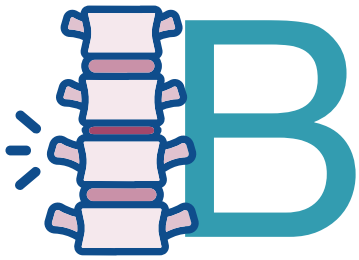
Be Prepared:
Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

BONES

(Spinal Cord Compression)

Canadian Home Care Association

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WHO WE ARE

Established in 1990, the Canadian Home Care Association (CHCA) is a national non-profit membership association dedicated to advancing excellence in home and community care. Our eiCOMPASS Project aims to empower home care providers to deliver emotionally intuitive, competency-based palliative care. We are enhancing the skills of frontline providers and improving team-based care that is compassionate, responsive, and person- and family-centred.

CHCA Website / X / LinkedIn

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Be Prepared:
Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion

This Conversation Guide is designed to help you, as the healthcare provider, have compassionate and effective conversations with patients, their caregivers, and families on how to manage a palliative care emergency at home.

Palliative Care Emergencies in the Home

Unexpected clinical changes can arise suddenly in patients receiving palliative and end-of-life care at home. These unforeseen events, often referred to as palliative care emergencies, might lead to an unplanned visit to the emergency department. According to the Canadian Institute for Health Information (2023), almost 1 in 4 patients receiving palliative home care were transferred to hospital at the very end of life.

Palliative care emergencies can significantly impact a patient's remaining quality of life and be deeply distressing for their caregivers. As a provider of home-based palliative care, it's crucial for you to recognize patients who are at risk and engage in clear, concise conversations with them and their caregivers. This empowers and equips them to manage emergencies while awaiting assistance from the palliative care team.

In response to requests from home-based palliative care providers, the Canadian Home Care Association (CHCA) has developed six Conversation Guides. Each guide addresses a palliative care emergency commonly experienced at home. The series, titled "Be Prepared: Palliative Care Emergencies in the Home", uses a simple memory key to easily identify and remember the following emergencies:

- B Breathing (dyspnea)
- B Balance (hypercalcemia)
- B Bleeding (massive hemorrhages)
- B Brain (seizures)
- B Bones (spinal cord compression)
- B Blockage (superior vena cava obstruction)

This Conversation Guide focuses on Bones (spinal cord compression).

Using the term "emergency" in palliative care discussions, despite initial alarm, is crucial for preparing both caregivers and patients with essential information and actions to respond effectively to critical situations, ultimately improving patient care.

How the Conversation Guides work

Embarking on difficult conversations about palliative care requires a nuanced approach, encompassing not just the clinical aspects, but also the emotional and practical actions to empower caregivers and patients. Here's what to expect in each guide:

A Holistic Approach

The "Head-Heart-Hands" approach provides a comprehensive framework for palliative care discussions. Given the profound challenges patients and caregivers face, including serious illnesses and emotionally charged decisions, this three-pronged approach ensures conversations are thorough and compassionate.

Head (Think): This cognitive component focuses on delivering clear information and dispelling misconceptions about illnesses and/or interventions. An informed patient or caregiver can make educated decisions, reducing uncertainties and alleviating fears.

Heart (Feel): Emotion is intrinsic to palliative care. Beyond physical symptoms, it's about addressing the emotional strains of serious illness. Using Emotional Intelligence (EI), you ensure patients and caregivers feel acknowledged and supported. This is about validating emotions, showing empathy, actively listening, and offering comfort.

Hands (Do): This actionable aspect provides patients and caregivers with concrete steps. Understanding and emotional support are pivotal, but knowing the tangible actions to take is crucial. Clear directions bolster confidence and competence in patients and their caregivers.

A Practical Tool

Each of the six Conversation Guides is structured into three distinct sections:

1 A Conversation Checklist

This is your blueprint for navigating challenging discussions about palliative care emergencies. It offers actionable advice on how to ready yourself for the conversation, relay clinical knowledge using the "Head-Heart-Hands" approach, and foster trust through key emotional intelligence techniques, such as empathy and active listening.

2 Details about the Palliative Care Emergency

In the "Palliative Care Emergency" section, you'll learn about the condition's intricacies, uncovering its underlying mechanisms, prominent signs and symptoms, and associated risk factors. You'll also find tailored conversation pointers for engaging both patients and caregivers. Additionally, you'll get a straightforward breakdown of potential treatment options and care solutions, enabling you to explain to patients and/or caregivers how to manage the situation, effectively and safely, at home.

