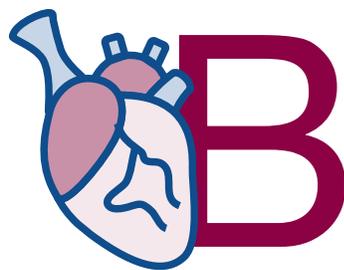


Be Prepared: Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

BLOCKAGE

(Superior Vena Cava
Obstruction)

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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.

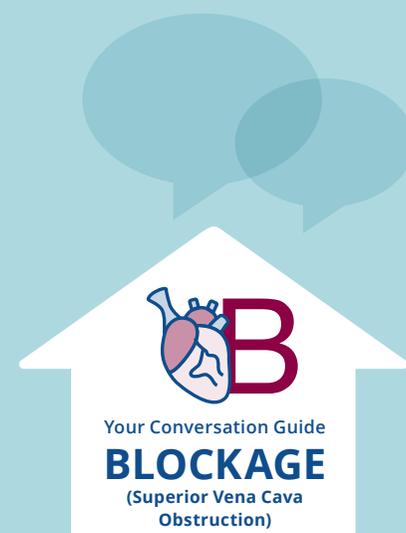
Palliative Care Emergencies in the Home

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 Blockage (superior vena cava obstruction).

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 superior vena cava obstruction with patients receiving home-based palliative care and their caregivers 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 BLOCKAGE (Superior Vena Cava Obstruction)



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 health and your risk for developing complications. If you develop a complication called Superior Vena Cava Obstruction, there are things we recommend to help you. 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 superior vena cava obstruction and provide information on what they might see and/or hear, how they may feel, and what they can do	<p><i>"Superior vena cava obstruction 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>

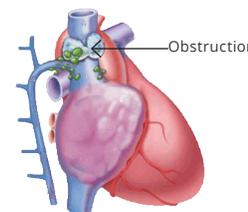
Superior vena cava obstruction can be emotionally taxing for patients receiving palliative care. The visible physical changes and distressing symptoms can lead to anxiety, depression, feelings of isolation and lower quality of life (Hammad et al. 2017).

The Palliative Care Emergency–BLOCKAGE (Superior Vena Cava Obstruction)

What is a Superior Vena Cava Obstruction?

Information for Nurses

Superior vena cava (SVC) obstruction is a medical condition characterized by the partial or complete blockage or compression of the superior vena cava, a large vein that carries deoxygenated blood from the upper part of the body back to the heart. The superior vena cava plays a crucial role in returning blood from the head, neck, and upper extremities to the right atrium of the heart.



How to describe SVC obstruction to Patients and/or Caregivers

“Superior vena cava obstruction is when a large blood vessel in your upper body, called the ‘superior vena cava’, gets blocked or squished. This vein carries blood from your head, neck, and arms back to your heart. When it’s blocked or narrowed, it can cause problems.”

Who may be at risk?

Information for Nurses

Certain serious illnesses or conditions are more commonly associated with the development of superior vena cava (SVC) obstruction:

- **Cancer:** Tumours in the chest, particularly lung cancer, lymphoma, or metastases, can compress or invade the SVC, leading to obstruction.
- **Deep vein thrombosis:** The formation of blood clots in deep veins, usually in the legs, can result from surgery, immobility, and clotting disorders. These clots can travel to the SVC or nearby veins and cause SVC obstruction.
- **Cardiovascular conditions:** Aortic aneurysms, particularly those involving the ascending aorta, can expand and compress the SVC, leading to obstruction.
- **Thyroid disorders:** Goiters, which are often caused by thyroid disease, can extend into the mediastinum and exert pressure on the SVC.
- **Infections:** As an example, mediastinitis (inflammation of the mediastinum) or tuberculosis, although rare, can lead to inflammation and compression of the SVC. These infections can be serious and may require intensive medical management.
- **Indwelling catheters:** Central venous catheters or pacemaker wires that are placed in or near the SVC can lead to mechanical obstruction if they become dislodged or if clots form around them.

How to describe who can be at risk for SVC obstruction to Patients and/or Caregivers

“While it is not common to have a blockage of the superior vena cava, there are some serious illnesses and conditions that can result in a blockage. The most common causes are cancers (lung cancer and lymphoma) and blood clots in the legs. Sometimes a catheter or pacemaker that is put near the big vein in your upper body can also cause problems.”

