consider this class of medication when life expectancy may be short,^(1, 5, 6, 8, 15) as these drugs work within hours to days.
- They often enhance opioid analgesia, reduce opioid sedation and improve appetite. They can improve attention, concentration and overall performance.
- Side effects include agitation, confusion, insomnia, anxiety and paranoia. Use cautiously in the elderly, avoid in delirious patients⁽¹⁾ and underlying medical conditions that may be compromised by increases in blood pressure or heart rate such as pre-existing hypertension, heart failure, recent myocardial infarction, or hyperthyroidism.⁽²¹⁾
- A common clinical practice is to start a psychostimulant and a SSRI together and then withdraw the stimulant while titrating the SSRI upward.
- Start methylphenidate at 5 mg PO at 8 AM and noon. Initial doses could be lower at 2.5 mg b.i.d. in very frail patients. Increase 2.5 to 5 mg every 1 or 2 days until desired effect is reached, or to a maximum daily dose of 30 mg per day.⁽²³⁾ Afternoon dosing can affect nighttime sleep and is generally not recommended.⁽⁵⁾

Tricyclic Antidepressants (TCA)^(1, 2, 5, 8, 10, 15)

Examples: **Nortriptyline, Amitriptyline, Desipramine, Imipramine and Doxepin**

- Requires a careful risk-benefit ratio analysis because the adverse effect profile may be troubling to patients in a palliative/hospice setting.⁽¹⁾ Effects include sedation and anticholinergic effects; dry mouth, blurred vision, urinary hesitancy, or retention, constipation.
- Avoid TCA's in patients with cardiac conduction delays,^(1, 2, 5, 6, 8, 15) coronary artery disease, or history of myocardial infarction in past six months.⁽²⁰⁾
- Adverse effects usually decrease 3 to 4 days after initiation of a TCA or after increasing the dosage.
- The secondary amines (desipramine and nortriptyline) generally have fewer side effects, such as sedation and anticholinergic effects, than the tertiary amines (imipramine, amitriptyline, and doxepin).⁽²³⁾
- The specific liver enzyme cytochrome P450 metabolism pathway may affect drug levels. From 5 to 10% of Caucasians have a recessive gene that results in deficient 2D6 metabolism which would affect desipramine and nortriptyline.⁽²⁰⁾ Twenty percent of Asians are deficit in the 2C19 enzyme affecting the metabolism of TCA's such as imipramine.⁽²⁰⁾
- Start at low doses (10 to 25 mg PO at bedtime) and increase by 10 to 25 mg PO every 4 days.
- Onset of antidepressant effect may take 2 to 4 weeks.
- May provide additional neuropathic pain benefits.

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**Approved by: Northern Health Hospice Palliative Care Consult Team,
October 2008**

HYPERCALCEMIA IN MALIGNANT DISEASE (PALLIATIVE MANAGEMENT)

Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice setting in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for the assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing the symptom of hypercalcemia. This guideline does not address disease specific approaches in the management of hypercalcemia.

Hypercalcemia is the most frequent metabolic emergency in oncology and occurs in 10% to 40% of cancer patients.⁽¹⁻³⁾ Hypercalcemia most commonly occurs in patients with advanced cancer and is an indicator of poor prognosis.^(1, 2, 4-6)

Definition of Terms

Hypercalcemia is defined as serum calcium (corrected) greater than 2.6 mmol/L.⁽³⁾

Standard of Care

1. Assessment
2. Diagnosis
3. Education
4. Treatment: Non-pharmacological
5. Treatment: Pharmacological

RECOMMENDATION 1 - HYPERCALCEMIA ASSESSMENT

Ongoing comprehensive assessment is the foundation of effective management of hypercalcemia, including interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and appropriate diagnostics. Assessment must determine the cause, effectiveness and impact on quality of life for the patient and their family.

Table 1: Hypercalcemia Assessment using Acronym O, P, Q, R, S, T, U and V*

O Onset	When did it begin? How often does it occur?
P Provoking/ Palliating	What brings it on? What makes it better? What makes it worse?
Q Quality	What does it feel like? Can you describe it?
R Region/ Radiation	
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom? Nausea/vomiting, constipation, weakness, loss of appetite, confusion or agitation?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* also include a Physical Assessment (as appropriate for symptom)

Signs And Symptoms:

The severity of symptoms are not always related to the degree of hypercalcemia but often reflect the rapidity of onset.⁽⁴⁾ Patients do not always exhibit all of the clinical features. The onset of hypercalcemia may be insidious.⁽³⁾

- **Neurological:** fatigue, lethargy, confusion, myopathy, hyporeflexia, seizures, psychosis and coma.⁽⁷⁾ The most frequent effect of hypercalcemia is delirium.⁽⁸⁾
- **General:** dehydration, polydipsia, polyuria.^(7, 9) Weakness and bone pain may also be present.⁽⁸⁾

- **GI:** anorexia, nausea and vomiting, weight loss, constipation, ileus and abdominal pain.⁽⁷⁻⁹⁾
- **Cardiac:** shortened Q-T interval, prolonged P-R interval, wide T waves, ventricular and atrial arrhythmias and bradycardia.^(7, 9) Arrhythmias, such as bradycardia, can be fatal.⁽⁸⁾
- **Renal:** polyuria, polydipsia, dehydration and development of kidney stones.⁽⁸⁾
- **Early:** polyuria, nocturia, polydipsia, dehydration, anorexia, easy fatigability, weakness, hyporeflexia, pain may be precipitated or exacerbated by hypercalcemia.⁽⁴⁾
- **Late:** apathy, irritability, depression, decreased ability to concentrate, obtundation, coma, profound muscle weakness, nausea and vomiting, constipation, increased gastric acid secretion, acute pancreatitis, visual disturbances, sudden death from cardiac dysrhythmias may occur if calcium rises fast, especially in patients taking digoxin.⁽⁴⁾

Laboratory Studies:

Always relate serum calcium levels to serum albumin levels

Method for Calculating Correction of Calcium Level to Reflect Albumin Level:

- If serum albumin is less than 40 grams per litre, increase measured calcium by 0.20 mmol per litre for every 10 grams of albumin below 40 grams per litre.
- If serum albumin is greater than 40 grams per litre, reduce measured calcium by 0.20 mmol per litre for every 10 grams of albumin over 40 grams per litre.

Alternatively:

- Corrected calcium (mmol/L) =
Measured calcium (mmol/L) + [0.02 x (40 – measured albumin g/L)].^(1, 3, 8)

Other possible abnormal results:

- Alkaline phosphatase – usually elevated, except in myeloma.⁽⁴⁾
- Chloride may be elevated in primary hyperparathyroidism.^(4, 5)
- BUN, creatinine may be elevated from renal damage.⁽⁴⁾
- Electrocardiogram – prolonged PR interval, widened QRS complex, shortened QT, widened T wave, bradycardia.⁽⁴⁾

RECOMMENDATION 2 - DIAGNOSIS

Management should include treating reversible causes where possible and desirable according to the goals of care. The most significant intervention in the management of hypercalcemia is identifying underlying cause(s) and treating as appropriate. While underlying cause(s) may be evident, treatment may not be indicated, depending on the stage of disease.

Whether or not the underlying cause(s) can be relieved or treated, all patients will benefit from management of the symptom using education, hydration and medications.

Identifying the underlying etiology of hypercalcemia is essential in determining the interventions required.

Causes:

- The majority of cases of humoral hypercalcemia of malignancy are associated with impaired gut absorption of calcium and low levels of vitamin D.⁽⁹⁾
- Secretion of parathyroid hormone-related protein by the tumour.^(6, 8, 10) This occurs in 80% of hypercalcemia cases.⁽⁸⁾
- Osteolytic skeletal metastases.^(4, 8) The extent of metastases does not correlate well with level of calcium.⁽⁴⁾
- Decreased renal clearance of calcium.⁽⁹⁾
- Increased gastrointestinal absorption of calcium in response to elevated levels of 1,25-dihydroxycholecalciferol (1,25 (OH)2D3, calcitriol) resulting from ectopic production of this vitamin by haematological neoplasms – this occurs rarely.⁽⁹⁾

Tumours most often associated with hypercalcemia:

- Multiple myeloma – 40% to 50%.^(4, 5)
- Breast – greater than 20% of cases with cancer-related hypercalcemia.^(4, 5)
- Lung – 20%, usually squamous cell, sometimes adenocarcinoma, rarely small cell.⁽⁴⁾
- Hypernephroma.⁽⁴⁾
- Squamous cell cancers of the head and neck and esophagus.⁽⁴⁾
- Thyroid.⁽⁴⁾
- Rarely or never – prostate or colorectal cancer.⁽⁴⁾

RECOMMENDATION 3 - EDUCATION

Teach patients at risk and their caregivers the signs and symptoms of hypercalcemia to promote early recognition of acute rises in serum calcium.⁽⁴⁾

RECOMMENDATION 4 - TREATMENT: NON-PHARMACOLOGICAL

Re-hydration

- Hydration alone may be sufficient for asymptomatic patients with borderline serum calcium.⁽⁴⁾
- Adequate hydration reduces serum calcium by a median of 0.25 mmol per litre.⁽³⁾
- All hypercalcemic patients are dehydrated due to polyuria and vomiting.⁽⁴⁾
- Hydration is appropriate for treatable hypercalcemia.⁽¹¹⁾ Re-hydration with 2 to 3 litres per day is now the accepted practice with daily serum electrolyte measurement to prevent hypokalemia and hyponatremia for cases of severe or symptomatic hypercalcemia.^(4, 9)
- Increase patient's oral fluid intake to 2 to 3 litres per day, as tolerated.⁽⁴⁾
- Most patients are usually 4 litres behind in their overall fluid balance when a diagnosis of hypercalcemia is made. Rehydration with normal saline should commence at 100 to 120 mL per hour I.V. or by hypodermoclysis based on patient's cardiac status (e.g., a slower rate should be used in patients prone to CHF).

Mobilization:

- Mobilization of the patient is important, in that it slows down the loss of skeletal calcium associated with immobility.⁽⁴⁾

Diet:

- Low calcium diet is needed to control hypercalcemia caused by elevated 1,25 (OH)₂D₃ but they are unpalatable, impractical and exacerbate malnutrition and have no place in palliative therapy.^(3, 4, 9)

RECOMMENDATION 5 - TREATMENT: PHARMACOLOGICAL

Bisphosphonates:

- Bisphosphonates are appropriate to administer when serum calcium (corrected) is greater than or equal to 3 mmol per litre or when serum calcium (corrected) is less than 3 mmol per litre when accompanied by symptoms.⁽³⁾

- Bisphosphonates cause a fall in calcium in 48 hours.⁽⁹⁾ These agents are very useful and well tolerated but are quite expensive.⁽¹⁾
- Oral bisphosphonates (like clodronate or alendronate) can be used, but in many palliative care patients are not well tolerated. Parenteral drugs including pamidronate and zoledronic acid have been used with success⁽⁸⁾ and are better tolerated and more effective than oral.⁽⁵⁾
- Do not give bisphosphonates until the patient is fully re-hydrated and has an adequate urine output.⁽⁴⁾
- Recheck serum calcium, electrolytes, urea, and creatinine on the 3rd day after administering bisphosphonates.⁽¹⁾
- Renal failure is the most serious adverse effect.⁽³⁾ Bisphosphonates are contraindicated in patients with serum creatinine greater than 400 umol per litre or calculated creatinine clearance of less than 10 mL per minute.⁽³⁾
- In patients with pre-existing renal disease and a serum creatinine less than 265 umol per litre, no change in dosage, infusion time or interval of pamidronate is required for multiple myeloma patients.⁽¹²⁾
- Caution is required in patients receiving other drugs that may affect renal function (NSAIDS, ACE inhibitors, aminoglycosides).⁽³⁾
 - **Pamidronate** 30 to 90 mg I.V. for severely elevated calcium (over 3.5 mmol per Litre) use 90 mg I.V. bolus in 250 mL^(13, 14) to 500 mL NS^(4, 10) over 60^(13, 14) to 90 minutes.^(2, 9)
 - Pamidronate has been shown to be superior to clodronate in terms of duration of normal calcium levels achieved.^(2, 9)
 - Best given with acetaminophen, 500 mg PO or rectally to prevent pamidronate fever.⁽⁴⁾
 - Usual expected duration of effect of pamidronate is 3 to 4 weeks.^(1,3)
 - **Clodronate** 1500 mg I.V. over 4 hours in 250 or 500 mL NS^(1, 3, 10) or 500 mg I.V. daily for 3 days – dilute in 500 mL NS.
 - Usual expected duration of action of clodronate is 2 weeks.^(1, 3)
 - Dose adjustment for decreased renal function: if creatinine clearance is 10 to 50 mL per minute a dose reduction of 25% to 50% is recommended.⁽³⁾
 - **Zoledronic acid** 4 mg in 100 mL NS over 15 minutes I.V.^(1, 2, 9, 12) Zoledronic acid has been shown to achieve normal serum calcium levels in more patients, faster and with longer duration than Pamidronate.⁽⁹⁾

- Usual expected duration of effect of zoledronic acid is 4 to 6 weeks.⁽¹⁾
- Useful for refractory hypercalcemia treatment.⁽¹⁾
- Fever is a common side effect of zoledronic acid, with renal impairment seen rarely.⁽⁵⁾
- Zoledronic acid has been found to be effective in reducing and delaying bone complications across a broad range of solid tumours and multiple myeloma.⁽²⁾
- Dose adjustment for decreased renal function:⁽³⁾

Baseline Creatinine Clearance (mL/min)	Zoledronic Acid Recommended Dose
Greater than 60	4 mg
50 to 59	3.5 mg
40 to 49	3.3 mg
30 to 39	3 mg

Calcitonin:

- Calcitonin 4 to 8 international units per kg given S.C. or I.M. q12h (can titrate up to q6h).^(3, 4, 16)
- Calcitonin has a rapid onset of action – approximately 4 hours⁽⁹⁾ but has a shorter duration of action⁽⁴⁾ and is very useful when a rapid lowering of serum calcium is required^(1, 3-5, 16) but needs to be combined with bisphosphonates.^(3, 5, 16)
- Possible side effects: flushing, mild nausea, crampy abdominal pain.⁽⁴⁾ A small risk of hypersensitivity exists due to salmon derivation.⁽³⁾

Steroids:

- Corticosteroids may lower serum calcium if they have an antineoplastic effect on the underlying malignancy.⁽³⁾ They should be reserved for situations in which bisphosphonates are not easily accessible or are ineffective or in which other indication for corticosteroids (pain or nausea) exist.⁽³⁾
- Prednisone 40 to 100 mg daily⁽⁹⁾ for up to one week.⁽⁴⁾
- Hydrocortisone 100 mg I.V. q6h.⁽⁷⁾
- Dexamethasone 4 mg S.C. q6h for 3 to 5 days.
- Steroids are particularly useful for hypercalcemia seen with lymphomas and multiple myeloma.⁽⁵⁾

Drugs promoting hypercalcemia (thiazide diuretics, lithium, ranitidine, cimetidine, vitamins A and D and preparations containing calcium) should be withdrawn.^(4, 9, 15)

The routine use of furosemide in conjunction with hydration to promote calcium excretion is not recommended, because of the risk of volume and electrolyte depletion.⁽³⁾

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Information was compiled using the CINAHL, Medline (1996 to April 2006) and Cochrane, DSR, ACP Journal Club, DARE and CCTR databases, limiting to reviews/systematic reviews, clinical trials, case studies and guidelines/protocols using hypercalcemia terms in conjunction with palliative/hospice/end of life/dying. Palliative care textbooks mentioned in generated articles were hand searched. Articles not written in English were excluded.

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**Approved by: Northern Health Hospice Palliative Care Consult Team,
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MALIGNANT BOWEL OBSTRUCTION

Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice setting in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for the assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing the symptom of bowel obstruction. This guideline does not address disease specific approaches in the management of bowel obstruction.

