

Be Prepared: Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

BLEEDING
(Massive Hemorrhages)

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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.

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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.

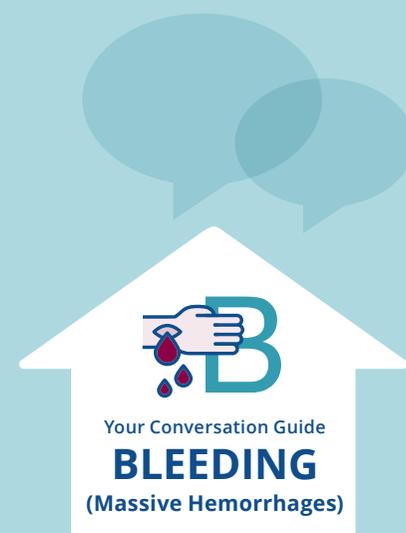
Palliative Care Emergencies in the Home

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 Bleeding (massive hemorrhages).

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 massive hemorrhaging 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 BLEEDING (Massive Hemorrhages)



A Conversation Checklist

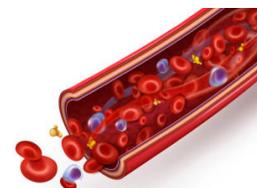
This checklist provides actionable steps to ready yourself for difficult conversations, to share clinical insights through the “Head-Heart-Hands” lens, and cultivate trust using emotional intelligence skills, like empathy and active listening.

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 your ability to recognize the signs of a hemorrhage 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 a hemorrhage and provide information on what they might see and/or hear, how they may feel, and what they can do	<p><i>"Losing a lot of blood can be scary. Understanding the 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 bleeding can be frightening or upsetting. Let's talk about how you 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>

Most patients in palliative care prefer to stay at home. However, managing a catastrophic hemorrhage at home requires specific interventions and preparedness, including having medications at hand, knowing how to apply pressure, and being prepared for emotional and psychological impacts (Porzio et al. 2009).

The Palliative Care Emergency–BLEEDING (Massive Hemorrhages)



What is a Massive Hemorrhage?

Information for Nurses

A massive hemorrhage refers to a rapid and significant loss of blood by a patient. On rare occasions, major bleeding from a primary artery can be fatal and is referred to as a terminal hemorrhage.

Individuals with serious illnesses may occasionally experience minor blood loss. While this is not classified as a massive hemorrhage, and isn't treated as an immediate crisis, it can serve as an indicator of a potentially larger bleed in the future. Although uncommon, a massive hemorrhage can happen rapidly, and family members might find themselves managing the situation alone, as a healthcare professional may not be immediately available.

How to describe hemorrhages to Patients and/or Caregivers

"A massive bleed is when someone loses blood fast."

"Sometimes, a bit of blood might be lost, which isn't an urgent situation, but it should be watched."

"Tell us about any bleeding; it helps us be ready for the future."

Who may be at risk?

Information for Nurses

Some patients may be at risk if they have a blood-related disorder, platelet abnormalities, or problems related to their blood clotting. Medical conditions, such as liver disease or head and neck cancers, can also increase the likelihood of unexpected bleeding. Some types of cancers, especially in the ears, nose, or throat, carry a higher risk of bleeding because metastatic wounds can expose major vessels. For patients with any type of esophageal lesion, erosion can also result in bleeding.

Certain medications might increase the risk of bleeding. These include steroids (e.g., dexamethasone), some non-steroidal anti-inflammatory drugs (NSAIDs), and anticoagulant medications (e.g., warfarin and heparin).

How to describe risk factors to Patients and/or Caregivers

"Some people with blood disorders, liver disease or certain types of cancers may experience unexpected heavy bleeding."

"There are also certain medications that might increase the risk of bleeding, for example, steroids, anti-inflammatories, and blood thinners."