3 A Tool for Patients and Caregivers

Equip patients and caregivers with a variety of techniques and actions to manage potential emergencies at home. This section also offers tips on how you can communicate this crucial information effectively. Designed for utility, this segment is meant to be left behind in the home, granting patients and caregivers immediate access to both the information and helpful diagrams, whenever necessary.

Furthermore, with guided prompts and questions, you'll be primed to structure your dialogue, gauge concerns, and offer clarity. It's imperative to remain attuned to the patient's care goals, especially during emergencies, to guarantee that proposed strategies align with their goals of care and life expectancy.

1

A Conversation about BONES
(Spinal Cord Compression)

Discussing the potential risk for spinal cord compression with patients and their caregivers in home-based palliative care is crucial for informed decision-making and preparedness. While the term "emergency" highlights the gravity of the situation, you can frame it in a way that doesn't cause alarm but encourages proactive planning.

With this Conversation Guide, you're better prepared to facilitate reassuring discussions on managing such emergencies at home. These situations require your dual expertise: connecting genuinely with patients and their families using emotional intelligence and clinical knowledge.

A Conversation Checklist

This checklist provides actionable steps to ready yourself for difficult conversations, to share clinical insights through the "Head-Heart-Hands" lens, and cultivate trust using emotional intelligence skills, like empathy and active listening.

What to include in your conversation	Helpful phrases for Nurses
Start with the following: a) Introduce the **purpose** and **importance** of having the conversation with empathy.	**PURPOSE/IMPORTANCE:** *"I appreciate that you may be facing some challenges. It's important that we talk about some of the situations that could happen at home so that you know how to manage them."* *"It is really important to have this conversation with you because this information will help you understand what is happening and how to manage in the moment or get help."*
b) Assess their **readiness** to have the conversation with sensitivity (i.e., ask for permission).	**READINESS:** *"We need to talk about your ability to recognize the signs of a spinal cord compression and when it is time to get help. When do you think would be a good time to talk about it?"*
c) Ask about their **fears and/or worries** and actively listen to their response(s).	**FEARS/WORRIES:** *"I'm genuinely interested in understanding your concerns. Can you share some of them with me?"* *"I want to make sure you feel you have the support you need. Is there anything about caring for (person's name) that worries or scares you?"*

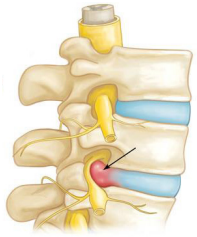
What to include in your conversation	Helpful phrases for Nurses
Describe spinal cord compression and provide information on what they might see and/or hear, how they may feel, and what they can do	*"Spinal cord compression can be alarming, but understanding its signs or symptoms can give you some peace of mind. Let's talk about the symptoms you may describe or see happen."* *"I realize that witnessing a loved one struggle can be heart-wrenching. Let's talk about how it might feel and ways to cope."* *"Having a better understanding of what is happening can help you feel more prepared if it happens. These are some really easy hands-on things you can do to help make the situation better."*
Provide reassurance and offer genuine hope	*"I know this may seem difficult for you, but I know you can do this. By working on this together, we will help you feel prepared."*
Encourage reflection, validate their feelings, and ask them to share what they have heard and/or understood	*"What you feel and think matters. Would you like to tell me how this is making you feel or what you are thinking about at the moment?"* *"Do we need to take a minute to go over anything we've just spoken about? Is there anything I've said that you are unsure about or isn't clear?"* *"How are you feeling about this information so far? Please let me know if anything feels overwhelming or unclear."*
Be observant of non-verbal cues and respond with compassion	*"Something seems to have (upset/worried/saddened) you. Would you like to talk about it?"*
Reiterate support with warmth and connection	*"Remember, you're not alone in this. Our team is here to guide, support, and answer any questions you might have."*
Wrap-up the conversation	*"Thank you for sharing your thoughts and feelings with me. Remember, our team is here to provide the care and support you need."*
Document the discussion to help the interdisciplinary healthcare team identify areas needing attention	*"I'll write down our talk and share it with the healthcare team, so that everyone is on the same page and we all work together."*

Approximately 5-10% of all cancer patients develop metastatic spinal cord compression (MSCC) during the course of their disease. This statistic emphasizes the relevance of MSCC in oncological and palliative care settings (Loblaw et al. 2003).

The Palliative Care Emergency–BONES (Spinal Cord Compression)

What is Spinal Cord Compression?