Obstruction occurs in 3% to 42% of malignancies, with the higher number in patients with ovarian cancer.⁽¹⁻⁶⁾ Most commonly seen with colorectal cancer and ovarian cancer^(7, 8) but may occur with any cancer having an abdominal or pelvic presence, usually occurring in advanced stages of the disease.^(1, 3, 9-12)

Obstructions may be partial or complete, acute or insidious and reversible or irreversible.⁽¹⁾ Obstruction usually leads to local inflammation with luminal accumulation of intestinal fluids, gases and solids producing symptoms and creating a vicious cycle of distension and secretion.^(1, 5, 11) The small bowel is more commonly involved than the large bowel (61% versus 33%).⁽¹³⁾

Definition of Terms

Bowel obstruction occurs when there is blockage of the forward flow of gastric and intestinal contents through the gastrointestinal tract and can occur in the large or small bowel.^(2,14,15) It can be due to direct infiltration, intraluminal obstruction or external obstruction. This may occur due to tumour growth, adhesions, carcinomatosis, fecal impaction, pharmacotherapy and/or neuropathy.^(2, 5, 9)

Standard of Care

1. Assessment
2. Diagnosis
3. Education
4. Treatment: Non-pharmacological
5. Treatment: Pharmacological

RECOMMENDATION 1 - ASSESSMENT OF BOWEL OBSTRUCTION

Ongoing comprehensive assessment is the foundation of effective management of bowel obstruction, including interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and the appropriate diagnostics (see *Table 1*). Assessment must determine the cause, effectiveness and impact on quality of life for the patient and their family.⁽⁹⁾

Table 1: Bowel Obstruction Assessment using Acronym O,P, Q, R, S, T, U and V*

O Onset	When did it begin? Have you had this before?
P Provoking/ Palliating	What brings it on? What makes it better? What makes it worse?
Q Quality	What does it feel like? Can you describe it? Is the pain constant, colicky or crampy?
R Region/ Radiation	Where is it? Does it spread anywhere
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom? Nausea/vomiting, constipation, weakness, loss of appetite, confusion or agitation?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* also include a Physical Assessment (as appropriate for symptom)

- Plain abdominal films may demonstrate dilated loops of bowel, air and fluid levels, fecal impaction and/or the obstruction.^(1, 5, 9, 11)

- Gastrograffin contrast studies may further elucidate the point of obstruction and is preferred over barium, because barium can interfere with other studies.⁽¹⁾
- CT scans may be required to determine the extent of the disease and help plan appropriate further treatments.⁽¹⁾
- It is difficult to differentiate between partial and complete obstruction.^(1, 5, 14)
- The functional adrenal insufficiency in cancer may contribute to intestinal obstruction in patients with carcinomatosis peritonei.⁽¹⁶⁾

RECOMMENDATION 2 - DIAGNOSIS

Identifying the underlying etiology of bowel obstruction is essential in determining the interventions required. The type of obstruction, the condition of the patient and the predicted prognosis determine the treatment plan for the obstruction.^(12, 14)

Clinical symptoms:

- Pain may be constant, crampy or colicky^(1,3,11,13,16) resulting from the accumulation of secreted bowel fluid.^(2,5,8) Suspect bowel strangulation if refractory to opioid analgesics.⁽⁵⁾
- Abdominal distension.^(2, 5, 11, 16)
- Nausea and vomiting are eventually present but may vary in their intensity based on the level of the obstruction and the degree of compromise of bowel patency. In obstructions of the stomach, duodenum, pancreas or jejunum, vomiting will develop early and in large volumes.^(1, 2, 5)
- Bowel sounds are usually altered and may be tympanic, high pitched, diminished or absent.^(5, 9)
- Abdominal exam may demonstrate visceral or peritoneal irritation or may prove benign.⁽¹⁴⁾
- In complete obstruction there will be an absence of feces and flatus.^(1, 5, 11)
- Fatigue.⁽¹¹⁾
- Anorexia.⁽¹¹⁾
- Diarrhea with partial obstruction (overflow diarrhea).^(2, 5)

Causes of Bowel Obstruction⁽⁹⁾

Tumour mass	Single or multiple Invasion and blockage of bowel (apple core) Extrinsic compression
Constipation	Impacted feces, obstipation
Adhesions	Post-operative Malignant Post-radiation
Volvulus	Around tumour Around adhesions Around fistula
Ileus	Infection, peritonitis Drugs
Peritonitis	Infection, bleeding
Massive ascites	

RECOMMENDATION 3 - EDUCATION

The patient and family should be involved in discussions. Information should be reinforced so that appropriate decisions regarding disease modifying or symptom modifying therapies can be made.^(3, 9, 13)

RECOMMENDATION 4 - TREATMENT: NON PHARMACOLOGICAL

- Acute or initial treatment may include; keeping patient NPO, administering intravenous or subcutaneous fluids and performing nasogastric tube drainage. Nasogastric tube drainage should be an intermittent and temporary measure for initial treatment and decompression or while waiting to make other treatment decisions.^(1, 2, 4-7, 9-14)
- Hydration should be considered in patients where dehydration causes agitated confusion or results in renal failure causing opioid metabolite accumulation leading to myoclonus or seizure^(5, 6, 14) and should be considered on an individual basis.⁽²⁾
- Total parenteral nutrition should only be considered for the patient who would have clinical or life-extending benefit. It is not recommended for most terminally ill patients^(5, 9) and is best used in patients with a true long term prognosis.⁽¹³⁾
- Good mouth care and ice chips should be given for dry mouth.^(2, 9, 13)
- Nasal care should be provided to patients who have a nasogastric tube inserted.⁽¹⁴⁾
- Support should be offered to patient and family as they confront the terminal nature of the disease.^(9, 13, 14)
- Give small, low residue meals for patients with controlled nausea and vomiting.⁽²⁾

Surgical Options:

- The rate of inoperable patients ranges from 6% to 50%.^(6, 10)
- While surgery is the primary treatment for malignant bowel obstruction, not every patient will be a suitable candidate because of poor prognosis or advanced disease.^(1, 9)
- Surgery should be avoided in patients exhibiting: palpable abdominal and pelvic mass, ascites exceeding three litres, multiple obstructive sites and pre-operative weight loss of greater than nine kilograms.^(4, 6, 12, 17)
- Interventions may include resection, bypass, stenting and venting gastric or jejunal tubes⁽⁴⁾ and should be considered when symptoms have not been relieved after 48 to 72 hours of conservative medical management.^(1, 9) Stenting and gastric or intestinal venting using percutaneous endoscopic gastrostomy tubes (PEG) are less invasive, generally well tolerated and can be done under sedation.^(3-7, 12, 18-20)
- Mortality from surgery may approach 30% hence careful clinical judgment must be exercised and involving other disciplines and family is advisable.^(1, 9, 17)
- Prognosis, disease progression, patient's wishes and co-morbidities must be considered.⁽¹⁾

RECOMMENDATION 5 - TREATMENT: PHARMACOLOGICAL

Treatment should always be parenteral as absorption via PO route is variable.

- Corticosteroids for inflammation - dexamethasone 4 to 16 mg S.C. daily for incomplete or small bowel obstruction.^(1, 5-7, 9) These were found to work better in patient populations that were not already taking steroids prior to the obstruction⁽⁷⁾ and should be discontinued if the patient does not respond to steroid treatment within 4 to 5 days.⁽¹³⁾
- Antiemetics for nausea – combinations work best.^(5, 9, 17) See *Northern Health Hospice Palliative Care Symptom Guidelines for Nausea and Vomiting*.
- Motility agents to stimulate bowel in cases of incomplete obstruction – metoclopramide 5 to 20 mg S.C. q.i.d.^(5, 6, 9, 17) It is contraindicated in complete bowel obstruction.^(5, 6, 13)
- Anti-motility agents may have a role in complete obstruction - hyoscine butylbromide 10 to 20 mg S.C. q.i.d.^(1, 2, 11, 21, 22)
- Anti-secretory agents - octreotide 50 to 150 mcg S.C. t.i.d.^(5, 9) or 300 to 900 mcg by continuous S.C. infusion.^(2, 5-7, 10, 11, 21) Octreotide was found to be more effective than hyoscine butylbromide in relieving gastrointestinal symptoms of advanced cancer patients.⁽²¹⁾ In another study, octreotide resulted in significantly reduced gastrointestinal secretions by the second day of treatment⁽¹⁰⁾ and it was also shown to reduce levels of nausea and

pain when compared to scopolamine butylbromide⁽¹⁰⁾ or hyoscine butylbromide.⁽¹¹⁾

- Analgesics for pain may be given via S.C. or I.V. or transdermal route.^(1, 5, 7, 9, 10, 21)
- Analgesics should not be avoided fearing aggravating an obstruction.⁽⁷⁾
- Cathartics via rectal route in cases of fecal impaction.⁽⁹⁾

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Information was compiled using the CINAHL, Medline (1996 to April 2006) and Cochrane DSR, ACP Journal Club, DARE and CCTR databases, limiting to reviews/systematic reviews, clinical trials, case studies and guidelines/protocols using bowel obstruction terms in conjunction with palliative/hospice/end of life/dying. Palliative care textbooks mentioned in generated articles were hand searched. Articles not written in English were excluded.

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REFRACTORY SYMPTOMS AND PALLIATIVE SEDATION THERAPY

How can Palliative Care help you manage difficult symptoms? What about refractory symptoms?

Palliative care aims to relieve suffering and to help patients and families with life limiting illness live as actively as possible with good quality of life, neither hastening nor postponing death. Although many palliative patients experience symptoms, most are well managed when appropriate medications and treatments are used. The [Northern Health \(NH\) Hospice Palliative Care \(HPC\) Symptom Guide](#) and [NH HPC Psychosocial Care Guide](#) are valuable evidence based resources to help manage symptoms.

At times, symptoms prove more difficult to manage or do not respond to commonly used medications. In these cases, palliative care consultation can provide a key interdisciplinary resource. Northern health has an interdisciplinary team of palliative care consultants that are available to support care providers. The [contact list](#) can be found on the NH iportal site.

The NEW HPC Symptom Guide '*Refractory Symptoms and Palliative Sedation Therapy*' will help healthcare teams determine when a symptom is **refractory** versus **difficult** to manage. Refractory symptoms are those where "all possible treatments have failed, or it has been determined that there is no method within the time frame and risk: benefit ratio the patient can tolerate" (Levy and Cohen, 2005)

Consultation is strongly recommended to determine if a physical symptom is refractory. Consultation MUST be sought when the refractory symptom is 'existential' e.g. non-physical suffering.

The guideline provides criteria and direction for when the extraordinary intervention of Palliative Sedation Therapy (PST) is an appropriate therapy. PST may only be considered for a patient with terminal illness in the last days of life experiencing refractory symptoms. Although sedative medications and brief periods of sedation may be the *unintended but predictable* adverse effect of medication used in aggressive symptom management, this is different than PST. **PST aims to relieve intolerable suffering from refractory symptoms by the intentional lowering of a patient's level of consciousness in the last days of life by the proportional and monitored use of non-opioid sedative medications.** Opioids alone do not provide adequate sedation and should never be used for that purpose. Pharmacological treatment choices appropriate for PST are outlined in detail in the guide including anti-anxiolytics, neuroleptics, and sedative anti-epileptics.

Users are guided through a process of informed consent with active involvement of the patient and substitute decision maker(s) and interdisciplinary health team. Recommendations for discussions, documentation, and patient and family support are included. Guide for initiating and adjusting sedation proportional for symptom relief are outlined.

PST is an extraordinary intervention requiring expertise in clinical care, communication and interdisciplinary team process. When used appropriately, the patient experiences symptom relief until death occurs through the natural course of the underlying disease, usually within hours to days. ^(deGraff and Dean, 2007)

NH-HPC Consultation team is available for support and guidance. If palliative sedation therapy is being considered it requires review of this Guide as well as the [Decision Support Tools](#) available on the palliative care iportal page.

If palliative sedation therapy is initiated in Northern Health, please follow the link to access a tool intended to obtain your **feedback and assess the utility of the guide**. Feedback is welcomed from any member of the patient care team using the [Palliative Sedation Clinician Feedback Form 10-513-7012](#).

Rationale

The NH Refractory Symptom and Palliative Sedation Therapy Guide has been adapted from the FH Refractory Symptom and Palliative Sedation Therapy Guide 2011 which underwent an extensive external and internal review process including appropriate interdisciplinary, ethics, legal, and practice council committees within Fraser Health.

The NH Refractory Symptom and Palliative Sedation Therapy Guide is available as a resource for generalist inter-professional primary care providers working in various settings in Northern Health, British Columbia. This Guide has been approved by the NH HPC Consultation team as a best practice resource.

Scope

This guideline provides recommendations for the on-going assessment and symptom management of adult patients (age 19 years and older) living with advanced life threatening illness and experiencing refractory symptoms in the last days of life. For the management of a specific symptom, see *Northern Health Hospice Palliative Care Symptom Guide on the relevant symptom*.

This guideline does not include or suggest any support for practice of physician assisted suicide (PAS) or euthanasia. It does not cover emergency sedation for crises such as exsanguinations and respiratory crisis in the last minutes of life.

Background

Palliative care aims to relieve suffering and to help patients live as actively as possible, neither hastening nor postponing death. NH HPC Symptom Guide are valuable evidence based resources for managing symptoms. Although many patients with life threatening illness experience symptoms, most are well managed when appropriate medications and treatment approaches are used.

When symptoms are difficult to manage, NH-HPC consultation provides a key interdisciplinary resource for providers, patients and families.

In rare circumstances, thorough interdisciplinary assessment and treatment of a palliative patient's symptoms may not result in sufficient relief. When all possible treatments have failed, or no methods are available for palliation within an acceptable time frame, the symptom is determined to be refractory.

The incidence and type of refractory symptoms vary significantly according to patient demographics, regional access to adequate pain management and palliative care, and the availability of interventions, healthcare professional treatment patterns and the standards of care.^(1,2) The most common refractory symptoms are: delirium, dyspnea, pain, nausea and vomiting.^(1,3-5)

It is strongly recommended that a HPC consultation is sought to determine that a physical symptom is refractory, to assist decision making, and to support managing sedation therapy. Consultation must be sought when the refractory symptom is thought to be existential suffering.

Palliative Sedation Therapy (PST) is an infrequent and extraordinary intervention that requires inter-professional expertise and effective communication skills of the caregivers involved.^(5, 6)

Definition of Terms

Palliative Care is defined by the World Health Organization 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 or postpone death;
- integrates the psychological and spiritual aspects of patient care;

- 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;
- will enhance quality of life, and may also positively influence the course of illness;
- 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."⁽²⁰⁾

Refractory Symptoms (also “Intractable”, “Unbearable”) are physical and emotional symptoms for which “all possible treatments have failed, or it is determined that any methods that are available would not work within a reasonable time frame, would cause undue suffering for the patient, or would cause intolerable or unacceptable side-effects.”⁽²⁾ Often geography and the relative availability of interventions influence the determination of refractoriness.⁽¹⁾

Difficult Symptoms, by contrast could possibly respond within a tolerable time frame, to aggressive interventions that yield adequate relief and preserve consciousness, without excessive adverse results.^(2, 6)

Suffering (also “Distress”, “Anguish”) is “a sense of helplessness or loss in the face of a seemingly relentless and unendurable threat to quality of life or integrity of self”.⁽²¹⁾ Although pain, dyspnea, delirium, nausea and vomiting are frequent causes of suffering at the end of life, hopelessness, remorse, anxiety, loneliness, and loss of meaning also cause suffering. Suffering involves the whole person in physical, psychological, and spiritual ways and can also affect family, friends, and caregivers.⁽²²⁾

Existential Suffering (also “Psychic” or “Spiritual” Suffering, Distress or Anguish) describes the experience of patients facing terminal illness who may or may not have physical symptoms but report distress that is related to “the meaninglessness in present life”, hopelessness, being a burden on others, feeling emotionally irrelevant, dependant, isolated or grieving, that is unrelated to a psychiatric disorder or social isolation.^(23,24) Existential distress specifically develops as a result of facing one's own mortality.

Moral Distress occurs as an “emotional and spiritual response when an individual is obligated to act in a manner which breaches their personal belief and value system” and/or “arises when one knows the right thing to do, but

institutional constraints make it nearly impossible to pursue the right course of action.”⁽²⁵⁻²⁷⁾

Natural Sedation or drowsiness occurs as part of the dying process. Progressive drowsiness or sedation is expected and occurs as part of reduced consciousness leading through coma to death. This is due to a combination of renal/hepatic/septic/neurologic processes resulting in body shutdown.⁽²⁸⁾

Consequential (ordinary/mild) Sedation is the unintended but predictable adverse effect of some drugs used for symptom control in patients who are not actively dying. This type of sedation may be transient and is often reduced or eliminated with dose adjustment, or as tolerance develops. Brief periods of sedation may be used in the general management of pain, dyspnea or delirium. This is not PST.⁽²⁸⁾

Respite Sedation (intermittent) is intended to be temporary. The patient is sedated, then awakened after an agreed upon period (usually 24-48 hours) to assess whether or not the symptom remains refractory.^(3,5,6,14,38-40) “The practice of respite sedation recognizes that either a symptom might respond to continued or future therapy or that the patient’s ability to tolerate the symptom may be improved following the rest and stress reduction provided by sedation.”⁽⁶⁾

Family is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be “like” a family member, regardless of blood relations.⁽³¹⁾

Assisted Suicide is the act of intentionally killing oneself with the assistance of another who provides the knowledge, means, or both. In **Physician Assisted Suicide**, the other person is a physician.⁽³²⁾

Physician Assisted Suicide means knowingly and intentionally providing a person with the knowledge or means or both required to commit suicide, including counselling about lethal doses of drugs, prescribing such lethal doses or supplying the drugs.⁽³²⁾

Euthanasia means knowingly and intentionally performing an act that is explicitly intended to end another person's life and that includes the following elements: the subject has an incurable illness; the agent knows about the person's condition, AND commits the act with the primary intention of ending the life of that person.⁽³²⁾

Palliative Sedation Therapy (PST) (also “Terminal Sedation”, “Controlled Sedation”, “Total Sedation”, “Deep Sedation”, “Continuous Sedation”) is the intentional lowering of a patient’s level of consciousness in the last days of life. It involves the proportional and monitored “use of sedative medications to relieve

intolerable suffering from refractory symptoms by a reduction in patient consciousness".⁽⁵⁾ The patient experiences symptom relief until death occurs by the natural course of the underlying disease, usually within hours to days.⁽⁵⁾

Decision-making is focused on relieving the patient's suffering and creating a more tolerable situation by adjusting the combination and doses of drugs administered.