Pathophysiology

Information for Nurses

A massive hemorrhage involves rapid and significant blood loss, which can quickly reduce the body's ability to deliver oxygen to its tissues. Initially, the body tries to compensate by increasing heart rate and constricting blood vessels. However, sustained bleeding overwhelms these mechanisms, leading to decreased blood pressure, organ malfunction due to lack of oxygen, metabolic changes like acidosis, and potential clotting issues.

This culmination of effects results in a state known as hypovolemic shock, where a person loses more than 20% of their body's blood or fluid supply. This severe blood loss makes it impossible for the heart to pump a sufficient amount of blood to the body, leading to a decrease in the amount of oxygen that reaches the body's organs.

Massive hemorrhages in patients with serious illnesses can occur for a variety of reasons, depending on the nature and progression of the underlying disease. Here are some reasons why such patients are at risk:

- **Tumour invasion:** Many advanced cancers can invade and erode into blood vessels. For instance, tumours in the gastrointestinal tract, such as the stomach or esophagus, can erode into major blood vessels causing significant bleeding. Similarly, tumours in the brain can cause intracranial bleeding.
- **Blood and platelet disorders:** Conditions like leukemia, blood diseases, or those affecting platelet production can impair the body's ability to create blood components or form clots, leading to increased bleeding risk.
- **Medication side effects:** Many seriously ill patients are on medications that can increase bleeding risk, including anticoagulants (like warfarin or heparin), which are used to prevent blood clots, or non-steroidal anti-inflammatory drugs (NSAIDs) that can cause gastrointestinal bleeding.
- **Liver disease:** The liver produces proteins vital for blood clotting. Patients with advanced liver disease (like cirrhosis) can have impaired clotting, leading to a risk of bleeding. Also, increased pressure in the blood vessels of the liver (portal hypertension) can lead to the formation of varices, which are dilated blood vessels prone to rupture.
- **Vascular fragility:** Some diseases, like connective tissue disorders, can cause fragility in the blood vessels, making them prone to rupture and bleeding.

How to explain what happens when a massive hemorrhage occurs

“When someone has a massive bleed, they lose a lot of blood fast. At first, the heart beats faster and blood vessels tighten to help, but if the bleeding continues, the body can't keep up. When someone loses a lot of blood, they go into shock where the heart can't send enough blood to the body, and the organs don't get the oxygen they need.

- *If someone has advanced cancers in places like the stomach or head, the cancer might grow into blood vessels, leading to bleeding.*
- *Liver problems, like cirrhosis, can make it hard for the blood to clot or cause weak spots in blood vessels that might break.*
- *Platelets in our blood help it to clot. Some serious conditions or treatments can decrease platelets, making bleeding more likely.”*

Signs and Symptoms

Information for Nurses

Whether the bleeding is externally visible, such as from a wound, or occurring internally, recognizing the symptoms is vital to ensure timely and appropriate care for patients. The signs and symptoms of a massive bleed for nurses to observe are:

- Externally obvious bleeding: This can be from a wound or visible tumour.
- Blood in urine: The urine may appear bright red or darker in colour.
- Bleeding in bowel movements: This can manifest as frank blood or melena (dark, tarry stools).
- Vomiting blood: The vomit might have the appearance of coffee grounds or show fresh blood.
- Increased heart rate: A noticeable rise in the patient's heart rate.
- Decreased blood pressure: A noticeable drop in the patient's blood pressure.
- Symptoms of shock: These might include cold or clammy skin, rapid breathing, and a weak but fast pulse.
- Rapid loss of consciousness: This can occur with no apparent external source of bleeding, indicating possible internal hemorrhage.