Information for Nurses



Spinal cord compression occurs when pressure is applied to the spinal cord, often due to tumours, herniated discs, vertebral lesions (e.g., fractures), abscess or other conditions. In the context of palliative care, it's commonly seen in patients with advanced cancers that have spread to the spine. This compression can disrupt the normal function of the spinal cord, leading to symptoms ranging from pain and numbness, permanent weakness, paralysis and loss of bowel and bladder control. This can be very distressing for both the patient and family members. Early detection and intervention are crucial to alleviate symptoms, improve quality of life, and prevent irreversible damage.

How to describe Spinal Cord Compression to Patients and/or Caregivers

"Spinal cord compression happens when something, like a tumour or bone fragment, presses on the spinal cord. This can damage the nerves and cause muscle weakness, loss of feeling, paralysis in the legs or arms, or trouble controlling the bladder or bowels."

Who may be at risk?

Information for Nurses

Spinal cord compression is a significant concern for individuals with certain serious illnesses. In particular, a cancer diagnosis elevates the risk of this condition, especially metastatic spinal cord compression (MSCC). While MSCC can manifest in individuals with various cancers, those diagnosed with multiple myeloma, melanoma, breast, lung, or prostate cancer are notably more susceptible. This heightened vulnerability arises from these cancers' tendency to metastasize or spread, particularly to the bones and spine.

Apart from metastatic cancer, several other causes can lead to spinal cord compression. Among the most at risk are those with degenerative disc disease, osteoarthritis, and the resulting bone spurs, as these can directly press on the spinal cord. Spinal injuries, often from trauma, pose a direct threat, while spinal tumours, whether benign or malignant, can cause compression. Additionally, conditions like spinal stenosis, which results in a narrowed spinal canal, and infections that lead to spinal inflammation significantly elevate the risk.

How to describe who may be at risk for spinal cord compression to Patients and/or Caregivers

"Spinal cord compression can happen for several reasons. People with cancers like breast, lung, or prostate cancer have a higher risk because these cancers can spread to the spine."

"People with wear and tear in their spine, like from arthritis, disc problems or injuries can also have this compression."

"It's important to be aware of these risks and let us know if you notice any unusual symptoms so we can help you be better prepared."

Pathophysiology

Information for Nurses

Spinal cord compression arises due to pressure on the spinal cord, commonly from tumorous growths or when cancer spreads to the spine. A primary tumour on the spinal column or cancer spreading to the spinal bones might lead to vertebral damage, subsequently compressing the spinal cord. In some cases, a tumour might penetrate the epidural space, placing pressure on the spinal cord or nearby nerve roots. Approximately 70% of spinal cord compression cases occur in the thoracic spine. This region is particularly vulnerable due to its proximity to the primary tumour sites and its structural characteristics. Here's a detailed explanation of the pathophysiology:

Causes and Mechanisms

- **Tumorous Growths:** Primary tumours located on the spinal column or metastatic cancers that spread to the spinal bones can cause compression. Common cancers that metastasize to the spine include breast, lung, and prostate cancers.
- **Vertebral Damage:** Weaken vertebrae are prone to fractures and collapse. This structural damage can compress the spinal cord.
- **Epidural Space Invasion:** Invasion into the epidural space, such as tumours or abscess (the area between the vertebrae and the spinal cord), exerts pressure on the spinal cord or nearby nerve roots.

Neural Pathway Disruption

The compression interrupts the neural pathways, obstructing the flow of nerve impulses between the brain and the body. This blockage can weaken or completely sever communication, leading to loss of function below the compression level.

Vascular Compromise

Pressure on the spinal cord can compromise its blood supply, leading to ischemia (reduced blood flow) and potential infarction (tissue death). This vascular compromise exacerbates neural damage and dysfunction.

Inflammatory Response

Compression triggers an inflammatory response, resulting in edema (swelling) within the spinal cord. Swelling further increases pressure, worsening the compression and neural impairment. The inflammatory response involves the release of cytokines and other mediators, contributing to further tissue damage and neural dysfunction.

Cellular Injury

The physical pressure on the spinal cord can cause direct injury to neurons and glial cells, disrupting their normal function. Cellular damage initiates a cascade of secondary injury processes, including apoptosis (programmed cell death) and necrosis (uncontrolled cell death), leading to further neurological decline.

Impact on Neural Structures

Compression can damage axons (nerve fibres), impairing their ability to transmit electrical signals effectively. The myelin sheath, which insulates nerve fibres and enhances signal transmission, may also be damaged, further disrupting neural communication.

How to explain why Spinal Cord Compression may occur to Patients and/or Caregivers

"Spinal cord compression happens when there's too much pressure on the spinal cord. This can be due to tumours on the spine or if cancer spreads to the bones of the spine. Sometimes tumours can also grow in the space around the spinal cord. When this happens, the nerves in the spinal cord can be damaged. This makes it hard for the brain to talk to the rest of the body."