PST can also be regarded as inducing and maintaining, "sleep" in very specific circumstances:

- for the relief of refractory suffering, when all other possible interventions have failed, and
- when the underlying disease is irreversible and death is expected in hours to several days.^(3,4,5,8,12,24, 33-38)

In clinical practice, PST usually does not alter the timing or mechanism of a patient's death, as refractory symptoms are most often associated with very advanced terminal illness.⁽³⁷⁻⁴⁵⁾

In using Palliative Sedation Therapy (PST) the intention is symptom relief by proportional use of sedative medications to lower consciousness only as much as is necessary to obtain symptom relief. In euthanasia or physician assisted suicide (PAS), there is no proportional use of medications as the primary intent is the death of the patient.⁽⁴⁶⁾

Standard of Care

1. Determine symptoms are Refractory
2. Determine criteria for implementing PST are met
3. Guide for Decision-Making
4. Documentation of Decision-Making
5. Initiating, Assessment and Care Provision
6. Supportive Care
 - a. Supporting the Family and Friends
 - b. Supporting the Care Team
 - c. Care after Death
7. Pharmacological Interventions - Initiating and Maintaining PST

RECOMMENDATION 1 - DETERMINE SYMPTOMS ARE REFRACTORY

A symptom or symptoms are considered refractory when “all possible treatment has failed, or it is estimated that no methods are available for palliation within a time frame and risk-benefit ratio that the patient can tolerate”.⁽³⁾

In considering the use of Palliative Sedation, the attending physician should ensure that the patient is assessed thoroughly to identify and treat reversible problems. The following points should be viewed:

- Non-pharmacological approaches, such as distraction and relaxation techniques, have been maximized
- All other pharmacological treatments, such as appropriate titration of opioids, have been maximized.

The **patient** must be the one suffering from refractory symptoms. It is not uncommon for families to request PST on behalf of their loved one, citing a perception of suffering, when in fact it is the family that is suffering.⁽⁴⁷⁾

In order to ensure that thorough assessment of and intervention for one or more difficult symptoms has been attempted, the reader is referred to the relevant symptom section in the [NH Hospice Palliative Care Symptom Guide](#). To determine if the criteria are met for a refractory symptom, consider the following questions regarding possible interventions, time frame and tolerability.^(3, 8, 16, 18, 22, 28, 59)

- Are further interventions capable of providing adequate relief?
- Are interventions likely to provide relief within a tolerable time frame?
- Will the intervention itself increase physical or emotional suffering?

A useful framework for assessing whether or not PST should be considered is the Latimer Ethical Decision Making Model.^(5, 7-9, 11-13, 14, 16, 19, 28-30, 60-61)

- Patient's Illness - extent of disease, prognosis, and nearness to death
- Patient's Experience - symptom intensity, impact on quality of life, suffering, demoralization, and lack of dignity
- Patient as a Person - goals, hopes, and plans in light of current symptom, and wishes as contained in an advance care plan (if one has been completed)

Explore other options and supports for the patient and family. Meaning based interventions, dignity conserving therapy and other spiritually based approaches have been useful to help patients and families find meaning in the dying process.⁽⁶²⁻⁷³⁾ See [NH HPC Psychosocial Care Guide](#).

The treating physician should also assess the patient for any conditions which may benefit from psychiatric consultation. ^(5, 22, 74)

It is important not to label difficult symptoms as refractory because of a lack of skill or knowledge on the part of the healthcare provider, or because of an unwillingness to request a consultation. **Consultation is strongly recommended in cases of refractory symptoms to ensure that all possible options have been explored.** Such consultation may be with a:

- member of the [NH HPC Consultation Team](#), even if this can only be done via telephone. ^(5,7-9,11-13, 14, 16, 19, 28-31,33)
- physician may also consult the Provincial Physician Palliative Hot Line by calling:
- **1-877-711-5757** (24/7 telephone service)
- physician colleague that is more experienced in palliative care

RECOMMENDATION 2 - DETERMINE CRITERIA FOR IMPLEMENTING PST ARE MET

Healthcare professionals providing end of life care have a responsibility to offer sedatives in appropriate circumstances, usually targeted at specific symptoms (ordinary sedation). Palliative Sedation Therapy (PST) is occasionally necessary to relieve otherwise refractory symptoms, with the degree of sedation proportional to the severity of the target symptom. PST is an extraordinary intervention, but can be viewed as part of the continuum of palliative care. ^(47, 59, 75-77)

PST should only be considered in the rare circumstance that thorough interdisciplinary assessment and treatment of a patient's refractory symptoms has not resulted in sufficient relief (or is associated with unacceptable side effects), and when sedation is needed to meet the patient's goal of relief from refractory symptoms. ^(3, 8, 16, 18, 22, 28, 59, 65, 74)

In cases of refractory symptoms, ethical principles and legal rulings support the use of palliative sedation therapy to relieve otherwise refractory symptoms. ^(46, 78) In Canada, the enactment of the Criminal Code is under federal jurisdiction, but the administration of justice is a provincial responsibility. The Attorney General of each province has discretion as to whether charges are laid. In accordance with these responsibilities, in November 1993, the British Columbia Ministry of the Attorney General issued guidelines for Crown Counsel (Policy 11-3-93, File no. 56880-01 Eut 1).⁽⁴⁶⁾ According to these guidelines, palliative care and withholding or withdrawing medical treatment will not be subjected to criminal prosecution when provided or administered according to accepted ethical medical standards.

The factors considered by Crown Counsel as to whether the acts of a qualified medical practitioner, or a person acting under the general supervision of a qualified medical practitioner, constitute “palliative care” include:

- Whether the patient was terminally ill and near death with no hope of recovery
- Whether the patient’s condition was associated with severe and unrelenting suffering
- Whether accepted ethical medical practices were followed, and
- Whether the patient was participating in a palliative program or palliative care treatment plan.

Criteria for implementing PST are as follows: (5, 6, 33)

- The patient is terminally ill and near death with no hope of recovery
- In all but the most unusual circumstances, death is anticipated within hours to days (8, 17, 18, 24, 28, 33-34, 77, 79)
- A “Do Not Resuscitate” order is in effect
- The patient is in a palliative program or has a palliative care treatment plan
- The patient has refractory symptoms
- The clinician’s intent is to relieve refractory symptoms
- The planned degree of sedation is proportionate to the severity of refractory symptoms
- The patient is fully informed and involved in the decision making. When the patient is ***not*** able to participate, consent needs to be provided by the patient’s substitute decision maker or legal representative who is acting in accordance with the patient’s values and beliefs. *See Recommendation 3 B for further discussion of consent. Refer to Appendix A for process of selection and duties of temporary decision makers.*

Management of **existential suffering** is controversial. Requests for sedation because of existential suffering are the most challenging and difficult to address. (2, 9, 30, 48-58)

PST for the management of refractory existential suffering should never be undertaken without consultation. Such consultation may be obtained from a member of an interdisciplinary hospice palliative team with knowledge and understanding of the patient’s belief system. This may be a hospice-palliative physician or a psychiatrist/clinical psychologist, in addition to a social worker, a medical ethicist, or a spiritual care practitioner.

RECOMMENDATION 3 - GUIDE FOR DECISION MAKING

The question of providing palliative sedation therapy may be raised by the patient or family/loved ones, either explicitly or indirectly, in the form of a request to relieve suffering. However, in deciding whether or not to initiate PST (or another plan of care that can still address the refractory symptoms of the patient), a formal discussion should take place. Most often, this is a family meeting with all relevant family/loved ones and healthcare professionals present to review the patient's condition and explore options.

Principles to Guide Decision-Making

A. Keep an open mind. The decision may be “For”, “Against”, or “Wait and See”.

Use a systematic and inclusive process for determining whether to use sedation for refractory symptoms and how sedation is to be used, such as this process outlined by deGraeff and Dean.⁽⁵⁾

1. Actively involve the patient and ideally substitute decision maker(s) (SDM)
 - Elicit patient's values, beliefs and goals
 - Determine preferences for information and involvement in the decision
 - If unable to participate, refer to previous discussions or advance care planning documentation
 - Discuss with patient and family that there is no chance of recovery and life expectancy is very limited
 - Discuss the therapeutic options, including potential benefits and risks
 - Make clear the intent of PST is comfort and symptom management, not hastening death
 - Facilitate patient-family discussion
 - If necessary, remind the substitute decision maker of the duty to uphold the patient's wishes, or to express what is known about the patient's previously expressed preferences
 - Provide support to family members finding it difficult to make critical decisions for a loved one
2. Involve all members of the team providing care for the patient. Those who should be present include:
 - The patient and ideally the SDM(s) - give the patient an opportunity to specify who s/he would like to be present at the meeting, and don't make assumptions about who should or shouldn't be there;
 - The physician who will be documenting the meeting and writing the orders;

- A nursing team member with knowledge of the patient's condition and care needs;
 - A psychosocial practitioner with knowledge of the patient and/or experience in palliative care or end-of-life decision-making, such as a palliative social worker, spiritual care practitioner, clinical psychologist, or medical ethicist;
 - A clinical pharmacist with knowledge of the patient, and/or experience in palliative care, especially in medically complex situations.
 - Agree on the goals of care and proportionality of PST
 - Elicit practical and ethical/moral concerns of the team about the use of PST in this case
 - Tailor the specific sedating interventions to the patient's values and clinical goal of care
3. Whenever possible, consider the needs of all those involved in choosing the time for initiating sedation.

B. Ensure informed consent. Actively involve the patient or the substitute decision maker.

As with all treatment, the use of PST requires informed consent.^(8, 28, 33) Under Provincial law, in deciding whether an adult is incapable of making a particular healthcare decision, the decision must be based on whether the adult demonstrates that he or she:

1. understands the information being given about his or her health conditions;
2. understands the nature of the proposed healthcare, including the risks, benefits and alternatives and
3. understands as well that the information applies to his or her situation

If a patient is not able to understand the above, then a substitute decision maker needs to be identified. The treating physician or other Healthcare professional should first determine whether there are any formally appointed substitute decision makers (Committee of Personal/Personal Guardian or Representative; as well as if advance care planning conversations or documents (including an Advance Directive) have been made or discussed. Copies of documents should be provided and reviewed by the healthcare team. Previously expressed wishes or instructions of the adult patient must be followed and carried out through consent by the substitute decision maker(s) (SDM), unless they are appointed as Committee of Personal/Personal Guardian. If such documents are not in place or information available is not sufficient/applicable, in British Columbia, the requirements for temporary substitute decision making are set out in The Healthcare (Consent) and Care Facility (Admission) Act.⁽⁸⁰⁾ See Appendix A for further information about selecting the SDM and his or her duties. Contact a social work department to consult with the Office of the Public Guardian (PGT) if no one is available to act as SDM or there is conflict about who should be the SDM. The PGT can appoint someone or act as SDM.

The care team should confirm that the patient's decision is not being affected by psychological or social pressure.⁽¹²⁾

C. Develop a plan. If the plan is “For PST”, consider and plan for:

- timing the initiation of sedation, consider the physical, emotional and physical needs of patient and family
- sedation to be proportional to the symptom distress/requirement for symptom relief
- whether to provide artificial hydration
- need for Foley catheter, continued bowel care
- concurrent medications for control of other symptoms

- how to support family and staff if the patient does not die within the expected time frame
- whether the sedation therapy will be discontinued or reversed after a period of time

D. If the plan is “No PST”, or “Wait and See”, determine when this decision might be reviewed.

E. In cases where no agreement about a plan can be reached, consider referral to the [NH Ethics Committees](#) or an independent patient advocate.

RECOMMENDATION 4 - DOCUMENTATION OF DECISION MAKING

Careful documentation of the team/family meeting, who was present, and the decision made is essential. It could be done by any member of the team, such as the physician, social worker, nurse, or other allied health professional and should be made in the permanent patient record.

The attending physician as a minimum, must document in the permanent record:

- A DNR / No CPR order and signed document is in place.^(17-18, 33)
- The criteria and rationale used to determine that the symptom is refractory.^(17-18, 33)
- The consultation process between the attending physician, palliative care consultants, patient and family.
- A summary of the discussion(s):
 - The people involved in the decision-making.
 - The information provided.
 - The decision reached.
 - Record the patient’s expressed wishes, in his or her own words, as much as possible, or refer to prior documented conversations between the patient and other healthcare worker(s).
 - Informed consent for PST has been given by the patient, substitute decision maker, or legal representative.
- A summary of the plan:
 - If NO sedation is desired, document the agreed upon care plan. Is there a plan for further discussions? Are further consultations to be requested? Is an ethical review required?
 - Document the plan in relation to:
 - Timing of initiation.

- Medical orders for sedation and for concurrent therapies, as needed.
- Hydration/Nutrition.
- Plan for managing foreseeable events
- Anticipate possible crises, and how they will be managed ⁽⁵⁾

RECOMMENDATION 5 - INITIATING, ASSESSMENT AND CARE PROVISION

Initiating palliative sedation may be an emotionally charged time, not only for the patient and family but also for healthcare providers. This is particularly true in situations in which the level of consciousness is rapidly lowered, rendering it difficult or impossible to communicate with the patient. It is beneficial to have the family and/or loved ones integrated into the plan of care as much as possible. Inform them of what to expect, reassure about expected changes in their loved one's condition, what practical things they can do while their loved one is sedated, and provide opportunities to express their emotions. ⁽²²⁾

Once the patient is sedated:

- Ensure frequent communication with the family for reassurance, support, feedback, and on-going decision-making.
- Ensure support is in place for patient and family, including palliative services, social work and spiritual care as available and desired by the patient or family. For communities without local support in this regard, please consider regional resources i.e. regional cancer care social worker. Through presence, intent, words, and touch, convey compassion for the patient and family. ⁽²²⁾
- Assume the patient can hear, and encourage visitors to talk or read to the patient, or play his or her favourite music if appropriate.
- Provide meticulous physical care because the patient will have reduced movement
- (e.g. loss of ability to blink, and other protective reflexes). ⁽²²⁾
- Encourage family to continue to touch their loved one.
- Discuss with family if they wish to participate in providing care. If desired, show them how to provide mouth care, eye care, hand or foot massage, or skin care as appropriate. If desired, include the family in repositioning the patient.
- Monitor for symptom relief.
- Assess for bladder emptying and place a urinary catheter when needed. Continue with appropriate bowel care. ⁽²²⁾

Assessments and Care Provision

The patient should be **monitored on a regular basis** to be sure that the goal of relief of refractory symptoms is being met.

After PST has been initiated, the following care should be provided and documented in the permanent record by the team members who are caring for the patient **regularly throughout the shift**:

- Response to PST - signs of symptom relief, Richmond Agitation Sedation Scale (RASS) See *Appendix B* or [RASS Form 10-513-5008](#) ⁽¹²¹⁾
- Assessment of the balance between symptom relief and level of sedation, along with appropriate drug and/or dosage changes
- Assessment of physical care needs and provision of care – skin care, mouth care, repositioning, bowel care, other care as needed
- Family coping and interventions to support the family
- Indicators for need to re-assess continuation of PST
- Outcome and care after death

Note: Respiratory rate and oxygen saturation should only be considered in exceptional cases. It is important to note that changes in respiratory rates and patterns, as well as reduction in oxygen saturation are normal end of life changes and will occur whether or not the patient is receiving PST. To titrate PST according to these parameters would therefore be inappropriate when death is imminent.

RECOMMENDATION 6 - SUPPORTIVE CARE

A. Supporting the family and friends

Palliative care includes comforting and supporting the patient's family and friends, who play an important role both when palliative sedation is being considered and while it is being carried out. They often serve as caregivers, observers, informants and representatives in addition to their role as partner, child, relative or friend. They each pass through their own emotional/spiritual journey, which may include feelings of doubt, guilt, fear, sorrow, and mourning. They may also feel relief that the suffering of their loved one has come to an end. Information, explanation, cooperation and on-going evaluation of the situation are essential if the palliative sedation is to work to good advantage and those involved can bid a meaningful farewell. The healthcare team should communicate with the patient's family using language they can understand. ⁽¹⁵⁾

Family members can be an important source of information about the well-being of the patient. It is helpful to meet with them at set times for periodic updates or to discuss new circumstances that may arise. It also allows the healthcare

providers to watch for signs of stress or burn-out in the family, and encourage them to care for themselves with adequate rest and nutrition.⁽²⁵⁾

Ascertain the level of involvement that the family wants in the process. Provide an opportunity for the patient, if possible, to express what s/he may want from their loved ones, or would find comforting, during the time they are sedated. Obtain information on anything that the patient would want or need before sedation is initiated, i.e., rituals, spiritual or religious rites, saying goodbyes or expressing their feelings to family or team members. Conversely, is there anything that a family member or loved one needs to say to the patient prior to the initiation of PST?

B. Supporting the care team

In cases where PST is being initiated, a profound empathy for the patient's suffering is common. To bear witness and still be professionally present and supportive for a patient and family can be an emotionally exhausting experience. Therefore, it is helpful that the team members caring for a patient and family discussing and possibly initiating PST be offered opportunities to discuss their own personal feelings. This may include formal or informal debriefings before or during the initiation of PST or after the death of the patient or individual meetings with team members.^(4, 15, 51, 59)

A more organized debriefing session for involved team members may be considered whenever:

- Management of refractory symptoms was especially challenging.
- The decision to initiate PST was difficult.
- Death was unusually arduous.
- Significant complications arose.
- Death occurred during intended respite sedation.

The debriefing session(s) should be facilitated by an experienced social worker, clinical counsellor, psychologist or spiritual care practitioner, who may or may not have been involved in the care of the patient. Most importantly, such offering of support can positively impact or offset any moral distress experienced by healthcare providers. It also serves as an opportunity for increased team cohesion, overall team functioning, and learning opportunities for what was done well or could have been done differently. Northern Health offers an [Employee and Family Assistance Program \(EFAP\)](#) that can be accessed for counselling support for any type of personal, family, or work-related concerns including but not limited to anxiety, stress, conflict, trauma, grief and loss.