Pathophysiology

Information for Nurses

The pathophysiology of SVC obstruction involves the physical blockage of this crucial blood vessel responsible for carrying deoxygenated blood from the upper body to the heart's right atrium.

Over time, pressure near the blockage rises and the body attempts to alleviate this pressure by creating these collateral pathways. These pathways can redirect blood flow to the heart, bypassing the blockage in the SVC. This is the body's adaptive response to overcome the blockage and maintain blood circulation.

How to explain why SVC obstruction may occur to Patients and/or Caregivers

"A blockage in the superior vena cava, an important vein carrying blood from the upper body to the heart, can happen when tumours grow and put pressure on it, or a blood clot blocks the vein. As this blockage continues, it creates a lot of pressure, so the body makes new pathways for the blood to reach the heart. These pathways help blood flow better by going around the blockage. It's how the body deals with the problem and keeps the blood moving. However, these new pathways can lead to swelling, trouble breathing, and visible swollen veins."

Signs and Symptoms

Information for Nurses

Superior vena cava (SVC) obstruction can present with various signs and symptoms, and recognizing these indicators is crucial for providing appropriate care to your patients. Here's what to watch out for:

- **Facial and upper body swelling:** noticeable swelling in the face, neck, and upper arms is often one of the earliest signs.
- **Dilated neck veins:** may be visible and engorged.
- **Shortness of breath:** difficulty breathing, especially when lying down or during physical activity.
- **Cough:** persistent, dry cough from irritation in the airways due to SVC obstruction.
- **Difficulty swallowing:** due to pressure on the esophagus caused by the obstructed SVC.
- **Headache:** from increased pressure in the head and upper body due to impaired blood flow.
- **Chest pain:** varies in intensity and location resulting from pressure on surrounding structures.
- **Changes in colouration:** Cyanosis (blue discolouration) of the face, lips and extremities, or a flushed appearance or excessive redness of the face and neck.

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

"If you know your loved one is at risk, it is important to know what signs to look for. Here's what to watch for:

- *Swelling in the face, neck, and arms.*
- *Shortness of breath, especially when lying down or being active.*
- *A dry cough that won't go away.*
- *New difficulties swallowing.*
- *Chest pain.*
- *The skin might turn bluish in the lips, hands, or the face, and neck might look really red."*

Treatment Options

Information for Nurses

When providing palliative care for patients with superior vena cava (SVC) obstruction, the primary focus is on improving the patient's comfort, managing symptoms, and enhancing their overall quality of life.

Pharmacological interventions:

- **Opioids:** Pain and breathing management can not only address the sensation of breathlessness but also provide an anxiolytic effect, usually at minimal therapeutic doses.
- **Steroids:** Dexamethasone may be helpful in reducing the pressure created by a mass blocking the superior vena cava.
- **Anticoagulants:** May be used to prevent the formation of blood clots and treat existing blood clots.
- **Benzodiazepines:** For patients displaying signs of heightened anxiety or panic, benzodiazepines can act as an effective anxiolytic.
- **Diuretics:** These help reduce fluid accumulation and prevent or alleviate swelling in some cases.

Comfort Measures:

- **Oxygen therapy:** Supplemental oxygen may be provided to relieve shortness of breath and improve oxygen levels in the blood.
- **Positioning:** Encouraging patients to find comfortable positions, such as sitting up or leaning forward, can help ease breathing difficulties associated with SVC obstruction.

Other possible interventions (dependent upon the patient's care wishes):

- **Chemotherapy:** This can be a helpful treatment for patients if the symptoms are not immediately life-threatening and if a tumour is blocking the SVC. The tumour may be sensitive to chemotherapy medications.
- **Radiotherapy:** This is often successful at reducing symptoms for most causes of obstruction.
- **Surgery:** A surgical procedure that involves inserting a stent (a tube that keeps the blocked blood vessel open) in the SVC may be warranted.

