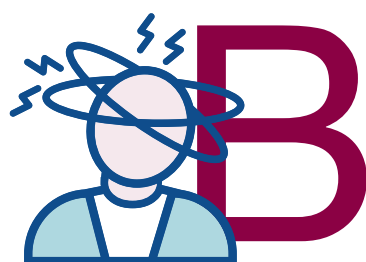


Be Prepared: Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

BALANCE
(Hypercalcemia)



Canadian
Home Care
Association

CONTRIBUTORS

Angelevski, Elizabeth, *Director of Projects and Knowledge Translation, Canadian Home Care Association*

Campagnolo, Jennifer, *Palliative Care ECHO Project Lead, Canadian Home Care Association*

Hall, Audrey-Jane, RN, *Assistant Director General and Director of Palliative Care, Society of Palliative Home Care for Greater Montreal Region*

Iancu, Andrea, MD, PhD, CCFP(PC), FCFP, *Teresa Dellar Palliative Care Residence, West Island Montreal CIUSS and Palliative Home Care*

McAlister, Marg, *Priority Projects Consultant, Canadian Home Care Association*

Mehta, Anita, RN, PhD, CFT, *Director of Education and Knowledge Exchange, Teresa Dellar Palliative Care Residence*

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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.

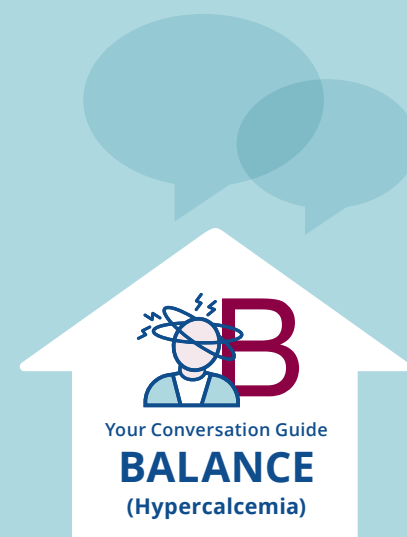
Palliative Care Emergencies in the Home

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:

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



This Conversation Guide focuses on Balance (hypercalcemia).

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

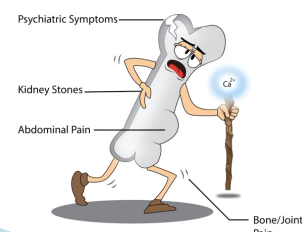
Equip patients and caregivers with a variety of techniques and actions to manage potential emergencies at home. This section also offers tips on how you can communicate this crucial information effectively. Designed for utility, this segment is meant to be left behind in the home, granting patients and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

Discussing the potential risk for hypercalcemia 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 about BALANCE (Hypercalcemia)



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
<p>Start with the following:</p> <p>a) Introduce the purpose and importance of having the conversation with empathy.</p> <p>b) Assess their readiness to have the conversation with sensitivity (i.e., ask for permission).</p> <p>c) Ask about their fears and/or worries and actively listen to their response(s).</p>	<p>PURPOSE/IMPORTANCE:</p> <p><i>“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.”</i></p> <p><i>“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.”</i></p> <p>READINESS:</p> <p><i>“We need to talk about how your health may affect the balance of minerals in your body and the things you can do to help prevent your calcium levels from changing and when it is time to get help. When do you think would be a good time to talk about it?”</i></p> <p>FEARS/WORRIES:</p> <p><i>“I’m genuinely interested in understanding your concerns. Can you share some of them with me?”</i></p> <p><i>“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?”</i></p>

What to include in your conversation	 Helpful phrases for Nurses
Describe hypercalcemia and provide information on what they might see and/or hear, how they may feel, and what they can do	<p><i>"Hypercalcemia can be alarming, but understanding its signs or symptoms can give you some peace of mind. Let's talk about what you might hear or see."</i></p> <p><i>"I realize that witnessing a loved one struggle can be heart-wrenching. Let's talk about how it might feel and ways to cope."</i></p> <p><i>"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."</i></p>
Provide reassurance and offer genuine hope	<p><i>"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."</i></p>
Encourage reflection, validate their feelings, and ask them to share what they have heard and/or understood	<p><i>"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?"</i></p> <p><i>"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?"</i></p> <p><i>"How are you feeling about this information so far? Please let me know if anything feels overwhelming or unclear."</i></p>
Be observant of non-verbal cues and respond with compassion	<p><i>"Something seems to have (upset/worried/saddened) you. Would you like to talk about it?"</i></p>
Reiterate support with warmth and connection	<p><i>"Remember, you're not alone in this. Our team is here to guide, support, and answer any questions you might have."</i></p>
Wrap-up the conversation	<p><i>"Thank you for sharing your thoughts and feelings with me. Remember, our team is here to provide the care and support you need."</i></p>
Document the discussion to help the interdisciplinary healthcare team identify areas needing attention	<p><i>"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."</i></p>