C. Care after death

A patient receiving PST will eventually show some or all of the indicators of impending death (mottling and cooling of the periphery, irregular and/or noisy respirations) and death will occur as a natural outcome of the underlying disease within hours or days.⁽¹¹⁸⁾ Palliative Sedation Therapy has not been shown to hasten death: there is no difference between the length of stay of those patients who receive palliative sedation and those who do not.^(39, 40, 43, 45, 119) Death can occur sooner or later than the family or team had expected, although more than 85% of patients receiving PST die within 3 days and 98% do so within 7 days.

The family may need advice about burial, cremation, financial arrangements etc. They may have cultural beliefs about who may touch or wash the body, and how it is to be laid out. During this time, they should be given a chance to express their feelings about the way the patient died. Some families might appreciate the opportunity to debrief with the care team following the patient's death. This can encourage expression of their emotions and their feelings about the role they played and the support they received from others and the professionals involved in the case.⁽¹⁵⁾ The family may find it particularly helpful to have the attending physician present during such a session.

Family and friends should be asked whether they would like to receive information about bereavement support. Bereavement support and follow up is available through [local hospice societies](#) or other community resources, and on various websites.

RECOMMENDATION 7 - PHARMACOLOGICAL INTERVENTIONS – INITIATING AND MAINTAINING PST

The patient's care location (home, hospice residence, acute medical unit, tertiary palliative unit, critical care unit) and the availability of medication administration routes, such as intravenous, primarily guide the PST medication used. The goal of pharmacological treatment is proportional reduction of consciousness to a level sufficient to relieve symptoms.

If a patient is already being treated with opioids and/or antipsychotics, these medications should be continued during sedation in accordance with the patient's needs. When an existing medication is being administered continuously via the parenteral route, it is preferable to administer the sedative drugs via a separate site. This avoids an undesirable increase in the existing medication when the doses of sedatives are increased, and avoids potential drug incompatibilities when mixed together.

There is no strong evidence to support a ranking of medications. Choices depend on the experience of the physician, drug availability, institutional policy, and location.

Anxiolytic Sedatives

The most common initial choice of PST medication in the literature is a benzodiazepine, such as midazolam or lorazepam. They provide a high potential for sedation, a low risk of respiratory depression at sedative doses, and a wide safety margin. Where feasible, the use of midazolam by continuous subcutaneous infusion (CSCI) is preferred, to permit responsive titration. In general, subcutaneous administration is preferable to intravenous administration because of the practical advantages of subcutaneous infusion and the greater risk of apnea when bolus injections are administered intravenously. Where continuous infusions are not possible, consider using longer acting lorazepam by intermittent injection or sublingual administration. In general, midazolam is preferred over lorazepam because of its more immediate titration responsiveness, although lorazepam SL or buccally might be the simplest method in the home.

When the patient has delirium, benzodiazepines are not recommended as sole agents for PST, and should be combined with a neuroleptic^(5, 81-82) or phenobarbital.

MIDAZOLAM	
Midazolam Initiation	<ul style="list-style-type: none"> • 1 to 5 mg subcut or IV q 5 minutes until settled. • In emergencies, when a very rapid lowering of consciousness is required, bolus injections can be given more frequently. In other situations, a quiet atmosphere and gradual changes in consciousness are more important than speed.
Midazolam Maintenance	<ul style="list-style-type: none"> • Follow bolus initiation dosing with 1 mg per hour CSCI or continuous IV infusion (CIVI)⁽¹⁰⁵⁾ and titrate every 15 minutes until adequately sedated. • For elderly patients with a low body weight, no previous treatment with benzodiazepines, and no urgent need for rapid sedation, a low initial dose of 0.5 mg per hour is preferable. • Usual dose is 30 to 100 mg per day, yet range is broad from 3 to 1200 mg per day.⁽⁸¹⁾
Midazolam Titration	<ul style="list-style-type: none"> • Individualized titration of midazolam is required. • Provide p.r.n. intermittent doses q1h p.r.n. equal to the hourly maintenance infusion rate. • Adjust the maintenance dose every 1 to 2 hours,⁽¹⁰⁵⁾ based on number of p.r.n. boluses needed. If sedation is insufficient, the dose of midazolam can be doubled every 1 to 2 hours in combination with a bolus until an adequate effect has been achieved. • At dosages greater than 20 mg/hour (480 mg/day) consider adding, or switching to, second line treatment.⁽¹⁰⁵⁾

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MIDAZOLAM	
Dosing Special Populations	<ul style="list-style-type: none"> Use lower initial doses in patients with no previous treatment with benzodiazepines, cachexia, age over 60 years, renal, hepatic or cardiac impairment, and concomitant opioid administration. Higher doses may be needed in patients with significant previous benzodiazepine exposure, patients requiring a long duration of sedation, or in young patients.⁽⁸³⁾
Precautions	<ul style="list-style-type: none"> Tolerance may develop to the sedative effects of midazolam, sometimes to the point where the patient may unexpectedly recover consciousness. The dosage of midazolam may have to be increased over time, watching for this tolerance effect, mainly in younger patients.⁽⁵⁾ Delirium is a rare complication (seen especially in elderly) on the initiation of sedation, and if occurs, it is advisable to increase the dosage rapidly. Paradoxical excitation reactions to midazolam, including hyperactive or aggressive behavior, have been reported (2% incidence). There have been some reports of successfully reversing paradoxical excitation with flumazenil, haloperidol, and ketamine; however, these reports have not involved PST.⁽⁸⁴⁻⁸⁹⁾ As the goal of PST is to sedate to symptom relief, flumazenil would not be the best choice. If paradoxical sedation occurs stop the midazolam to prevent further episodes and sedate with an alternate drug.
Infusion Solution	<ul style="list-style-type: none"> Compatible in solutions of normal saline, D5W or Lactated Ringers.⁽³⁵⁻³⁷⁾ Compatible with morphine and hydromorphone in the same syringe or mini-bag,⁽⁹⁴⁾ but does not allow for individual titration of medications.

LORAZEPAM	
Lorazepam Initiation	<ul style="list-style-type: none"> 0.5 to 1 mg subcut or IV q 15 minutes. Alternatively: start with 1 to 4 mg sublingually or buccally.
Lorazepam Maintenance	<ul style="list-style-type: none"> Continue with 1 to 4 mg subcut or IV q 2 to 4h regularly or 1 to 8 mg sublingually or buccally. Usual dose is 4 to 40 mg per day.⁽⁷⁴⁾
Lorazepam Titration	<ul style="list-style-type: none"> Titrate with intermittent doses of 0.5 to 2 mg q 2h p.r.n.⁽⁷⁴⁾
Dosing Special Populations	<ul style="list-style-type: none"> Lorazepam pharmacokinetics remain unaltered with age,⁽⁹⁰⁾ but elderly may be more sensitive.⁽⁹¹⁾ Renal impairment may require dosage adjustment, guidelines unavailable.⁽⁹⁰⁾ Liver impairment – no dosage adjustment generally necessary.⁽⁹⁰⁾ Pharmacokinetics altered less in hepatic dysfunction versus most other benzodiazepines.⁽⁹⁰⁾ Cirrhotic patients may require lower dosing.⁽⁹¹⁾ Obese patients may need greater doses.⁽⁹¹⁾
Precautions	<ul style="list-style-type: none"> Volume becomes a problem if used subcut at higher doses.
Infusion Solution	<ul style="list-style-type: none"> NS, D5W preferred⁽⁹⁰⁾ but compatibility is concentration dependent, time limited and temperature sensitive.⁽⁹⁰⁻⁹²⁾ Lorazepam is best avoided for infusion due to risk of precipitation.

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Midazolam is the most commonly used drug for palliative sedation⁽⁸³⁾ yet if it, or lorazepam, is inadequate to provide the desired effect, consider proceeding to, or adding, the following alternatives.

Neuroleptics

Methotrimeprazine is a useful second-line choice for PST. It acts on multiple receptors and has some antiemetic and analgesia effects.⁽¹¹³⁾ It provides significant sedation, can be administered intravenously, subcutaneously, continuously or intermittently. It can be used in combination with midazolam. Other neuroleptics have been used for PST, but experience with them is much more limited. Haloperidol does not provide the degree of sedation necessary for PST; however, it remains useful as an adjuvant treatment for nausea and vomiting.

METHOTRIMEPRAZINE	
Methotrimeprazine Initiation	<ul style="list-style-type: none"> • 10 to 25 mg subcut or IV q 15 to 30 minutes until settled. • No dilution necessary for subcut intermittent administration; however for IV intermittent doses or continuous infusion consult parenteral manual for dilution instructions.⁽⁹⁶⁾
Methotrimeprazine Maintenance	<ul style="list-style-type: none"> • 10 to 50 mg subcut q 4h or 0.5 to 8 mg per hour infusion subcut or IV.⁽¹⁰⁵⁾ • Dose range is 25 to 250 mg per day.^(81,95)
Methotrimeprazine Titration	<ul style="list-style-type: none"> • Use p.r.n. doses up to q 1h p.r.n.⁽¹¹⁴⁾ Once settled, adjust regular doses every 8 hours until stable. May accumulate due to its long half-life, dosage reduction may be needed, especially after a few days.⁽¹⁵⁾
Dosing Special Populations	<ul style="list-style-type: none"> • Coadministration in patients on opioids or phenobarbital may need dose reduction by one-half.^(93,96) • Subcut administration reported to be twice as potent as oral.^(93,97) • Prostatic hypertrophy patients may be more sensitive to anticholinergic effects. • Phenothiazines can lower seizure threshold, avoid in patients in whom cerebral irritation is a potential problem.⁽⁹⁹⁾ • Hepatic and renal impairment – use with caution, no specific dosing available.
Precautions	<ul style="list-style-type: none"> • Extrapyramidal side effects may appear with high doses of any neuroleptic and may limit the dose of methotrimeprazine.⁽¹⁰⁷⁾ • Used alone, a neuroleptic can reduce the seizure threshold or induce myoclonus in severely ill patients. • May cause skin irritation and require site rotation based on patient tolerance. Rotation at least every 72 hours suggested.⁽⁹⁴⁾
Infusion Solution	<ul style="list-style-type: none"> • D5W 93,94,96 NS has also been used.^(94,96) • IV: Maximum 100 mg per 250 mL.⁽⁹⁶⁾

Tolerance to methotrimeprazine is rare (unlike the benzodiazepines and barbiturates).⁽¹⁰⁷⁾ If the benzodiazepine and methotrimeprazine have insufficient effect, stop both and start phenobarbital.

Sedative Antiepileptics

Some clinicians consider phenobarbital a first-line PST medication, while others use it as a third line option that provides sedation in cases of inadequate response to anxiolytic sedatives and/or methotrimeprazine. Phenobarbital has a long duration of action with a rapid onset, reportedly faster than midazolam. It can be administered intravenously, by CSCI, or intermittent subcutaneous injection. Its antiepileptic properties may be of additional anticonvulsant value.

PHENOBARBITAL	
Phenobarbital Initiation	<ul style="list-style-type: none"> 1 to 10 mg per kg induction bolus subcut or IV or 100 to 200 mg subcut.^(99, 116) May repeat induction bolus dose every 1 to 4 hours x 2 doses to maximum of 30 mg per kg total in first 24 hours.⁽¹¹⁶⁾
Phenobarbital Maintenance	<ul style="list-style-type: none"> Use induction dose q 8h regularly or 5 to 100 mg per hour CSCI. Usual dose is 600 to 1600 mg per day.⁽⁷⁴⁾ Range is 200 to 2500 mg per day.⁽⁸¹⁾
Phenobarbital Titration	<ul style="list-style-type: none"> p.r.n. dose should be q 4 to 8h at half or the full amount of the induction dose. If symptoms uncontrolled after 10mg/kg Loading Dose, may repeat q 2h to max of 30 mg/kg; after loaded to 30 mg/kg, may titrate CSCI rate if symptoms uncontrolled.⁽¹¹⁶⁾ Requires individualized dosing due to considerable variability in pharmacokinetics.⁽⁹⁹⁾ Can accumulate due to its long half-life, of 1.5 to 4.9 days,⁽³⁴⁾ and dosage reduction may be needed, especially after a few days.
Dosing Special Populations	<ul style="list-style-type: none"> Adjustments may be necessary in elderly patients or those with hepatic or renal dysfunction.⁽¹⁰¹⁾ Review concurrent medications for potential drug interactions, as several exist.
Precautions	<ul style="list-style-type: none"> Extravasation can cause skin irritation⁽⁹⁸⁾ ranging from slight to frank tissue necrosis⁽¹⁰⁰⁾ due to its alkaline pH (9.2-10.2)⁽¹⁰²⁾ However, CSCI usually well tolerated.⁽⁹⁴⁾ Abrupt withdrawal after prolonged use may precipitate seizures.⁽⁹⁸⁾
Infusion Solution	<ul style="list-style-type: none"> NS, D5W. May have complex mixing requirements in combination with other drugs.^(94,110) Mix just prior to use, visually inspect and do not use solution if precipitate forms.⁽¹⁰¹⁾

Generally, phenobarbital should be used in preference to propofol because it is less complicated for clinical staff to titrate and monitor.⁽¹²²⁾ However, if phenobarbital does not meet the goal of symptom relief, discontinue it and try another option.

General Antiepileptics

Propofol is generally regarded as a fourth line PST medication, when symptom relief has not been achieved by the above medications. However in a hospital setting, where intravenous access is readily attainable and an anesthesiologist is available, it may be preferable to consider as a second line agent.⁽¹⁰⁵⁾ It requires intravenous access, and should be administered only by a physician with experience using this drug. Administration should preferably be done under supervision of an anaesthesiologist.⁽¹⁰⁵⁾ It provides immediate onset, rapid titratability due to an ultra-short duration of action, and possesses antiemetic activity.

PROPOFOL	
Propofol Initiation	<ul style="list-style-type: none"> Induction bolus dose of 0.25 to 0.5 mg per kg IV. Give over 3 to 5 minutes.⁽¹¹²⁾ May repeat q 5 to 10 minutes until settled. Slow infusion techniques preferable over rapid bolus administration.
Propofol Maintenance	<ul style="list-style-type: none"> Maintenance by infusion should immediately follow the induction dose.⁽¹⁰⁹⁾ A variable rate infusion is preferable over intermittent bolus dose administration.⁽¹⁰⁹⁾ Continuous IV infusion (CIVI) at 0.25 mg per kg per hour to a maximum of 4 mg per kg per hour (4 mcg/kg/min to 67 mcg/kg/min).⁽⁸¹⁾ Generally start with 0.5 mg/kg/hr (8 mcg/kg/min) for refractory nausea and vomiting or 1 mg/kg/hr (17 mcg/kg/min) for agitated delirium or intolerable distress.⁽¹²²⁾ Usual dose is 500 to 1100 mg per day. Dose range is between 400 to 9,600 mg/day.⁽⁸¹⁾ Doses greater than 4 mg/kg/hr (67 mcg/kg/min) are associated with increased risk of adverse effects.^(121,123)
Propofol Titration	<ul style="list-style-type: none"> May repeat boluses q 5 to 15 minutes p.r.n. and increase CIVI by 0.25 to 0.5 mg/kg/hr q 30 to 60 minutes.^(81,108) If patient is too sedated, turn off infusion for 2 to 3 minutes and restart at lower rate.⁽¹²²⁾ May require p.r.n. bolus doses before turns, dressing changes, or potentially painful procedures.⁽¹⁰⁶⁾
Dosing Special Populations	<ul style="list-style-type: none"> May require dosage reduction of 20 to 30% in elderly, debilitated, or hypovolemic.⁽¹⁰³⁾ Concurrent opioids may lower BP, reduce heart rate and cardiac output.⁽¹⁰³⁾ Interpatient variability in dosage requirements may occur over time.⁽¹⁰³⁾ Accumulation may occur with long-term use.⁽¹¹¹⁾ Tolerance can develop, necessitating a dose increase, but generally not within one week.⁽¹²²⁾

PROPOFOL	
Precautions	<ul style="list-style-type: none"> • Potential bradycardia, hypotension. Also apnea during induction.⁽¹¹²⁾ • Hypotension more likely with rapid bolus or in elderly patients or those with compromised myocardial function, intravascular volume depletion or abnormally low vascular tone (e.g. sepsis).^(103,109) • High incidence of injection skin reaction (18%), and immediate or delayed discomfort may occur in 90% of adults.⁽²⁴⁾ Occurs more frequently when small veins are used. Extravasations may cause local pain, swelling, blisters and tissue damage.⁽²⁴⁾ • Transient local pain during injection may be reduced by prior injection of 10 mg of IV lidocaine (preservative and epinephrine free).^(103,109,122) • Propofol infusion syndrome (one or more symptoms of bradycardia, metabolic acidosis, renal failure, cardiac failure, cardiopulmonary arrest) is rare, but may occur at high doses over 4 mg/kg/hr, or in patients with refractory status epilepticus.^(104,123) • Do not use subcutaneously.⁽¹¹²⁾
Infusion Solution	<ul style="list-style-type: none"> • Shake well before use as propofol is mixed in an egg lecithin and soybean oil vehicle. • Replenish infusion quickly when a container empties,⁽¹⁰⁸⁾ as effect wears off in 10-30 min.⁽¹²²⁾ • Pain at infusion site can be minimized by using a large vein and adding a maximum of 20 mg of preservative and epinephrine free lidocaine per 200 mg propofol immediately prior to starting infusion.⁽¹²²⁾

Propofol is generally regarded as a fourth line PST medication, when symptom relief has not been achieved by the above medications. However in a hospital setting, where intravenous access is readily attainable and an anesthesiologist is available, it may be preferable to consider as a second line agent.⁽¹⁰⁵⁾ It requires intravenous access, and should be administered only by a physician with experience using this drug. Administration should preferably be done under supervision of an anaesthesiologist.⁽¹⁰⁵⁾ It provides immediate onset, rapid titratability due to an ultra-short duration of action, and possesses antiemetic activity.