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

"Recognizing the signs of heavy bleeding is crucial for your loved one's well-being. Here's what you should watch for:

- *Visible Bleeding: You might see blood coming from a wound, sore, or when they cough.*
- *Change in Urine: You'll notice the urine turning bright red or becoming dark.*
- *Blood in Stool: The stool may appear very dark or show visible blood.*
- *Blood in Vomit: The vomit might resemble coffee grounds or contain bright red spots.*
- *Fast Heartbeat: You'll feel or notice their heart beating faster than usual.*
- *Low Blood Pressure: They might seem dizzy or lightheaded.*
- *Signs of Shock: Their skin may feel cold, look pale, they might breathe rapidly, and their pulse could be weak yet fast.*
- *Fainting or loss of consciousness: If they suddenly faint or become very drowsy or lose consciousness, it could indicate internal bleeding."*

Treatment Options

Information for Nurses

Given the complexities and rapid progression that can be associated with a massive hemorrhage, having a predefined plan and immediate access to necessary medications and support can be crucial. Here are some treatment options and supportive measures that can be taken:

- **Immediate assessment:** A rapid assessment of the patient is necessary to identify the source of the bleed and its severity. This can guide subsequent interventions.
- **Positioning:** Depending on the source of the bleed, positioning the patient appropriately can be beneficial. For example, if the person is bleeding from a foot wound, elevating the foot and leg may help slow the bleeding.
- **Pressure dressings:** If the bleed is external, applying pressure with clean cloths or dressings can help control the hemorrhage.
- **Pharmacological interventions:**
 - **Sedatives:** Medications, like midazolam, can help calm an anxious patient and provide comfort.
 - **Anticoagulant reversal agents:** If the patient is on blood thinners, medications like vitamin K (for warfarin), or specific reversal agents for newer anticoagulants, can be administered to counteract their effects.
 - **Hemostatic agents:** Some medications can help promote clotting and stop bleeding, like tranexamic acid (Cyclokapron).
 - **Opioids:** Can be used to manage any associated symptoms like breathlessness.
- **Comfort measures:** In cases where the bleed cannot be controlled, the focus might shift to ensuring the patient is comfortable. This may involve using medications to relieve anxiety, breathlessness, or any pain that might be associated.
- **Communication:** It's essential to keep the patient and their family informed about the situation, what is being done, and what to expect. A helpful way to guide the conversation is to focus on the "4 Step Process" to manage a bleed, known as the A.B.C.D. Approach (adapted from the BC Centre for Palliative Care).
 - **Assure:** Assure the patient you know what to do and reassure them that you will not leave them alone.
 - **Be present:** Do not leave the patient alone, and if you must, make sure someone is always with them.
 - **Calm and comfort:** Stay calm and talk to the patient in a gentle tone. You can use touch or hold them to help soothe them.
 - **Dignity:** Maintain dignity for the patient by trying to minimize the visual signs of a bleed. Use dark towels, absorbent dressings and wipe the patient's face and body as needed.
- **Emergency response:** Depending on the wishes of the patient and the family, activating emergency services might be appropriate. Some patients might have advance care plans or directives in place which specify their wishes in such situations.

What to say to the Caregiver to help them respond to a bleeding emergency

"It's important to know how to respond if your loved one has a massive bleed."

"The best thing you can do is stay by their side, remain calm, and try to make them comfortable."

"I'll guide you on simple steps you can take, like using dark towels and sheets to lessen any distress from the blood, adjusting their position for safety, and using certain medications to help keep them calm."

"Our main goal is to keep your loved one comfortable and informed."

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 heavy bleeding. Your healthcare provider will review the actions with you.