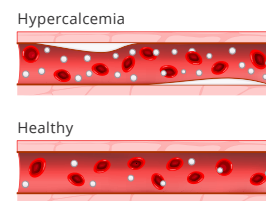
Hypercalcemia can result in a range of symptoms that severely impact quality of life. Around 50% of patients with hypercalcemia may be asymptomatic, but the other half can exhibit symptoms such as fatigue, constipation, polyuria, cognitive changes, and even coma. These symptoms can significantly reduce quality of life, especially in palliative care settings (Tebben et al. 2016).

The Palliative Care Emergency–BALANCE (Hypercalcemia)

What is Hypercalcemia?

Information for Nurses

Hypercalcemia refers to the condition where there are elevated levels of calcium in the bloodstream. It is usually caused by primary hyperparathyroidism or certain types of cancers. It is crucial to recognize and manage, especially in home-based palliative care, as it can affect a patient's comfort and overall well-being.



How to describe hypercalcemia to Patients and/or Caregivers

"Hypercalcemia means there is too much calcium in the blood. This may happen when changes occur in the bones of people living with cancer, even if the cancer hasn't spread to the bones. I know this sounds concerning, but recognizing and managing it at home is important for your loved one's comfort and well-being."

Who may be at risk?

Information for Nurses

Hypercalcemia, or high calcium levels in the blood, is seen in 10-20% of patients with advanced cancer. It's especially common among those with bone metastases and in cases of breast, lung, and kidney cancers. Additionally, patients with diagnoses of lymphoma, multiple myeloma, or tumours in the kidney or genitourinary region are at risk. Other cancers associated with hypercalcemia include those of the head and neck, thyroid, esophagus, skin, cervix, and bladder.

There are two primary causes for hypercalcemia:

- Overactive parathyroid glands: Known as primary hyperparathyroidism, this condition arises when the four parathyroid glands in the neck produce too much parathyroid hormone. This hormone increases calcium levels in the bloodstream.
- Certain cancers: These cancers might raise calcium levels either because they produce substances resembling parathyroid hormone or because they cause the bones to break down, releasing more calcium.

How to describe who may be at risk for hypercalcemia to Patients and/or Caregivers

"Because of your specific type of cancer or overactive parathyroid glands] diagnosis, you might experience elevated calcium levels in your blood. Knowing that this could happen is important because, together, we make a plan to help you manage it at home."

Pathophysiology

Information for Nurses

Hypercalcemia refers to elevated calcium levels in the bloodstream. This imbalance can occur when calcium's entry into the bloodstream exceeds its removal by the kidneys or its incorporation into bones.

- **Cancer and hypercalcemia:** Certain cancers, including solid tumours and specific blood cancers, like leukemia, are known contributors to hypercalcemia. This can happen through:
 - Tumour secretion of Parathyroid Hormone-related Protein (PTHrP), accelerating bone breakdown and increasing renal calcium retention.
 - Direct bone invasion by cancers, causing localized bone to dissolve and, subsequently, release calcium.
- **Parathyroid hormone-related protein (PTHrP) dynamics:** An overactivity of PTHrP can heighten osteoclastic bone resorption, leading to increased calcium levels in the bloodstream. It's essential to be vigilant of its influence, especially in patients with cancer-related hypercalcemia.
- **Osteoclastic resorption:** This process, where bones break down and release calcium, can intensify in patients with advanced malignancies, impacting their overall comfort.
- **Medication-related considerations:** Certain medications, particularly thiazide diuretics, such as hydrochlorothiazide (HCTZ), and supplements (like calcium and Vitamins D and A), can elevate serum calcium levels. It's imperative to assess and adjust medication regimens in palliative care settings.
- **Vitamin D's role:** Excessive Vitamin D can heighten calcium levels by promoting its absorption from the intestines, increasing reabsorption from the kidneys, and reabsorbing from bones.
- **Other factors:** While less common, other conditions like prolonged immobilization (long periods of bed rest) can induce hypercalcemia.

How to explain why hypercalcemia may occur to Patients and/or Caregivers

"Hypercalcemia is a calcium balance issue in the body. It can happen when the body either puts too much calcium into the blood, doesn't remove enough of it through the kidneys, or doesn't store enough in the bones."

"Some types of cancers can cause this imbalance because they produce a substance (PTHrP) that speeds up bone breakdown or tumours may grow into bones, causing them to release calcium."