If propofol alone does not provide adequate symptom relief, supplement with midazolam by CSCI.⁽¹²²⁾

Palliative Sedation Treatment Dosing

If the patient recovers consciousness after initially being adequately sedated, it is important to check whether the indications for PST are still present.

If the patient is not appropriately sedated to the point of symptom relief, ensure that the mode of administration and the medications are in order. Ensure there is no drug extravasation, blocked or kinked lines, or equipment malfunction. Check that delivered therapy matches intended prescribed dose.

When a patient is being cared for in the home, the use of a pump for continuous subcutaneous administration may not be logistically feasible. This is particularly the case where life expectancy is extremely short (1 to 2 days). In such

circumstances, intermittent administration of sedatives is an acceptable alternative. Depending on the situation, any of the following drugs can be used for this purpose:

- Midazolam: 5 to 10 mg subcut q 4h regularly, and PRN
- Lorazepam: 1 to 4 mg SL or subcut q 4h regularly, and PRN
- With or without Methotrimeprazine: 10 to 50 mg subcut q 4h, and PRN

Drugs NOT RECOMMENDED for Palliative Sedation Therapy

Opioids alone do not provide adequate sedation. Trying to achieve sedation with opioids is very likely to produce neuroexcitatory adverse effects such as myoclonus or agitated delirium.

They **do have a role as analgesics** and are frequently used concurrently with PST.⁽⁷⁴⁾ During PST, as with patients under general anaesthesia, pain is still registered within the central nervous system, even if the patient is not consciously aware of, or able to indicate it. Thus, previously prescribed opioid medications must be continued once PST is initiated.

Increasing pain and analgesic requirement may be expected due to disease progression and drug tolerance. However, any increase of opioid doses in a sedated patient should be supported by careful document of signs of pain.⁽¹¹⁷⁾ Signs of pain in the sedated patient may include, tearing, moaning, tachycardia, tachypnea, hypertension, and movement.

Thiopental is not recommended as it is a common drug used for physician-assisted suicide in those jurisdictions where it is practiced. Its use in PST could be misinterpreted.

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APPENDIX A: SELECTION AND DUTIES OF THE SUBSTITUTE DECISION MAKER⁽⁸⁰⁾

To obtain substitute consent to provide major or minor healthcare to an adult, a healthcare provider must choose the first, in listed order, of the following who is available and qualifies (see below).

1. A court-appointed Committee of Person/Personal Guardian: Under the Patients Property Act⁽¹²⁴⁾ (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/0096349_01), the court may have appointed a committee for an adult who is incapable of making healthcare decisions.
2. A representative: An adult may, when able to do so, have planned for their future by making a Representation Agreement (section 9 agreement is required for consent to life sustaining treatment) under the Representation Agreement Act⁽¹²⁵⁾ (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/0096405_01) authorizing a representative to make healthcare decisions on their behalf if they were unable to make their own decisions.
3. Advance Directive: This needs to be valid and relevant to the healthcare. If no Representative is appointed, it can stand alone and no TSDM needs to be appointed.
4. A Temporary Substitute Decision Maker: If there is no representative or court-appointed committee of Person/personal guardian, under the Healthcare (Consent) and Care Facility (Admission) Act⁽⁸⁰⁾ (http://www.bclaws.ca/EPLibraries/bclaws_new/document/ID/freeside/0096181_01) a healthcare provider must choose the nearest relative as ranked below:
 - The adult's spouse (common law, same gender);
 - The adult's children (equally ranked);
 - The adult's parents (equally ranked);
 - The adult's brothers or sisters (equally ranked);
 - The adult's grandparent (equally ranked)
 - The adult's grandchild (equally ranked)
 - Anyone else related by birth or adoption to the adult
 - A close friend of the adult
 - A person related immediately to the adult by marriage
 - Another person appointed by Public Guardian and Trustee

When no one from the ranked list of substitute decision makers is available or qualified, or there is a dispute between who to appoint that cannot be resolved,

the healthcare provider must contact a **Healthcare Decisions Consultant at the Public Guardian and Trustee** who will appoint or act as TSDM.

To qualify to give, refuse or revoke substitute consent to healthcare for an adult, a person must:

- a. be at least 19 years of age,
- b. have been in contact with the adult during the preceding 12 months,
- c. have no dispute with the adult,
- d. be capable of giving, refusing or revoking substitute consent, and
- e. be willing to comply with the duties below.

Duties of Representatives:

Representatives must:

- Act honestly and in good faith;
- Exercise the care, diligence and skill of a reasonable prudent person; and
- Act within the authority given in the Representation Agreement
- Consult, to a reasonable extent, with the adult to determinate his or her current wishes and
- Comply with those wishes if it is reasonable to do so. Please note, however, that in a section 9 Representation Agreement an adult may provide that the Representative need only comply with any instructions or wishes the adult expressed while capable.

Duties of Temporary Substitute Decision Makers:

Temporary Substitute Decision Makers:

- A person chosen to give or refuse substitute consent to healthcare for an adult must be 19 years of age or older, have had communication within the last 12 months with the patient and not be in dispute with the patient. Before giving or refusing substitute consent, the TSDM(s) must consult to the greatest extent possible:
 - a. with the adult, and
 - b. if the person chosen under section 16 is a person authorized by the Public Guardian and Trustee, with any friend or relative of the adult who asks to assist, and
 - c. comply with any instructions or wishes the adult expressed while he or she was capable.
- If the adult's instructions or wishes are not known, the person chosen must decide to give or refuse consent:

-
- a. on the basis of the adult's known beliefs and values, or
 - b. in the adult's best interests, if his or her beliefs and values are not known.
- When deciding whether it is in the adult's best interests to give, refuse or revoke substitute consent, the person chosen must consider
 - a. the adult's current wishes,
 - b. whether the adult's condition or well-being is likely to be improved by the proposed healthcare,
 - c. whether the adult's condition or well-being is likely to improve without the proposed healthcare,
 - d. whether the benefit the adult is expected to obtain from the proposed healthcare is greater than the risk of harm, and
 - e. whether a less restrictive or less intrusive form of healthcare would be as beneficial as the proposed healthcare

APPENDIX B: RICHMOND AGITATION SEDATION SCALE (RASS)

TERM	SCORE	DESCRIPTION
+4	<i>Combative</i>	<ul style="list-style-type: none"> Overly combative or violent. Immediate danger to staff.
+3	<i>Very agitated</i>	<ul style="list-style-type: none"> Pulls/removes tubes or catheters. Has aggressive behavior toward staff.
+2	<i>Agitated</i>	<ul style="list-style-type: none"> Frequent non-purposeful movement.
+1	<i>Restless</i>	<ul style="list-style-type: none"> Anxious or apprehensive but movements not aggressive or vigorous
0	<i>Alert and calm</i>	
-1	<i>Drowsy</i>	<ul style="list-style-type: none"> Not fully alert, but has sustained (greater than 10 sec) awakening with eye contact to voice.
-2	<i>Light sedation</i>	<ul style="list-style-type: none"> Briefly (less than 10 sec) awakens with eye contact to voice.
-3	<i>Moderate sedation</i>	<ul style="list-style-type: none"> Any movement (but no eye contact) to voice.
-4	<i>Deep sedation</i>	<ul style="list-style-type: none"> No response to voice, but any movement to physical stimulation.
-5	<i>Unrousable</i>	<ul style="list-style-type: none"> No response to voice or physical stimulation.

Procedure for RASS Assessment

STEP	PROCEDURE	SCORE
1	<ul style="list-style-type: none"> Observe patient Patient is alert, restless, or agitated 	0 to +4
2	<ul style="list-style-type: none"> If not alert, state patient's name and say to open eyes and look at speaker. 	-1
	<ul style="list-style-type: none"> Patient awakens with sustained eye opening and eye contact 	-2
	<ul style="list-style-type: none"> Patient awakens with eye opening and eye contact, but not sustained Patient has any movement in response to voice but no eye contact 	-3
3	<ul style="list-style-type: none"> If patient does not respond to voice, physically stimulate patient by shaking shoulder and/or rubbing sternum*: 	-4
	<ul style="list-style-type: none"> Patient has any movement to physical stimulation 	-4
	<ul style="list-style-type: none"> Patient has no response to any stimulation 	-5

* Rubbing the sternum is not appropriate for palliative care patient assessment, and is not recommended.

Adapted from Ely EW, Truman B, Shintani A, et al: Monitoring sedation status over time in ICU patients: Reliability and validity of the Richmond Agitation Sedation Scale (RASS). JAMA 289:2983-2991, 2003.⁽¹²¹⁾

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PSYCHOSOCIAL CARE

Rationale

This guideline is adapted for interprofessional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice settings in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for assessing and addressing psychosocial issues of adult patients (age 19 years and older) who are facing a progressive life limiting illness. It is designed to provide some general considerations and information about psychosocial care, support and interventions to assist all healthcare providers within their scope of practice and to enhance their engagement with patients and families.

This guideline is not intended to be prescriptive. While medically oriented clinical practice guidelines tend to focus on specific disease sites and describe, “which particular treatment is most effective for which particular symptom”⁽¹⁾, psychosocial care is contextually and historically based in the unique experiences of patients and their families. This guideline is intended to assist all healthcare providers to look beyond the physical aspect of a patient’s illness and explore the patient’s perception of their illness and its impact upon them. The goal is to assist patients and their families to find meaning within their situation using a holistic approach.

Definition of Terms

Advance Care Planning is an ongoing process of reflection and communication in which a capable adult makes decisions with respect to future healthcare in the event that they become incapable of giving informed consent. The process should be placed in the context of one’s values and beliefs and involve discussions with healthcare providers and significant others with whom the person has a relationship.⁽²⁾

Burnout is a process in which one’s attitudes and behaviour change in negative ways in response to job strain⁽³⁾ arising out of work environment triggers such as frustration, powerlessness and an inability to achieve work goals.⁽⁴⁾

Coping refers to unique and personal strategies used to manage stressful situations that could be perceived by others as being positive or negative.⁽⁵⁾

Comfort Care refers to both a philosophy of care and a program of services aimed at relieving suffering and improving the quality of life for persons who are living with, or dying from, a life limiting illness or who are bereaved.⁽⁶⁾

Compassion Fatigue refers to emotional residue of exposure to working with those who suffer. Natural consequent behaviours and emotions resulting from knowing about a traumatizing event experienced by a significant other, the stress resulting from helping or wanting to help a traumatized or suffering person.⁽⁷⁾

Complicated Grief is marked by the presence of symptoms such as intrusive thoughts of the deceased, yearning and/or searching for the deceased and excessive loneliness since the death, experienced daily or to a marked degree, for at least 6 months, causing clinically significant impairment in social, occupational or other areas of functioning.⁽⁸⁾

Culture is not a single variable but is comprised of multiple variables, affecting all aspects of experience. It is inseparable from economic, political, religious, psychological and biological conditions. Cultural processes frequently differ within the same ethnic or social group because of differences in age cohort, gender, political association, class, religion, ethnicity and even personality. It is highly desirable for healthcare providers to be sensitive to cultural difference by engaging in an ongoing process of exploring the patient's lived experience of an illness, trying to understand the illness as the patient understands, feels, perceives and responds to it.⁽⁹⁾

Cumulative grief is the occurrence of multiple deaths, either at the same time or in serial fashion. This often occurs in a hospital unit or hospice residence, and may lead to bereavement overload, or what has been called cumulative grief. Cumulative grief is the caregiver's emotional response when there is no time or opportunity to completely or adequately grieve for each person who has died.⁽¹⁰⁾

Disenfranchised grief is when a person experiences a sense of loss but does not have a socially recognized right, role or capacity to grieve.⁽¹¹⁾

Employee and Family Assistance Program offers confidential assessment, counseling and referral services designed to assist with resolving problems that affect an individual's personal life and, in some cases, job performance. The service is provided at no cost to eligible employees and their family members.⁽¹²⁾

Family is a term that is used to describe those who are closest to a patient. It is not exclusive to those who are related by blood or by marriage. It is a term used to describe someone that a patient considers to be "like" a family member, regardless of blood relations.⁽¹³⁾

Life Review is a progressive return of the memories of past experience in search of meaning and in striving for emotional resolution.⁽¹⁴⁾

Quality of Life refers to an acceptable, if not desired, state of living that suggests fulfillment for an individual. Quality of life is individually defined by each patient. The goal of hospice palliative care is to "provide the best possible quality

of life for the terminally ill by ensuring their comfort, care, and dignity at their end of their lives.”⁽¹⁵⁾

Standard of Care

Recommendation 1: Care for the Healthcare Provider

- Reflective Practice
- Self-Care

Recommendation 2: Care Considerations

- Understanding and Assessing Patient and Family Experience
- Understanding Grief and Loss
- Understanding Children’s Grief
- Understanding Culture

Recommendation 3: Caring for the Patient and their Family

- Psychosocial Support
- General Strategies
- Communication
- Fostering Hope
- Helping Children
- Desire to Die Statements

Recommendation 4: Help for Challenging Care Situations

- Indicators for Specialized Consultation

Recommendation 5: Evaluation

RECOMMENDATION 1 - CARE FOR THE HEALTHCARE PROVIDER

Reflective Practice

To provide effective, compassionate and comprehensive end-of-life care, healthcare providers must develop a level of comfort with death and dying. Unfortunately “clinicians often do not have the skill, comfort level, and experience needed to care for dying patients.”⁽¹⁶⁾ As a result, healthcare providers may end up avoiding uncomfortable or difficult conversations with patients and family members and direct their attention towards more technical aspects of care. Consequently, healthcare providers as well as patients and families may lose out on an important opportunity to clarify their understanding and expectations of the current medical situation with a view towards developing effective end of life care. Self-reflective practice is a proactive process, which seeks to overcome this

reluctance and to enhance relationships with particular people, events, or situations.

Reflection can take place not only retrospectively in thinking about an experience after it has occurred, but also simultaneously as it is occurring, and even proactively before it occurs (or is anticipated to occur), thus, critical reflection before, during and after the experience. Being a reflective healthcare provider requires an “in-the-moment” awareness of our own issues, attitudes, feelings, values and beliefs, both personal and professional, around death and dying. Reflective practitioners are willing to explore and challenge their assumptions of themselves and others where appropriate.⁽¹⁶⁾ It may help to engage in this process with others on the team rather than exclusively on an individual basis. How does one become more critically reflective in their practice around end of life care?

Think about the following questions:

- What are the assumptions, feelings, values, and beliefs guiding my current actions and behaviours?
- How are my actions and behaviours influenced by these assumptions?
- What do I know about the assumptions, feelings, values and beliefs of the patients and families with whom I am working?
- How might their actions and behaviours be influenced by these assumptions?
- What strategies have been and/or are working, and which strategies are not?

By developing and using reflective practice consistently, you will be able to bring forward ideas to help improve and enhance end of life practice. Effective professionals continually reflect on their work and continue to do so throughout their careers.

Self-Care

Although providing care to palliative patients and their families can be extremely rewarding, it can also be stressful and emotionally draining. The chronic exposure to related stresses and human suffering can lead to adverse physical, emotional, social and psychological effects.⁽¹⁷⁾ This is commonly referred to as burnout or compassion fatigue.

“Working with the dying and the bereaved touches caregivers in profound ways...it makes them painfully aware of the losses in their own lives; it increases anxiety regarding their potential and future losses...and it arouses existential anxiety in terms of their own death awareness.”⁽⁸⁾ Over time, as healthcare providers are exposed to multiple deaths, they can become vulnerable to

experiencing cumulative or disenfranchised grief. It is not uncommon for this grief to be denied, displaced and/or distorted.⁽¹⁰⁾

Without adequate coping skills to deal with the exposure of working with patients and families at end of life, healthcare providers may begin to withdraw, have difficulty communicating and avoid emotional involvement with patients and families, all of which affect the quality of care they are able to provide.⁽¹⁸⁾

Burnout may be experienced as a variety of symptoms including:

Physical	Emotional
<ul style="list-style-type: none"> • Headache • Nausea • Dizziness • Insomnia • Skin problems • Gastrointestinal problems • Physical exhaustion 	<ul style="list-style-type: none"> • Depression • Isolation and/or social withdrawal • Emotional exhaustion • Discouragement • Oversensitivity • Irritability • Anger⁽¹⁹⁾

It may be difficult to find encouragement to access outside forms of support due to the generalized culture of healthcare. However, it is essential that healthcare providers have the ability to identify the impact of their work and engage in efforts to recognize and address any negative consequences. The use of self-reflective practice, as described in Recommendation 1, can assist us in clarifying or identifying the source of any ‘burnout’ or ‘cumulative grief’. This can be done through a combination of self-reflection, education about the effects of caring, development of effective coping skills, and the creation of a work culture that supports self-care.^(10,20) It may mean that we need to take more time for ourselves, debrief with a trusted co-worker around a specific patient, or utilize an Employee Family Assistance Program for counseling.⁽¹²⁾

Types of self-care activities:

- Basic Needs – nutritious food, exercise, adequate sleep.
- Balance – between personal life and work life.
- Relaxation and Self-reflection – taking time to assess personal feelings, might include meditation, prayer and journaling.
- Informal Support – family and friends.
- Formal Support – peers, supervisor, debriefing, might include access to counseling and support groups.
- Ritual – memorial services or other forms of remembering and providing closure.