Actions you can take	Comforting Words
<p>Use dark towels or sheets (such as black, brown, or red) to mask the appearance of bleeding, helping to prevent distress or alarm for the patient, or others, when seeing a large amount of blood.</p> 	<p><i>"I'm going to clean up a bit; taking away the blood may help you feel better."</i></p>
<p>Apply pressure to the bleeding area(s)</p> <ul style="list-style-type: none"> Carefully apply pressure with towels or dressings to the bleeding area(s). If you have been shown, pack the area with gauze. 	<p><i>"I'm gently pressing here to help the bleeding. Tell me if you're uncomfortable."</i></p> <p><i>"I'm going to squeeze your nose to help. Just a little pressure, okay?" (e.g., for a nose bleed).</i></p>
<p>Stay with your loved one</p> <p>Try to keep them calm and explain what's happening to them.</p> 	<p><i>"I'm staying right beside you. You are having some bleeding that the nurses have shown me how to help you with."</i></p> <p><i>"I'm right here with you. I will not be leaving."</i></p>
<p>Administer medication</p> <p>If prescribed, give any medications as you were shown by the nurse to help with the bleeding or calm your loved one.</p> 	<p><i>"This medication will help you relax and slow the bleeding. The nurse has shown me how to administer it."</i></p>
<p>Adjust positions</p> <ul style="list-style-type: none"> Gently place your loved one on their side to avoid swallowing or choking on blood. If the bleeding is coming from an arm or leg, raise that body part to slow bleeding. If they are in shock, and not bleeding from their mouth, lay them flat on their back with their legs elevated. This position increases blood flow to vital organs, especially the brain. 	<p><i>"Let me gently adjust you; it's to help with the bleeding and make sure you're comfortable."</i></p>
<p>Keep them warm</p> <p>Cover your loved one with a blanket. They can quickly become very cold if they are losing a lot of blood.</p> 	<p><i>"I know that you are feeling cold. I am going to try to warm you up with this blanket."</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 heavy bleeding.
- ✓ you have questions about what to do.



Call your Healthcare Team

Day time: _____

Evening: _____

Night time: _____

5 things you should know about a Massive Hemorrhage



1 What is a massive hemorrhage?

A massive bleed is when someone loses blood fast. Sometimes, a bit of blood might be lost, which isn't an urgent situation, but it should be watched.

2 What causes a massive hemorrhage?

Some people with blood disorders, liver disease or certain types of cancers may experience unexpected heavy bleeding. There are also certain medications that might increase the risk of bleeding (e.g., steroids, anti-inflammatories, and blood thinners).

3 What signs should I look for?

Recognizing the signs of heavy bleeding is crucial for your loved one's well-being. Here's what you should watch for:

- **Visible bleeding:** You might see blood coming from a wound, sore, or when they cough.
- **Change in urine:** You'll notice the urine turning bright red or becoming dark.
- **Blood in stool:** The stool may appear very dark or show visible blood.
- **Blood in vomit:** The vomit might resemble coffee grounds or contain bright red spots.
- **Fast heartbeat:** You'll feel or notice their heart beating faster than usual.
- **Low blood pressure:** They might seem dizzy or lightheaded.
- **Signs of shock:** Their skin may feel cold, look pale, they might breathe rapidly, and their pulse could be weak yet fast.
- **Fainting or loss of consciousness:** If they suddenly faint or become very drowsy or lose consciousness, it could indicate internal bleeding.

4 How can we treat a massive hemorrhage?

It's important to know how to respond if your loved one has a massive bleed. The best thing you can do is stay by their side, remain calm, and try to make them comfortable.

Actions you can take if a massive bleed happens include using dark towels and sheets to lessen any distress from the blood, adjusting their position for safety, and administering certain medications to help keep them calm and slow the bleeding.

5 When should I call the healthcare team?

Always know your healthcare team is available to support you. Some specific situations when you should urgently contact the healthcare team if a person has a massive hemorrhage are:

- **Uncontrolled bleeding:** If the hemorrhage doesn't stop or slow down despite applying pressure or using other first-aid measures.
- **Change in consciousness:** If the patient becomes dizzy, disoriented, loses consciousness, or exhibits any signs of going into shock.
- **Significant pain:** If the patient expresses or shows signs of severe pain or discomfort that isn't alleviated with usual pain management techniques.
- **Recurrent hemorrhaging:** If the patient experiences multiple episodes of heavy bleeding in a short period, even if each episode seems to stop.
- **Pale or blue skin:** If the patient's skin becomes notably paler than usual, cold to touch, or starts turning bluish, indicating potential significant blood loss or reduced oxygenation.