Signs and Symptoms

Information for Nurses

Patients with hypercalcemia can exhibit a spectrum of symptoms which can include:

- **Fatigue:** A noticeable decrease in energy or increased tiredness.
- **Gastrointestinal disturbances:** This includes nausea, vomiting, and constipation.
- **Altered hydration status:** Patients may report increased thirst and find themselves urinating more frequently.
- **Neurological changes:** Confusion, lethargy, or a general sense of feeling "off" mentally.
- **Muscular effects:** Muscle weakness may be present, potentially affecting mobility.
- **Skeletal complaints:** Persistent or unusual bone pain.

How to describe signs and symptoms to Patients and/or Caregivers

"It's important to be aware of the signs that calcium is not in balance. If you notice them, let your healthcare team know right away so we can help. Some of the things to watch for are:

- *Feeling more tired than usual.*
- *Feelings of nausea, maybe even throwing up, and constipation.*
- *Feeling thirstier and going to the bathroom more often.*
- *Moments of confusion or not being able to concentrate.*
- *Muscles might feel weaker, making it harder to move around.*
- *Unusual or lasting pain in the bones."*

Hypercalcemia



BONES

Abnormal bone remodeling (bone growth and maintenance) and fracture risk



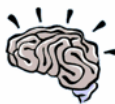
STONES

Increased risk for kidney stones



GROANS

Abdominal cramping, nausea, ileus, constipation



PSYCHIATRIC OVERTONES

Lethargy, depressed mood, psychosis, cognitive dysfunction

Treatment Options

Information for Nurses

Hypercalcemia is a common metabolic issue in cancer patients receiving home-based palliative care. If not addressed, it can severely affect the nervous system, heart, and kidneys.

Assessment & decision making:

The team may opt for a blood test to confirm hypercalcemia. For end-of-life patients, the primary focus might be comfort rather than aggressive intervention. The treatment chosen should align with both the patient's condition and care goals. Always prioritize the patient's comfort and well-being.

Primary treatments:

Hydration: This helps flush excess calcium. Fluids, like normal saline, might be given intravenously or subcutaneously to prompt calcium elimination.

Medications:

- **Bisphosphonates:** Strengthens bones by slowing down the body's bone absorption processes.
- **Calcitonin:** Stops the bones from releasing more calcium.
- **Steroids (e.g., Prednisone):** Useful if caused by high vitamin D levels.
- **Diuretics:** Boosts calcium removal, especially during hydration, preventing fluid buildup.

Comfort measures:

Comfort measures for someone with hypercalcemia are interventions and strategies aimed at alleviating symptoms and enhancing the quality of life, rather than targeting the root cause of the elevated calcium itself. Here are some comfort measures tailored for hypercalcemia patients:

- **Pain management:** Administer pain-relief medications, as needed, especially if the patient is experiencing bone pain.
- **Constipation relief:** Since constipation is a common symptom of hypercalcemia, gentle laxatives, stool softeners, or dietary adjustments (e.g., increasing fibre intake) can help.
- **Safety measures:** Due to potential confusion or muscle weakness, ensure a safe environment. This may include bed rails, non-slip mats, and regular supervision to prevent falls.
- **Mental engagement:** Soft music, light reading, or gentle conversation can help distract from discomfort and alleviate feelings of confusion or lethargy.
- **Dietary adjustments:** Limit calcium-rich foods, if advised by the healthcare team. Ensure a balanced diet to support overall well-being.
- **Skin care:** Regularly moisturize and check the skin for any pressure sores or breakdowns, especially if mobility is limited.
- **Relaxation techniques:** Encourage deep breathing exercises, guided imagery, or gentle massage to alleviate symptoms and promote relaxation.



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

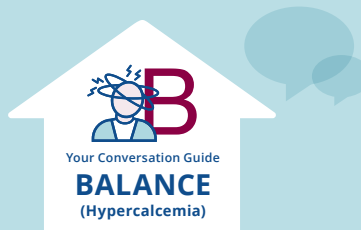
"If you notice the signs of a calcium imbalance, let your healthcare team know right away. We can request a blood test to confirm if this is happening and we can determine a plan of treatment."

"Your doctor or palliative care specialist can prescribe medications that help keep calcium in the bones or help remove it from the bloodstream."






"If death is near, you may decide not to have any active treatments. This is okay. We will focus on the things that can be done to make your loved one as comfortable as possible."

Be Prepared: Palliative Care Emergencies in the Home

A Tool for Patients and Caregivers



This tool helps you know the actions you can take and reassuring words to use if your loved one is experiencing an imbalance of calcium in their blood. Your healthcare provider will review the actions with you.