- Education and Training – aimed at understanding issues regarding dying and grief, effects of providing care, communication techniques.⁽¹⁰⁾

RECOMMENDATION 2 - CARE CONSIDERATIONS

Understanding and Assessing Patient and Family Experience

Living with a life limiting illness and awareness of approaching death creates unique stressors and new challenges. Patients and families are faced with having to manage the new demands associated with the illness while maintaining quality of life and meaning within their relationships.

Some of the unique stressors of living with a life limiting illness for patients and families may include:

1. Coping with remission and relapses associated with the often uncertain course of the illness.
2. Experiencing grief associated with adjusting to multiple losses prior to the death.
3. Dealing with the demands of living with and caring for someone who, while is still living, is slowly dying.
4. Managing and meeting the increased demands in all areas of living: financial, social, physical and emotional.
5. Having to address long term family disruption and working at family reorganization to cope with illness.
6. Feelings of loss of control. Witnessing the progressive decline of a loved one and not being able to stop it.
7. Managing psychosocial conflicts, emotional exhaustion, physical debilitation, social isolation, family tension, and commonly experienced emotional reactions to loss (guilt, anxiety, sorrow, depression, anger and hostility).
8. Managing intensive treatment regimens and their side effects.
9. Becoming familiar with healthcare systems, language, and professionals.
10. Confronting dilemmas regarding decision making and treatment choices.⁽²¹⁾

Understanding the factors related to a patient's quality of life is paramount in providing comfort care to patients and their loved ones. The provision of psychological support for patients and families confronted with a life limiting illness is one that is often overlooked and can be even more undermined when physical pain becomes the main focus of the treatment plan.⁽¹⁵⁾

The psychosocial assessment is focused more on the significance and functioning of the patient in relationship to themselves, others and their

environment. The assessment should ascertain how quality of life is defined and experienced by the patient. Ideally it should identify their goals, barriers to achieving those goals and strengths available to overcome and/or adapt in the presence of constant change.

Assessment serves the purpose of understanding the illness from the perspective of patients and families as well as articulating goals of care. A comprehensive assessment helps clarify and identify strengths, challenges, areas of support and overall functioning.

It is the groundwork for planning interventions, addressing needs, assisting with informing decision-making, facilitating care planning and delivery as well as contributing towards team functioning.^(5,22) If applicable, the use of professional interpreters should be utilized so as to not place family members (especially children) or even healthcare providers in the role of mediating decision making or translating difficult or 'bad' news.

Questions which can help to obtain the patient and family's perspective:

1. What is your understanding of the illness?
2. What do you think caused the illness?
3. What kind of impact has the illness had on you and your family?
4. How have roles and relationships changed within your family?
5. How would you describe your communication style?
6. What do you fear the most?
7. Who do you turn to for help?
8. Who should be involved in decision making?
9. What is most important to you?
10. What would be most helpful to you at this time?^(9,23,24)

The assessment may include patients and families' competencies, interactions and environmental influences that could hinder one's abilities to adapt. The assessment is not a diagnosis. The psychosocial assessment is an empowering and ongoing collaborative process of moment by moment interactions that begins upon first contact.⁽⁵⁾

An effective assessment is guided by theories rooted in cognitive and behavioural therapy, ego-psychology, family systems and social sciences.

Considerations for a comprehensive assessment within the context of the patient's life limiting illness may include but is not limited to:

- **Ecological factors** – marital status, status of children, family, social support systems (e.g., kin, co-workers, friends, and neighbors), pattern and style of communication, family structure, roles, dynamics, abuse and/or violence, sexuality.
- **Psychological factors** – self-concept, self-esteem, coping abilities, affect, attitude, mental status, substance abuse, developmental stage, defense mechanisms, cognitive abilities, response to previous losses, social skills.
- **Cultural factors** - beliefs, identity, practices, rituals and values.
- **Social factors** – education, employment, housing, financial and/or legal status, leisure activities, physical environment and healthcare experiences.
- **Spiritual factors** – meaning applied as to what gives purpose, hope.

There is no single, standardized instrument for psychosocial assessment currently being used within the Northern Health Hospice Palliative Care Program. However, through the use of various techniques such as interviews, family meetings, questionnaires, and specific validated tools such as the Beck Hopelessness Scale, Caregiver Burden Scale, Distress Thermometer, Fam-Care, Herth Hope Index and the McGill Quality of Life questionnaire, the patient and family perspectives can be elicited and shared with all involved interprofessional team members.^(25,26)

Understanding Grief and Loss

Patients and family members, in their own way and in their own time, may be grieving many different aspects associated with expected and actual losses. These losses go beyond changes in health status and can include loss of capabilities, roles and responsibilities, employment and income, residence of choice, leisure activities, social connections, sense of self, innocence, faith, and expectations for the future.

Grieving can begin at the time when an individual is first diagnosed with a life limiting illness and arises from an awareness that ‘the world that is’ and ‘the world that should be’ are different.⁽²⁷⁾ Since this “should be world” is a unique construction of each person, the reactions to losing it can be unique.⁽²⁷⁾

Grief and mourning are terms which are often used interchangeably. However, “grief” can be defined as “the personal experience of loss”, while “mourning” is “the process which occurs after a loss.”⁽²⁸⁾ “Mourning” can also be applied to more formal ways in which the larger community (family, society and culture) addresses and expresses the experience of loss.

Grief is the emotional, physical, intellectual, behavioural and spiritual process of adjusting to loss.⁽²⁷⁾ It is an active process which can be experienced as the result of a loss or prior to a loss, known as anticipatory grief.⁽²⁹⁾ There have been

many different models for describing and understanding the grief experience. One of the most familiar is the 1969 work of Elisabeth Kubler-Ross which describes five stages of grief.⁽³⁰⁾ These include denial, anger, bargaining, depression and acceptance. Although the stages were not proposed to be sequential and mutually exclusive, they were seen to be progressive with 'acceptance' as the goal or resolution of grief.⁽³⁰⁾

In more recent years, grief models describe grief as a whole life process which varies in its intensity⁽¹⁶⁾ rather than a single experience or series of stages. The concept of 'denial' has been re-conceptualized to recognize the griever's experience of 'setting aside reality' while "...body, mind, and soul adjust to the distressful situation by closing down to protect and rebuild in small increments".⁽³¹⁾ Various emotional states are described as the reality of the loss is fully experienced including searching, yearning, anger, disorganization, detachment and apathy. The outcome of grief work is not so much about 'acceptance' as it is about exploring and adjusting to life without the person who has died. For the griever this involves taking on the changes the loss has created, developing a new sense of self and investing in new roles and relationships. Rather than being a progressive series of stages these various emotions and experiences can be concurrent, cyclical and overlapping. It is the hope that things will get better in time, that there is a life after the death of a loved one, "...that all of this must have some meaning..."⁽³⁰⁾ that enables grievers to heal, rebuild and begin focusing on future possibilities rather than past losses.

An important part of working with people who are grieving is to help "normalize" the experience. Normalizing grief can provide reassurance and give people permission to acknowledge some of their difficult feelings (i.e., anger and guilt).⁽³²⁾ "Although grief can become prolonged or complicated it is not an intrinsically pathological state, but rather a normal and needful adjustment response."⁽³¹⁾ It is important to remember that each grief experience is unique and individual. Each person will experience the above factors differently, so what may be very difficult for one person to experience may not be as difficult for another.

The length of time required to move through these processes varies with each individual. Although there is no "correct" time frame for mourning, an overly lengthy process may indicate complications in grieving that should be addressed.

Factors that may contribute to complicated grief:

- Sudden and unexpected death.
- Loss of a child.
- Death after a lengthy illness.
- Death that the mourner perceives as having been preventable.

- A relationship with the deceased that was markedly angry, ambivalent, or dependent.
- Multiple losses (past or present) or additional stressors.
- Mental health concerns.
- A mourner's perception of lack of support.⁽²⁵⁾

When grieving becomes more complicated, a referral for more intense grief counseling may be required to help the person manage his and/or her grief.

Understanding Children's Grief

Much has been written on children's grief but it is still an area that may be difficult for people to address. As adults, we want to protect children. We may try protecting the child from pain by trying to hide the reality of death. Research indicates that children grieve in a healthier way if the adults around them are open, honest, and available to talk when the child is ready.⁽³¹⁾ Children need an opportunity to say goodbye and can benefit from participating in funeral rituals. It is important to answer children's questions as honestly and age appropriately as possible because children can imagine things that are often far worse than the truth. Children learn through example. If the adults in their lives are open with their feelings, the children may feel more able to express their feelings as well.

Children's grief is greatly influenced by their age and developmental stage.⁽³³⁾ A chart from The Hospice at the Texas Medical Center shows how concepts of death and grief responses change as children age⁽⁶⁴⁾ (see *Appendix A*).

As children grow up they may re-grieve a loss that occurred at a younger age. With their new understanding, knowledge, and sense of self, they may take another look at the loss and how it affects them at each developmental stage. It is important for a parent to realize this may happen because it can be stressful for the parent (who may also be grieving) to revisit the loss themselves.

It is important that we encourage family members of all ages to share stories and to talk with one another, to the person who is dying, and to professional caregivers (re: questions, concerns and requests). Knowing that someone you love is dying, gives you the opportunity to address any "unfinished business" and to say good-bye. It can be a very rich time for families, as members do their grief work together and spend time with their loved one who is dying.

Understanding Culture

Culture refers to commonalities around which a group of people have developed values, norms, family styles, social roles and behaviours in response to the political, economic and social realities they face.⁽³⁴⁾ Culture is an important factor in determining how individuals experience and express pain, maintain hope in the

face of a poor prognosis, make end-of-life care decisions, and respond to illness, treatment, grief and loss. However, culture is not limited to ethnicity and may include categories such as age, gender, spirituality, faith, religion, ablement, sexual orientation, gender identity, lifestyle, national origin, linguistic transition and socioeconomic status.^(35,36)

Healthcare providers are likely to care for persons with very different explanatory models about illness, as well as different expectations about care and views regarding death. Given this diversity, the process of assessment and intervention can present a challenge, and we, as healthcare providers, may be tempted to steer patients and their families toward choices that suit us instead of trusting and empowering them to make their own choices.

Healthcare providers need to anticipate and address institutional barriers to caring for patients with a life limiting illness. These barriers often include a lack of trained medical interpreters and the predominance of the western biomedical explanatory model in the healthcare service delivery with its inherent individualistic values and beliefs. These encourage healthcare providers to, for example: openly disclose the diagnosis to the dying patient, ask that an advance care plan be developed and minimize physical suffering through symptom management.

While these measures are generally very helpful to the patient, they may be inappropriate for patients from a culture in which:

- Pain and suffering are expressed differently.
- A serious diagnosis is not disclosed to the dying patient.
- Dying is not talked about openly.
- It is understood that the family, and not the patient, makes the final healthcare decisions as instructed by the patient.⁽³⁶⁾

Knowing the cultural formula does not always predict clinical success. Culture is most meaningful when interpreted in the context of an individual's unique history.

It is, therefore, helpful to meet with the patient privately and ask what she or he wants to know about her or his condition; whom to talk to about her or his treatments and potential outcome; and whom she or he wants to make healthcare decisions for her or him.

Healthcare providers must remember to ask questions which elicit the patient's own perspective toward their illness and expectations for care. They should offer to make all the information available to the patient first, but allow her or him to decide. They should use professional interpreters to facilitate communication with the patient and family and accommodate all reasonable requests of the patient and their family to build a trusting relationship.

Cultural competence encompasses a set of values, behaviours, attitudes, knowledge and skills which enable healthcare providers to offer patients the kind of care that is respectful and inclusive of their cultural backgrounds.⁽³⁶⁾ Understanding how to cope with differences in a comfortable, skilled and competent way allows patients to receive the holistic care they need as the end of their life approaches.

RECOMMENDATION 3 - CARING FOR THE PATIENT AND THEIR FAMILY

Psychosocial Support

Psychosocial support of a patient and their family is a responsibility all healthcare providers share. Supports are aimed at enhancing overall well-being for the patient and their family, strengthening their own skills and abilities, and using their own resources for overcoming challenges. Psychosocial support involves attending to the emotional, psychological, social, spiritual, practical needs and wishes of the individual within the context of their community of family, friends, neighbours and associations with others, such as pets.⁽³⁷⁾ To fully appreciate and provide support, healthcare providers must attempt to comprehend all significant factors influencing patients and their families' life progress.

Psychosocial interventions are implemented with specific goals in mind and often involve healthcare providers with specialized knowledge and skills, such as Social Workers, Clinical Counsellors and Mental Health providers. Interventions are agreed upon, ideally, with the patient and their family, with the goal of overcoming barriers, resolving, stabilizing and/or bringing meaning to what is causing distress.⁽³⁸⁾ Intervention is distinct from diagnosis in that it is viewed as being a 'process' that is put into effect as an ongoing outcome of our observation.⁽³⁷⁾ Some interventions may be tangible or information based, such as requiring information about different systems, benefits or resources that impact a patient and their loved ones.

General Strategies

Exploring internal and external resources - Internal resources can include resiliency, one's honesty in facing challenging situations, having awareness of one's limitations and ability to express them, ability to cope.

External resources include tapping into patient's supportive network, if one exists such as: family, friends, organization and/or spiritual affiliations, work colleagues. It may include connecting with new resources to assist with coping – counseling, spiritual care, and massage and/or therapeutic touch. Exploring one's internal and external resources can be helpful in assisting with addiction issues and in crisis. Practical tips and suggestions, that is found in patient information

handouts, can be helpful to assist patients and families in coping with a life limiting illness (see *Appendix B*).

Enhancing the existing strengths of the patient and family - Through the assessment, one can identify the history and current functioning of the patient and their family, areas of strength, competence and skill. Discuss and explore ways these strengths can be maximized. ⁽³²⁾ Familiarize the interdisciplinary team with patient and family strengths and make clear to each team member roles in supporting optimal patient and family functioning.

Providing information – Gain understanding of what the patient and/or family already understand or how much they want to know about their diagnosis, prognosis or other matters related to their quality of life.

Assist with decision making – Identify patient’s goals of care and end of life plans. If having difficulty in ascertaining information, asking patients’ what is most meaningful to them or what their biggest fears are can help prioritize needs. Utilize available resources to familiarize yourself with available options to help promote discussion (see *Appendix C*).⁽²⁾

Teamwork – Good supportive palliative care is delivered by interdisciplinary teams.⁽⁴⁰⁾ The Hospice Palliative Care model is designed on the premise of providing interprofessional care in order to approach each client in a holistic manner and provide “whole person” care. Each member of a team will have a range of overlapping roles, some medical and some non-medical, each focused on a specific state of patient needs. Even if a particular patient or family may choose to not have a specific discipline involved, it can be helpful to include them in the discussion of providing care to patients. Each discipline has their own approach to working with patients and families, which can be helpful in gaining a holistic perspective on the patient and their situation in context.

Advocacy – Advocate for the needs, choices, decisions and rights of patients and families in palliative and end of life care. Advocacy should address clinical and social issues that are affecting the life of the patient and foster human dignity and self-worth.⁽²⁵⁾

Resources – Utilizing community resources can play an integral part in stabilizing and/or maintaining functioning of a patient and/or family. Social Workers are often familiar with existing resources in the community as it relates to housing, financial benefits, guardianship for children, food programs, and other means that can provide support and guidance for families.

Communication

Supportive/Adaptation Counseling - Counseling is a goal-oriented process which involves employing active listening skills, reflection and exploring inner and

external resources all of which can lead to a powerful experience.⁽²⁵⁾ Often, people are not looking for their problems to be solved, but for someone to deeply hear and be present to the depth of the pain they are experiencing.⁽⁴⁰⁾

Companioning – An intention to bring a respectful, nonjudgmental presence to the dying while liberating them from self-imposed or popular expectations to say or do the right thing. The companioning model, adapted from renowned grief educator Dr. Alan Wolfelt’s model of caring for mourners, offers a refreshing departure from traditional counseling formulas and prescriptions.⁽⁴¹⁾

Active Listening - Listening and talking to patients is one of the key tasks in hospice palliative care.⁽⁴⁰⁾ Active listening is a valuable skill because it enables us to demonstrate that we understand what another person is saying, through empathy, and how he or she is feeling about it. Additionally, it also allows the healthcare provider to check whether their current understanding is correct. Active listening does not mean the same as agreement but rather a demonstration that you intend to hear and understand another point of view. Skills in active listening include: restating, paraphrasing, reflecting back to confirm and ensure understanding of what is being expressed, responding to feelings, summarizing, checking perceptions and allowing for silence.

Normalizing – Discussing common and expected outcomes and responses to situations can be helpful to decrease anxiety about the unknown, apprehension about what “comes next” and for minimizing the common response that their feelings are not “healthy”.