Signs and Symptoms

Information for Nurses

Spinal cord compression can manifest in various signs and symptoms, which can vary based on the location and severity of the compression. Here are some common signs and symptoms:

Pain:
- Back or neck pain, which may radiate to other areas (e.g., chest or stomach).
- Pain that worsens at night or with activity.
- Pain will often precede neurologic deficits by weeks to months, but sometimes there may be no warning pain at all.

Sensory changes:
- Numbness, tingling, or weakness in the extremities (arms, legs, hands, or feet).
- Loss of sensation or altered sensation in the affected area.

Motor symptoms:
- Weakness in the muscles or trouble moving parts of the body (e.g., legs or arms).
- Stiffness or spastic movements.

Bladder and bowel dysfunction:
- Incontinence (loss of bladder or bowel control).
- Retention (inability to empty the bladder or bowels).
- Increased frequency or urgency to urinate.

Sexual dysfunction:
- Difficulty with sexual function or reduced sensation.

Mobility issues:
- Difficulty walking or maintaining balance.
- Clumsiness or lack of coordination.

Neurological symptoms:
- In severe cases, paralysis can occur in the affected limbs or body regions.

What to say about signs and symptoms to Patients and/or Caregivers

"Your loved one might be at risk for spinal cord compression due to their illness. Here's what you should watch out for:

- *Back Pain: It might feel like a constant muscle spasm, get worse over time, or spread down the legs. This pain can be sharper when they lie down, cough, or sneeze.*
- *Chest or Stomach Pain: It could feel like there's a tight belt around them.*
- *Spine Tenderness: The spine might be sensitive when touched.*
- *Leg Weakness: They might find it hard to stand or walk.*
- *Numbness or Tingling: Especially in the legs or toes.*
- *Bladder or Bowel Issues: They might lose control or have trouble going to the bathroom.*

If you notice any of these signs, please let us know right away so we can help."

Treatment Options

Information for Nurses

For patients with spinal cord compression who are receiving palliative care, treatment aims to alleviate pain, improve neurological function, and maintain quality of life. Here's a summary of treatment options:

Pharmacological interventions:

- Prevention: Bisphosphonates: Prescribed for those at risk to protect bones from the detrimental effects of certain cancers, they also prevent osteoporosis which can contribute to spinal cord compression.
- Treatment: Corticosteroids (e.g., dexamethasone): Initiated promptly to enhance neurological function and minimize pain and inflammation.
- Pain management:
  - Conventional analgesics: Such as Tylenol or Non-Steroidal Anti-Inflammatory Drugs (NSAIDs) like Advil.
  - Opioids: Considered when conventional pain medications are insufficient.
  - Neuropathic pain medications: For nerve pain, options include gabapentin or pregabalin.

Other treatment approaches:

- **Surgery:** Neurosurgical decompression may be considered, especially if the patient is still mobile and functional, to prevent irreversible paralysis.
- **Radiotherapy:** An option that can work in conjunction with surgery or independently to manage symptoms.
- **Supportive therapies:** Physiotherapy and occupational therapy might be recommended for recovery, and psychosocial support can address the emotional and mental well-being of the patient.

Each patient's treatment is tailored based on their specific condition, needs, and desires.

What to say to about treatment options to Patients and/or Caregivers

"There are several ways to treat spinal cord compression."

"Some treatments focus on easing symptoms to make sure the person is comfortable. This doesn't necessarily treat the compression directly. For this, we have medications to manage pain and lessen swelling. Gentle exercises can also help with movement and reduce stiffness."

"Other treatments aim to directly address the compression. We can consider surgery to ease pressure on the spinal cord or use radiation therapy to target and treat the affected area."

"Choosing a treatment should fit with what you want for your care. Whether you're focused on comfort or seeking active treatments, we'll work with you to guide you on what to expect."

Be Prepared: Palliative Care Emergencies in the Home

A Tool for Patients and Caregivers

Your Conversation Guide
BONES
(Spinal Cord Compression)

This tool helps you know the actions you can take and reassuring words to use if your loved one is experiencing a spinal cord compression. Your healthcare provider will review the actions with you.