Actions you can take	Comforting Words
<p>Keep hydrated</p> <ul style="list-style-type: none"> • Drinking fluids can help lower calcium levels in the blood and help prevent painful kidney stones. • Take regular, small sips every 10-15 minutes. • Try flavoured drinks, like herbal teas or fruit-infused water. Ice chips or popsicles are a good way to increase fluid intake subtly. <p><i>Note: If there are heart or kidney concerns, make sure to ask about any restrictions.</i></p>	 <p><i>"It's important to try and drink fluids to stay hydrated. It will lower the calcium level in your blood and help you to feel better."</i></p>
<p>Short walks or easy exercise</p> <ul style="list-style-type: none"> • If possible, take short walks or try simple exercises in bed. • Simple weight-bearing exercises (provided by the healthcare team) can be done to help prevent bone fractures. <p><i>Note: Hypercalcemia can cause confusion and muscle weakness. Make sure the living space is free of obstacles to reduce the risk of falls.</i></p>	 <p><i>"Let's try some easy exercises or a short walk. This will help you feel better."</i></p> <p><i>"Let's do a little bit of activity at a time. This will help make you and your bones stronger."</i></p>
<p>Medications</p> <ul style="list-style-type: none"> • Medications can help with pain, constipation or nausea. The nurse will explain how and when to give these. • Watch for any side effects from medications and share any concerns with the healthcare team. 	 <p><i>"This medication will help you. The nurse has shown me how to administer it."</i></p> <p><i>"Tell me how you are feeling..."</i></p>
<p>Stay calm and provide comfort</p> <ul style="list-style-type: none"> • Help manage symptoms by offering cold compresses for nausea, massaging aching muscles, or providing a calm soothing environment. 	 <p><i>"I'm here with you" or "I'll be right here when you need me."</i></p> <p><i>"We are taking care of you."</i></p> <p><i>"I am going to keep you comfortable."</i></p>
<p>Be aware of the signs and symptoms</p> <ul style="list-style-type: none"> • Tell the healthcare team if you notice any signs and symptoms. They may arrange further tests if they feel they can make the patient more comfortable and prevent further physical problems. 	 <p><i>"I have contacted our healthcare team. They are ready to help us."</i></p>

IF:

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



**Call your
Healthcare
Team**

Day time: _____

Evening: _____

Night time: _____

5 things you should know about Hypercalcemia



1 What is Hypercalcemia (imbalance of calcium)?

Hypercalcemia means there is too much calcium in the blood.

2 What causes an imbalance of calcium?

A calcium balance issue can happen when the body either puts too much calcium into the blood, doesn't remove enough of it through the kidneys, or doesn't store enough in the bones.

Some types of cancers can cause this imbalance because they produce a substance (PTHrP) that speeds up bone breakdown or tumours may grow into bones, causing them to release calcium.

3 What signs should I look for?

The signs that calcium is not in balance include:

- Feeling more tired than usual.
- Feelings of nausea, maybe even throwing up, and constipation.
- Feeling thirstier and going to the bathroom more often.
- Moments of confusion or not being able to concentrate.
- Muscles might feel weaker, making it harder to move around.
- Unusual or lasting pain in the bones.

4 How can we treat an imbalance of calcium in the blood?

A blood test will show if there is an imbalance of calcium in the blood. Medications help keep calcium in the bones or help remove it from the bloodstream and simple actions such as drinking and moving can also help.

If death is near, you may decide not to have any active treatments. There are several things that can be done that can help make the individual more comfortable and help with any pain or other symptoms.

5 When should I call the healthcare team?

When helping someone with hypercalcemia watch for these symptoms and situations and immediately communicate them to the healthcare team:

- **Thinking changes:** If the person seems more confused or forgetful than usual.
- **Muscle issues:** If they feel weaker, or if their muscles twitch or cramp.
- **Heart problems:** Any chest pain, or if the heart feels too fast or too slow.
- **Stomach issues:** Bad constipation, feeling very nauseous, or throwing up.
- **Bathroom changes:** If they're going to the bathroom a lot, drinking more water than usual, or not peeing much.
- **Bone pain:** If they complain about their bones hurting more than before.
- **Medication worries:** Bad reactions to their medicines or confusion about when to give them.
- **Feeling too tired:** If they suddenly feel way more tired or lazy than usual.
- **Drinking/eating issues:** If they're not drinking enough.
- **Issues after treatment:** If they feel worse or different after a treatment for high calcium levels.
- **Returning symptoms:** If they seemed better, but now the signs of high calcium come back or get stronger.