Creating a safe space for the “telling of their story” – A life review can be an effective way of allowing a person to have closure in their life, review life’s accomplishments and/or achievements, highlight unresolved issues, and to provide an opportunity for forgiveness of self and others.⁽⁴⁰⁾ Telling of one’s story can also be a useful tool to explore previous coping skills (that were either helpful or not effective), when faced with hardship.⁽⁴²⁾

Family Meeting - In hospice palliative care, the family meeting can be an effective way to allow for all members of the family to be heard and understood, allow for observations of relationships among family members, and provide a forum to voice and acknowledge feelings.⁽⁴³⁾ It is important to prepare for family meetings and to decide, often with the patient, who should be there and who should facilitate. In the presence of family conflict, the family should do most of the talking as the aim is to help them solve the problem, not to solve it for them.⁽⁴⁰⁾

Fostering Hope

Learning to live with a life limiting illness involves patients, their loved ones and healthcare providers in a continuous process of 'meaning making' and adaptation as they transition:

- From goals of cure to comfort care.
- Through shifts in hopes and expectations.
- With personal, psychosocial and spiritual issues.
- Possibly between care settings (home, hospital, residential care facility and/or hospice residence).⁽⁴⁴⁾

Patients and families require time to adjust and cope with each change. At any stage it is possible that a patient's expressed understanding or disease experience may be different from others, including family members and/or care providers. Identifying and appreciating the 'truth' about an illness within the context of the patient's experience and from the perspective of their loved ones helps to ensure that their values, goals, priorities and preferences will be heard and respected. Throughout the progress of their illness, patients and families may even express hope for outcomes that appear to be unrelated to what is expected based on test results and physical functioning.

While healthcare providers have an obligation to provide patients and families with accurate information about their disease, prognosis, treatment and/or care options (to the degree desired by patient and family) it is not their responsibility to ensure that hope is 'realistic.'⁽⁴⁵⁾

If hope is defined solely in terms of cure or remission of disease, the hopes of terminally ill patients might be viewed as a form of denial or false reality.⁽⁴⁶⁾ Hope for palliative patients needs to be understood and supported as a dynamic process that shifts from hope for a cure to:^(46,47)

- Hope for survival.
- Hope for comfort.
- Hope for the energy to keep going.
- Hope for dignity.
- Hope for intimacy, reconciliation with what gives meaning.
- Hope for a better day or better moments.
- Hope for a peaceful death.
- Hope that surviving family will not suffer after patient's death.
- Hope for an afterlife.

For those in the terminal phase of an illness, hope can be a powerful coping mechanism, an inner resource necessary to endure life circumstances. Hope can provide the psychological and physical energy required to endure suffering and achieve goals. It can help people find meaning and direction, "...to stay engaged in the living while shouldering the burden of an uncertain future."⁽⁴⁶⁾ It is crucial to approach each patient as a living human being who has the need and the right to maintain a sense of hopefulness, and to be cared for by those who can maintain a sense of hopefulness, however changing this may be, until the moment of their death.⁽⁴⁸⁾

Healthcare providers can foster hope by:

- Being authentic.
- Facilitating caring relationships.
- Using humour and play.
- Encouraging determination and courage.
- Assisting patients and families to establish short-term, attainable goals.
- Supporting spirituality.
- Engaging in reminiscing.
- Being physically present in crisis.
- Listening attentively.
- Managing pain and other symptoms.⁽⁴⁷⁾

It is through these types of activities that healthcare providers can sustain their own sense of hope while supporting the evolution of patient and family hope from a curative focus to one that transcends the illness experience.

Helping Children

Adults often struggle while talking with children about sickness, changes in the family and the possibility of death. Adults often don't want children to worry, become upset or they themselves may not be comfortable with giving information because they may still be coming to terms with the diagnosis of a life limiting illness, as well as feeling distracted by the emerging decisions.⁽²¹⁾ Despite these fears and feelings, adults can help children by knowing how to provide them with information and support in healthy meaningful ways that respects their experience of grief.

It is not an easy task to talk with children about death and dying and teaching them how to grieve requires the adults supporting them to face those very issues and venture into the unknown themselves.⁽⁴⁹⁾ Adults are often in the position of role modeling for children and that happens with one's response to loss and grief as well. Children will often take cues of expressing emotion and behaviour from

the adults around them. Consequently, it is important for healthcare providers to provide education, guidance and support to all of the adult caregivers involved with the children, for their own grief as well as for understanding the developmental stages of children as it relates to grief, loss, intellectual and emotional limitations.⁽⁵⁰⁾

The value of talking with children about the diagnosis, its implications and possible changes in the family will increase their trust, lessen anxiety, promote their feeling of being a part of the family and dispel any false imaginings as to what they may think is happening from what they may have heard.⁽⁵¹⁾

It is always good to begin with a plan before talking with children and some things to consider are:

- What is known about the illness, treatments, and effects?
- Decide who will talk with the children and when.
- Decide what emotional support is needed.
- General knowledge of available age appropriate materials and community resources.⁽⁵¹⁾

Suggested guide for talking with children:

1. Ask what they know so far.
 - Clarify further by asking what the words mean, i.e., cancer.
 - Clarify any misinformation or misunderstandings.
2. Encourage them to ask questions or share worries, reassuring that all are 'okay'.
 - This includes information such as location of care, treatments, procedures, possible side effects, physical appearance, etc.
3. Avoid minimizing fears or concerns.
 - Tell them who will be there to take care of them and where.
 - Let them know of any changes to their day-to-day routine.
 - Tell them that you will give regular updates as to what is happening.
4. Answer honestly, be clear and concrete. When you don't have an answer, say so.^(49,50)

Desire to Die Statements

Expression of wanting to end one's life of living with a life limiting illness is not uncommon.^(52,53,54) Every individual adapts to the inevitability of death in many ways.

When we are young, we deny death through parental reassurance, transform death through personification, engage in daredevilry, and when we are older; we transform it into a positive experience, "going home".⁽⁵³⁾ It is imperative for healthcare providers to distinguish between patients who contemplate suicide due to fears or questions that can be addressed by an interprofessional hospice palliative care team and those who will, and have the means, to actively take their own life.

Expressing the desire to die surfaces from the need to find meaning within suffering and find reason to live.⁽⁵⁶⁾ Meaning is found within relationships which bring life, hope, strength and a sense of completeness.⁽⁵⁶⁾ A goal of psychosocial care within hospice palliative care is to support and assist patients and their families in achieving a peaceful awareness of death, life that has been lived and life as it is by helping to sustain meaning.

Statements made by patients with a life limiting illness that either explicitly or implicitly suggests a desire to die can have a variety of meanings. Some thoughts about death and dying are appropriate and do not necessarily indicate suicidal ideation or depression.⁽⁵⁷⁾ Typical concerns may include fears around the dying process, contemplation of an afterlife, and other existential issues.⁽⁵⁷⁾ More simply, statements made by patients that they have a desire to hasten their death may only be a request to be heard and to be understood.⁽⁵²⁾

The most common factors associated with patients expressing a desire to die include:

- Guilt.
- Being a burden to others.
- Loss of autonomy and control.
- Uncontrolled physical symptoms and/or discomfort.
- Depression and hopelessness.
- Existential concerns.
- Fear of the future.^(22,54)

Most of the reasons commonly associated with a patient's desire to die can be addressed, however many healthcare providers often feel inadequately prepared to respond to such statements.⁽⁵²⁾ Seeking to understand the meaning behind a

patient's desire to die is crucial to formulate a professional response and appropriate intervention.⁽⁵⁸⁾

Healthcare providers can engage in meaningful communication when responding to a patient's statement of a desire to die by: inquiring about the patient's emotional state, conveying a willingness to talk about their distress, and helping them to identify their motivations for the request to die. The very fact that there is communication and expression of wanting to die, suggests the expectation of an interaction with the physician or healthcare team.⁽⁵⁹⁾ The approach to respond to patients, who express a desire to hasten their death, should be guided by a principle that seeks to understand, rather than to act.

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

1. Exploring their current feelings and/or fears:
 - “Sometimes people feel so overwhelmed by things that they feel everything is just ‘too much’. Would you say that you have felt that way?”
2. Assessing their state of suffering and distress (physical, emotional, spiritual):
 - “What do you feel could be improved in your care and treatment?”
3. Exploring their specific reasons and plan for suicide, if present:
 - “Have you thought about or decided how you would end your life?”
 - “If we could relieve the problem, would you still be interested in ending your life?”
4. When they are seeking healthcare providers assistance with hastening death:
 - “Can you tell me how you’ve come to feel like this and why you want to take this action?”⁽⁵²⁾

Through a thorough assessment, a healthcare provider should ascertain if the patient is an immediate threat to themselves or to others. Healthcare providers must be careful not to stigmatize their thoughts as suicide but to provide validation of a patient's distress and a commitment to respond to their suffering. If it is determined that there is an imminent threat, one should contact an emergency response team (911 or local Mental Health Unit/Hospital) or the patient's Family Physician for direction.

RECOMMENDATION 3 - HELP FOR CHALLENGING CARE SITUATIONS

Indicators for Specialized Consultation

There may be instances where psychosocial intervention is not necessary, but a hospice palliative care Social Worker or Counsellor may be helpful (see *Appendix D*). Based on assessment, some of the following factors may be present that could indicate a greater likelihood of a need for psychosocial support/intervention:

- Emotional anguish experienced by the patient and/or family.
- Feeling overwhelmed and/or unable to make decisions.
- No caregiver in home, caregivers' ability is compromised or patient is primary care provider for another.
- Language, cultural considerations.
- Change in family function e.g., tension, conflict, new roles and responsibilities taken on reluctantly by family members.
- Guardianship with children, young children in the home.
- Unresolved grief from previous and/or traumatic losses (date of identified loss may not be relevant).
- Thoughts of meaninglessness, suicide (either passive or active).
- Concerns regarding active or historical use and/or presence of: alcohol, substance abuse, physical or emotional abuse.
- Concerns regarding physical, psychological and/or financial abuse, neglect and/or self-neglect of adults age 19 and older see NH Adult Guardian Response Flowchart - Reorder# 10-040-6007 (*available on Document Source or Adult Protection Services Manual*).
- Absence of advanced end of life planning (i.e., such as personal, healthcare, financial, legal).
- Spiritual needs, concerns or questions. See *Northern Health Hospice Palliative Care Symptom Guideline for Spiritual Distress (currently under development)*
- Educational needs related to community resources and methods to access.
- Mental Health concerns and/or maintenance of mental health wellness.
- Presence of cognitive impairment, learning disability.
- Financial and practical stressors.

Recommendation 35 - Evaluation

Palliative and end of life care situations are complex and marked by ongoing changes in patient and family needs, goals and priorities.⁽⁶¹⁾ It is important to have a process that supports the continuous evaluation of interventions and outcomes to ensure that needs are clearly identified and responded to as effectively as possible.⁽⁶¹⁾ Monitoring the efficacy of selected interventions and the progress towards stated goals of care can:

- Enhance and assure consistent quality of care.⁽⁵⁾
- Recognize successes.
- Indicate when a redirection of efforts may be needed.
- Assure that healthcare providers remain accountable to patients.
- Facilitate hope.
- Help patients mark the completion of important end of life tasks.

A collaborative process for assessing and reassessing interventions recognizes patients and families as “their own best experts”⁽⁶²⁾ and actively seeks their guidance and feedback. Evaluation processes might also include the use of open-ended interviews, formal assessment tools to monitor pre-and-post intervention changes and clinician self-reflection.

Questions that can help guide evaluation processes include:

1. Was the desired goal of care reached? (Effectiveness)
2. Was the goal of care reached in the most direct way? (Efficiency)
3. Was the patient’s autonomy ensured? Were others’ autonomy ensured? (Impartiality)⁽⁶³⁾

Opportunities may also arise during the course of evaluating outcomes for a specific patient to identify themes, issues or patterns on a global level that can be useful in looking at program policies and procedures for working with the palliative population.

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Approved by:

Endorsed by:

APPENDIX A - CHILDREN AND DEATH – THE HOSPICE AT THE TEXAS MEDICAL CENTER⁽⁶⁴⁾

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

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APPENDIX B - TOOLS FOR COPING WITH SERIOUS ILLNESS

The following are ideas that you may find useful in assisting you while coping with a serious illness, whether it is for yourself or a loved one. These ideas/tools may trigger or reinforce some of your own. They are not all inclusive nor do they corner the market on truth. If some of these ideas do not work for you, ignore them. Take only what fits. Each of us is unique in how we handle difficult situations. Use these ideas to stimulate more of your own.

- **Deal with your emotions:** Allowing ourselves to deal with our emotions, whether they are up or down, is a part of the healing process. When we have a lot of stress in our lives, our defences are down and emotions are closer to the surface.
- **Drink water:** Dehydration occurs when we are under stress of any kind. This can affect our energy level, etc.
- **Eat healthy:** This is tough when you don't feel like eating. When you are stressed, your appetite is affected. Follow any guidelines given to you by your doctor or healthcare professional, but eating small amounts more often is usually better than trying to face a big meal. Food replacements such as Ensure® or Boost® may be helpful.
- **Enlist the support of others:** Studies show that a support network can be helpful in coping with this situation. Because your friends and family may not be able to support you as often, or in the way you would like, or may be struggling to cope as well, it may be helpful to utilize additional resources such as religious or community supports, healthcare staff, etc.
- **Take a deep breath:** When under stress we tend to breathe very shallowly, which doesn't allow enough oxygen to the brain. Breathing deeply every so often helps to maintain that balance and give you an edge.
- **Personal coping kit:** Based on what gives you energy; put together a kit. This kit may contain pictures, mementos, videos, letters, crossword puzzles, a good book, magazines, etc. – whatever you think would help you through the difficult times.
- **Write down your thoughts:** A journal is one way of sorting through your experiences. Sometimes ideas and thoughts run around in your mind and it is hard to get a handle on what really is happening for you. Writing is one way to help with this. You cannot write as fast as you think and, as a result, your mind is forced to slow down.
- **Utilize your sense of humour:** Humour will go a long way to carry you through this stressful time. Laughter creates a release of tension and releases endorphins into the system to give you a sense of well being. This will help to cope with the stress of dealing with serious illness.

Also....for family and friends:

Being there for someone who is ill is difficult work at any time. However, when faced with a life-threatening situation, things are even more complex, and events may take on a different meaning. While the ideas above may apply to you, also remember the following:

- **Time out:** Take breaks to allow your body time to rejuvenate. Take short walks, get some fresh air, even if only for 5 minutes at a time. A change of

scenery gives you a break from the intensity of the situation and can give you renewed energy to continue to be present.

Common Reactions when Coping with Serious Illness

Information for individuals, friends and family

There are a wide variety of feelings and reactions that come into play when you are facing a serious illness either yourself or of someone you love. It is important to note that no two people react in the same way to a crisis like this. Everyone is unique and, as a result, will handle the situation somewhat differently.

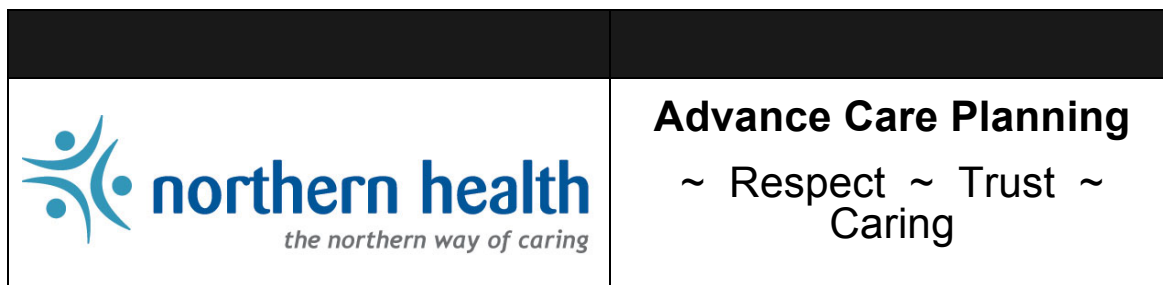
As you go through this experience, you may find yourself reacting in ways that are very uncharacteristic for you. This does not mean that you are “losing it”; it does mean, however, that your reactions are “normal” or can be “expected” given these unusual circumstances. Be gentle with yourself, give yourself permission to take breaks, and ask for support from those around you.

You can expect that there will be some emotional reaction to this situation. Some of the common reactions you may experience include:

- **Inability to focus or concentrate:** Things which may have been routine in your daily life are now difficult, such as reading, etc.
- **Poor memory:** Even such things as a familiar phone number may be a challenge to recall.
- **Physical reactions:** Reactions such as tight muscles, headaches and exhaustion may also be a part of this experience. If you are experiencing these symptoms, it is a good idea to check with your family doctor.
- **Increased irritability:** Your tolerance level may not be as high as it used to be. This may be particularly true within your own family, or with those you care about.
- **Confusion / disorientation:** You may find yourself losing track of place/ time.
- **Less self-confidence than usual:** This incident has turned your world upside down and has shaken up your beliefs, including what you believed about yourself.
- **Difficulty in making decisions:** Sometimes what once seemed the simplest of decisions becomes a challenge.
- **Change in sleeping patterns or difficulty sleeping:** When you try to sleep or rest, your thoughts may run all over the place. (A healthcare professional may be able to give you some suggestions to help deal with this).
- **Sense of unreality:** “This can’t really be happening!”
- **Feelings of helplessness:** The feeling that there must be something you could do to make a difference to the situation.
- **Feelings of being “on alert” at all times:** You may find that you are easily startled and that it is hard to settle yourself down, particularly at night.
- **Being on an “emotional roller coaster”:** You may feel that you are never quite sure what is going to happen day by day as you deal with the situation.

This is not a complete list and you can add many other things that you experience. Use only what works or fits for you.

APPENDIX C - ADVANCE CARE PLANNING



WHAT IS ADVANCE HEALTHCARE PLANNING

Modern medical treatment means that most of us enjoy longer, healthier lives. However, medical technology can also prolong the dying process and may keep a patient alive even though they are at the natural end of their life.

Advance Care Planning is an on-going process that involves encouraging capable adults to have meaningful discussions about personal values, beliefs and possible future medical decisions with their loved ones and physicians/healthcare team.