Actions you can take	Comforting Words
Watch for signs Look for signs of spinal cord compression. Early identification and treatment can help alleviate symptoms and improve overall comfort (see listing on flip side). 	*"It is important for us to look out for early signs and let the nurse know."* *"Have you noticed any unusual back pain or tingling lately?"* *"Do your legs feel weak when you try to stand or walk?"*
Medication management Ensure the patient takes prescribed pain relief or anti-inflammatory medications as directed by the healthcare professional. Having these medications on hand and administering them promptly can help alleviate acute symptoms (your nurse will show you how). 	*"This medication will help you. The nurse has shown me how to administer it."*
Comfortable positions Help the patient in finding a comfortable resting position. This might be reclining with the head slightly elevated or lying flat, depending on what the patient finds most relieving. Using pillows for support can also help. Your healthcare team will show you how to safely do this. 	*"I'm here with you" or "I won't be leaving"* *"Let's make you more comfortable with some pillows. Let me know if you feel any pain."*
Cooling or heating Applying a cold pack or warm compress to the affected area can sometimes help in reducing inflammation and alleviating pain. Always use a cloth barrier between the skin and the pack to avoid burns or frostbite. Your healthcare team will suggest what and how to use it. 	*"Would you like a warm or cold compress for your back? It might help with the pain. I'll make sure to wrap it in a cloth so it's comfortable on your skin."*
Contact your healthcare team If the flare-up is severe, unusual, or doesn't improve with at-home measures, contact your nurse right away so they can take steps to make the patient more comfortable and prevent further physical problems. 	*"I've called the nurse. They will be able to help us."*

IF:

- ✓ you feel overwhelmed and need help.
- ✓ you feel your loved one is not feeling better after trying different strategies.
- ✓ you are worried about spinal cord compression.
- ✓ you have questions about what to do.

Call your Healthcare Team

Day time: _____

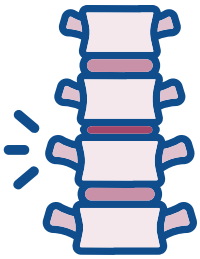
Evening: _____

Night time: _____

Canadian Home Care Association

YOUR LOGO HERE

5 things you should know about Spinal Cord Compression



1 What is spinal cord compression?

Spinal cord compression happens when something, like a tumour or bone fragment, presses on the spinal cord. This can damage the nerves and cause muscle weakness, loss of feeling, paralysis in the legs or arms, or trouble controlling the bladder or bowel.

2 What causes spinal cord compression?

Spinal cord compression happens when there's too much pressure on the spinal cord. This can be due to tumours on the spine or if cancer spreads to the bones of the spine. Sometimes tumours can also grow in the space around the spinal cord. When this happens, the nerves in the spinal cord can be damaged. This makes it hard for the brain to talk to the rest of the body

3 What signs should I look for?

Individuals with certain types of serious illnesses can have a higher risk for spinal cord compression. Here's what you should watch out for:

- **Pain:** There might be an unusual, severe pain in the spine that changes with posture or disrupts sleep. Sometimes, this pain can shoot down the leg or arm or even wrap around the chest or stomach.
- **Sensation:** The individual may also experience sensations like tingling, or electric shocks, in the arms or legs, and there could be new numbness in the legs, arms, chest, or lower body.
- **Movement:** Movement-wise, there can be a noticeable stiffness or a feeling of heaviness that affects walking or balance, along with a new onset of weakness in the legs or arms.
- **Bladder/Bowel:** There may be issues related to bladder or bowel control, including an inability to control or fully empty them.

4 How can we treat spinal cord compression?

There are several ways to treat spinal cord compression.

- Some treatments focus on easing symptoms to make sure the person is comfortable. This doesn't necessarily treat the compression directly. For this, medications can manage pain and lessen swelling. Gentle exercises can also help with movement and reduce stiffness.
- Other treatments aim to directly address the compression; surgery can ease pressure on the spinal cord or use radiation therapy to target and treat the affected area.

The healthcare team will work with the patient and their caregivers to determine which option is best for them.

5 When should I call the healthcare team?

Always know your healthcare team is available to support you. In any of these situations, it's crucial to get in touch with the healthcare team promptly to prevent further complications and ensure the patient's comfort and safety.

- **Sudden or severe pain:** If the patient experiences a sudden increase in pain or severe pain that is not alleviated with their usual pain relief methods.
- **Loss of movement:** If the patient suddenly can't move their arms or legs, or if there's a significant decline in their ability to walk or move about.
- **Bladder/Bowel control:** If the patient suddenly loses control over their bladder or bowel, or if they can't empty their bladder or bowel at all.
- **New or worsening numbness:** If there's a sudden onset of numbness or tingling, especially in the legs or arms, or if existing numbness becomes more pronounced.
- **Breathing difficulties:** If the patient experiences trouble breathing, especially if the compression is in the cervical (neck) area of the spine, which can affect respiratory function.