It is a process of learning, deciding, and talking about what health and personal care one would want in the future if they are unable to make or communicate those decisions themselves. If a patient is unable to make health and personal care decisions, others will have to make these decisions for them. Unless a patient tells people what they want now, these people will have to guess when the time comes. To plan for future healthcare, a patient needs to:

1. **Learn** about what healthcare treatments are available and what they can do for them. For example -- What is tube feeding? What is cardiopulmonary resuscitation (CPR)? In what situations could these treatments help them? Make sure their decisions are based on information about their choices.
2. **Discuss** with their family, friends, and healthcare providers what they think about the treatments that are available. Talk these things over before they decide. Make sure their decisions are based on their values and beliefs, on what they think about their life and death.
3. **Decide** what healthcare they want in the future based on their learning and discussing. They also need to consider and decide **who** they want to make decisions for them if they are unable to do so themselves.
4. **Document** their decisions. Make sure everyone (family, doctor, caregiver) has a copy.

Resources available to help promote discussion/decision making at end of life:

1. BC Ministry of Health Services information on planning for the End of Life Care: <https://www.health.gov.bc.ca/hcc/endoflife.html>
2. Nidus- Personal Planning Resource Centre and Registry, resources for adults wanting to plan their future care: www.nidus.ca
3. Public Guardian and Trustee of BC. Information on healthcare decision making and consent to healthcare: www.trustee.bc.ca
4. British Columbia No Cardiopulmonary Resuscitation Form: <https://www.health.gov.bc.ca/exforms/bcas/302.1fil.pdf>
5. Joint Protocol for Expected/Planned Home Deaths in British Columbia: http://www.health.gov.bc.ca/hcc/pdf/expected_home_death.pdf
6. British Columbia Notification of Expected Death in the Home Form: http://www.health.gov.bc.ca/hcc/pdf/expected_death.pdf

APPENDIX D

When to Call Your Local Social Worker and/or Counsellor...

For consultation on any aspect of psychosocial assessment and/or care planning regarding the provision of care to hospice palliative care patients and their families/caregivers.

For information and resources (i.e., pamphlets, books, referrals) for clients and families/ caregivers regarding palliative care, grief and bereavement, financial and community resources.

For collaboration with primary care staff in a joint visit or family meeting to:

- Assist with assessing psychosocial needs.
- Discuss goals of care.
- Provide support with challenging psychosocial situations.
- Describe the hospice palliative care program to a patients and/or family members.

For specialized support and counselling in complex situations where assistance is needed regarding:

- Difficult family dynamics and/or adjustment to illness.
- Exploring and/or assisting patients and their family/caregivers in the expression of emotions such as anxiety, anger, depression, meaningfulness and hope.
- Financial and/or legal planning options related to end-of-life.
- Ethical dilemmas including conflicting expectations regarding treatment and/or care planning.
- Cultural issues.
- Caregiver issues (i.e., Protection concerns of young children or dependent and/or vulnerable adults including issues of abuse or neglect).
- Advance Care Planning or discussions regarding end-of-life decision making.

To facilitate case reflections (staff 'debriefings') regarding complex and/or challenging hospice palliative caregiving situations, current or recent.

To discuss any personal/professional challenges you may be experiencing in working with hospice palliative care patients and families — including grief or boundary issues.

In Northern Health, there may be times when a local social worker is unavailable.

In this case, please contact the social worker in your nearest community or the NH cancer care social worker at 250-565-2863

Indicators of Potential Challenging Psychosocial Situations in which Social Worker Involvement Should be Considered

Potential conflict among family members

- Hostility expressed by one family member toward another. This can be subtle like “ Ohhh, *his* daughter might not agree with us on this.”
- Different ideas about future planning issues. For example a palliative patient stating that she is tired of treatment but family members indicating importance of continuing treatment
- One family member may want to take charge but this may not be supported by all.

Multiple grief issues or unresolved grief issues within the family unit or social support system of patient

- Example statement: Having cancer reminds me so much of how I felt when my son Johnny died. He was so young.
- Remember that grief doesn't mean just the death of a loved one, it can mean the loss of important identity issues. Example: recent move, loss of house, loss of finances, loss of health

Multicultural issues

- There are different ways of expressing concern, grief and approaching death (which may be at odds with medical system approach)
- Remember that cultural competency doesn't mean to know about a culture. It is about knowing about who the person is and how they live their life in relation to their culture.
- Remember that the “non identified” ethnic groups have cultural issues as well (the 90 year old British female or the 70 year old male born in Germany)

Noted signs of caregivers being overwhelmed, stressed, depressed, passive, indifferent, frustrated, angry, etc.

In Northern Health, there may be times when a local social worker is unavailable.

In this case, please contact the social worker in your nearest community or the NH cancer care social worker at (250) 565-2863

SPINAL CORD COMPRESSION

Rationale

This guideline is adapted for inter-professional primary care providers working in various settings in Northern Health, British Columbia and any other clinical practice setting in which a user may see the guidelines as applicable.

Scope

This guideline provides recommendations for the assessment and symptom management of adult patients (age 19 years and older) with advanced life threatening illness and experiencing the symptom of spinal cord compression. This guideline does not address disease specific approaches in the management of spinal cord compression.

The vertebral column is the most common site of skeletal metastasis.⁽¹⁾ Seventy percent of patients dying from cancer have spinal metastases at autopsy.⁽¹⁾ Cord compression occurs in 5% to 10% of all patients with malignancy⁽¹⁻⁸⁾ but account for 25% of all central nervous system tumours.⁽³⁾

Definition of Terms

Spinal Cord Compression develops when the spinal cord is compressed by a tumour, abscess or other lesion. It is regarded as a medical emergency independent of its cause, and requires swift diagnosis and treatment to prevent long-term disability due to irreversible spinal cord injury.^(9, 10)

Standard of Care

1. Assessment
2. Diagnosis
3. Prognosis
4. Education
5. Treatment: Non-pharmacological
6. Treatment: Pharmacological

RECOMMENDATION 1 - ASSESSMENT OF SPINAL CORD COMPRESSION

On-going comprehensive assessment is the foundation of effective management of spinal cord compression, including interview, physical assessment, medication review, medical and surgical review, psychosocial review, review of physical environment and appropriate diagnostics (*see Table 1*). Assessment must

determine the cause, effectiveness and impact on quality of life for the patient and their family.

Table 1: Spinal Cord Compression Assessment using Acronym O, P, Q, R, S, T, U and V*

O Onset	When did it begin? How long have you had the pain, constipation, weakness? Have you had this before?
P Provoking/ Palliating	What brings the pain on? What makes it better? Does cough, sneeze or pressure make it worse?
Q Quality	What does it feel like? Can you describe it? Is it a band-like pain?
R Region/ Radiation	Where is it? Does it spread anywhere?
S Severity	What is the intensity of this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Right now? At best? At worst? On average? How bothered are you by this symptom? Are there any other symptom(s) that accompany this symptom?
T Treatment	What medications and treatments are you currently using? How effective are these? Do you have any side effects from the medications and treatments? What medications and treatments have you used in the past?
U Understanding/ Impact on You	What do you believe is causing this symptom? How is this symptom affecting you and/or your family?
V Values	What is your goal for this symptom? What is your comfort goal or acceptable level for this symptom (On a scale of 0 to 10 with 0 being none and 10 being worst possible)? Are there any other views or feelings about this symptom that are important to you or your family?

* also include a Physical Assessment (as appropriate for symptom)

Symptoms:

- **Pain** is the presenting symptom in 90 to 95% of patients^(1, 11) Two types of pain:⁽¹⁾
- **Local back pain** (midline/paravertebral) nearly always present.⁽¹⁾
 - Usually constant, close to site of lesion.⁽¹⁾
 - Relieved by sitting or standing up (as opposed to disc disease which is relieved by laying down).^(1, 8)

- Exacerbated by any increase in intrathoracic pressure (sneeze, cough, Valsalva maneuver, straining at stool).^(1, 4)
- Above historic points may be only clue to impending spinal cord compression.⁽¹⁾
- **Radicular pain** from spinal root compression occurs in 66% of patients.⁽¹⁾
 - More common with lumbosacral (90%) and cervical (79%) metastases than with thoracic metastases (55% of cases).⁽¹⁾
 - Patients complain of a band or girdle of pain/tightness radiating from back to front; in extremities, radicular pain usually unilateral.⁽¹⁾
 - Exacerbated by recumbency, movement, cough, sneeze, Valsalva maneuver.^(1, 3, 12)
 - Worse at night.^(1, 3, 8, 12)
 - Improved by sitting or standing.^(1, 8)
 - Radiates in a dermatomal pattern.⁽¹⁾
 - May produce numbness and tingling (cervical, thoracic or lumbar root).⁽¹⁾ When progresses numbness usually precedes weakness.
 - May resemble pain from intervertebral disc disease, pleurisy, cholecystitis or pancreatitis.⁽¹⁾
 - Distinguish from brachial or lumbosacral plexus involvement.⁽¹⁾
 - Localizes the lesion within one or two vertebral segments.⁽¹⁾
- **Weakness** in legs is the next symptom if left untreated (76% of patients).⁽¹⁾
 - Experienced as stiffness, dragging of a limb or unsteadiness.^(1, 12)
- **Sensory disturbances** may accompany or be preceded by (in 51% of patients).⁽¹⁾
 - Numbness usually begins in the toes, gradually ascends to level of cord compression (usually without paresthesias).^(1, 12)
 - Sensation of coldness.^(1, 12)
 - Upper limit of sensory level often one to two vertebral bodies below site of compression.⁽¹⁾
 - Sensory loss progresses to ataxia (3% of patients).⁽¹⁾
- **Autonomic dysfunction** (57% of patients).⁽¹⁾
 - Early signs: loss of bladder control, hesitancy, urgency.
 - Late signs: urinary retention, overflow incontinence.^(1, 12)
 - Constipation.⁽¹⁾
 - Loss of perspiration below level of the lesion.⁽¹⁾

- Sexual difficulties.⁽¹²⁾
- Signs and symptoms probably not due solely to compression of cord; ischemia secondary to vascular involvement may also be a factor (especially when cord compression develops suddenly over a few hours).^(1, 8)

Distribution:^(1, 3, 5, 12)

- Thoracic spine – 70%^(8,13) which has a smaller ratio of spinal canal to cord diameter than the other two spinal segments.⁽⁸⁾
- Multiple contiguous levels – 10% to 38%.⁽⁷⁾
- Lumbosacral spine – 20%.
- Cervical spine – 10%.

Incidence In Malignancy:⁽¹⁾

- Lung – 16%
- Breast – 12%
- Unknown primary – 11%
- Lymphoma – 11%
- Myeloma – 9%

RECOMMENDATION 2 - DIAGNOSIS

Management should include treating reversible causes where possible and desirable according to the goals of care. The most significant intervention in the management of spinal cord compression is identifying underlying cause(s) and treating as appropriate. While underlying cause(s) may be evident, treatment may not be indicated, depending on the stage of the disease.

Whether or not the underlying cause(s) can be relieved or treated, all patients will benefit from management of the symptom using education, specialist intervention or medications.

Identifying the underlying etiology of the spinal cord compression is essential in determining the interventions required.

The importance of early diagnosis cannot be over-emphasized; symptoms are usually present for some weeks before neurological emergency occurs.^(3, 4) In rural communities where treatment may require travel the importance of early diagnosis is even more crucial.

- Extent of diagnostic workup indicated in any given case depends on overall condition of patient. In patients expected to live more than 1 to 2

months and who are not already paraplegic the following tests are indicated:⁽¹⁾

- Evidence of epidural metastases may be seen on plain x-rays in approximately 85% of patients⁽¹⁾ but only predicts the level of compression in 19%.⁽³⁾
- Urgent referral for **CT scans and MRI** improves early detection. MRI scans are more sensitive than CT Scans and are the standard for diagnosis.^(3, 6, 7) Whole spine MRI is more sensitive in detecting small CNS metastases that can be missed with other imaging methods.^(6,11) Myelography has a place where CT scan and MRI are not available.⁽⁴⁾

RECOMMENDATION 3 - PROGNOSIS

- The degree of neurologic function at diagnosis and the start of treatment is the most significant factor in determining the recovery of function.^(1, 14)
- Rapid onset (less than 48 hours) and progression of symptoms are poor prognostic indicators.⁽²⁾ Patients who are not mobile at presentation do not generally regain the ability to walk.⁽⁶⁾ Of patients who are paraplegic pre-treatment, only 10% will regain ambulation after treatment.⁽¹³⁾
- If the patient has been paralyzed for more than 48 hours, the chance of neurological recovery is very poor.⁽³⁾ “Emergency” treatment at this point may not be indicated but palliative radiation for pain management may be beneficial (per British Columbia Cancer Agency).⁽¹⁵⁾

Start I.V. corticosteroids to reduce edema and improve neurological function while completing diagnostic workup when history and physical examination suggest spinal cord compression.^(1, 3, 16)

- Spinal cord compression is an emergency necessitating immediate assessment and treatment^(2, 3, 6, 14) requiring urgent consultation of the radiation oncologist and neurosurgeon at the closest available site.⁽¹⁰⁾ A Radiation Oncologist will treat with radiotherapy on weekends.⁽¹³⁾

RECOMMENDATION 4 - EDUCATION

- Patients at risk should be identified and taught the signs and symptoms of spinal cord compression and the urgency of reporting promptly.⁽¹⁾
- Explain procedures and details of ongoing investigations with patients and family.⁽⁶⁾

RECOMMENDATION 5 - TREATMENT: NON-PHARMACOLOGICAL

- Malignant spinal cord compression should be individualized and should take into consideration pretreatment ambulatory status, previous treatment, co-morbidities, technical surgical factors, the presence of bony

- compression and spinal instability, potential surgical complication, potential radiotherapy reactions and patient preferences.⁽¹⁷⁾
- Management requires a combined effort from the family physician, radiation oncologist and spinal surgeon.⁽¹⁴⁾
 - **Radiation therapy** should be started immediately after diagnosis.^(1, 6, 13)
 - Radiation therapy provides definitive treatment in most patients.^(2, 3, 5, 8, 14, 16) Indications for radiation therapy include known radiosensitive tumour and no spinal instability^(1, 5, 7, 11, 17) and for palliative therapy in patients who present with paraplegia.⁽⁷⁾
 - Radiation therapy alone gives equivalent results to laminectomy plus adjuvant radiation therapy^(1, 4) and is effective in over 85% of cases of spinal cord compression.⁽⁶⁾
 - Patients who are ambulatory at the time of the diagnosis have a higher probability of obtaining good response to treatment and a longer survival.⁽³⁾
 - Patients who experience progressive neurological deficits despite receiving radiotherapy should be considered candidates for urgent surgical decompression and/or stabilization.⁽⁷⁾
 - **Surgery** may be considered if the patient is ambulatory and otherwise stable with good performance status.⁽¹⁻³⁾
 - Surgery is the first choice where the site of the primary tumour is unknown, where there is relapse after radiation treatment, and in cases of spinal instability or vertebral displacement.^(8, 11) It should also be considered when neurological symptoms progress during radiotherapy, in plegia of rapid onset, or where tumours are not radiosensitive.^(4, 12, 14)
 - **Rehabilitation** must commence on diagnosis and must encompass the skills of various professionals. Ensure that goals are short term and attainable so as to achieve the best possible quality of life.^(6, 8)
 - If patient immobile, treat as if they have an unstable spine during repositioning.⁽⁶⁾
 - Apply anti-embolic stockings if patient has impaired mobility.⁽⁶⁾
 - Ensure emotional and psychosocial support for patient and family.⁽⁶⁾

RECOMMENDATION 6 - TREATMENT: PHARMACOLOGICAL

Dexamethasone 10 to 100 mg I.V. STAT^(3, 4, 11) then 16 to 96 mg PO daily, then taper over 10 to 14 days after improvement or irreversibility.^(1, 5, 11)

- Shown to improve neurologic function and relieve pain, reduce edema and have a direct oncolytic effect.⁽¹⁾ Dexamethasone may also temporarily prevent the onset of cord ischemia.⁽²⁾

- In patients with short prognosis or poor performance status, corticosteroids may be the only treatment feasible.^(1, 2)
- Consider the use of prophylactic heparin if the patient has impaired mobility.⁽⁶⁾

Severe pain will usually require rapid titration of an opioid drug to achieve analgesia.⁽¹⁾

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Information was compiled using the CINAHL, Medline (1996 to April 2006) and Cochrane DSR, ACP Journal Club, DARE and CCTR databases, limiting to reviews/systematic reviews, clinical trials, case studies and guidelines/protocols using spinal cord compression terms in conjunction with palliative/hospice/end of life/dying. Palliative care textbooks mentioned in generated articles were hand searched. Articles not written in English were excluded.

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**Approved by: Northern Health Hospice Palliative Care Consult Team,
October 2008**

SUPERIOR VENA CAVA OBSTRUCTION

This section is currently under development

Causes

- Compression or invasion by a mediastinal tumour

Clinical features

- General
 - Dyspnea, cyanosis, neck vein distension, edema of the face, neck and upper extremities
- A mediastinal tumour may cause cough, dysphagia, hoarseness or chest pain.
- Neurologic symptoms include blurred vision, dizziness, syncope and headache.

Diagnosis

- Clinical presentation, CXR, CT scan

Treatment

- General – Fluid and salt restriction with diuretic (furosemide), oxygen, elevation of the head of the bed.
- Dexamethasone 16-24mg PO/SC/IV daily
- Treatment of tumour
 - radiotherapy or chemotherapy for sensitive tumours
 - Further treatment will depend on stage of disease and prognosis

The above information provided from the first edition of the NH Palliative Care Guidelines and Protocols, December 2004.

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