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

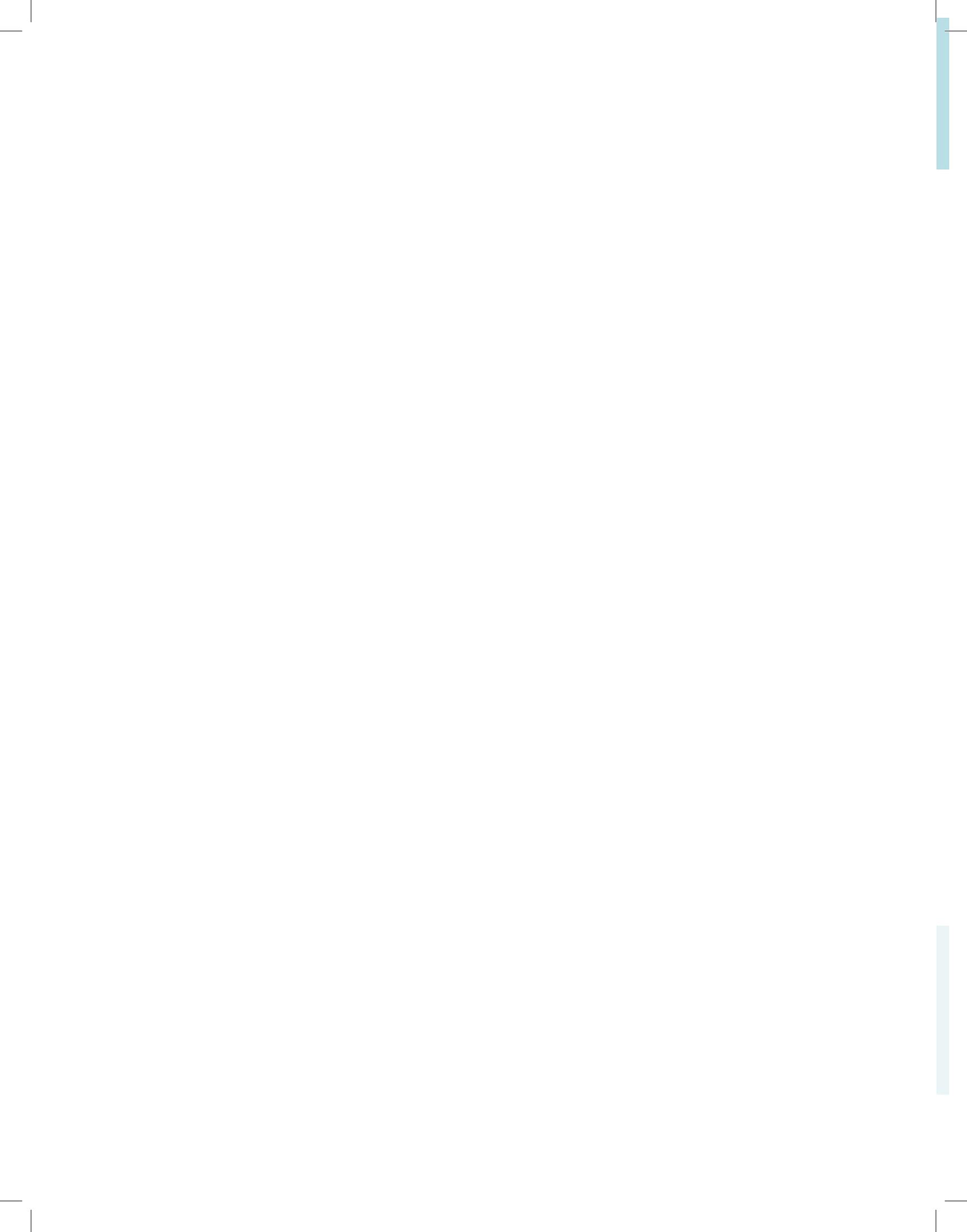
"To help with SVC obstruction, we focus on comfort and managing the symptoms. Here's what we can do:

Medicines can help with pain, breathlessness, and anxiety, making it easier to breathe and feel calmer.

We can use steroids to reduce pressure from anything blocking the vein.

Giving oxygen may ease shortness of breath and improve oxygen levels in the blood. Also, sitting up or leaning forward can make breathing easier.

Options like radiotherapy, chemotherapy or surgery may offer relief, but these would need to be discussed with your loved one and the healthcare team."



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 a superior vena cava (SVC) obstruction. Your healthcare provider will review the actions with you.

Actions you can take	Comforting Words
<p>Raise the person's head</p> <p>Elevate the head of the bed or raise the head on pillows to help with breathing. This will help to relieve the pressure and swelling in the head and neck.</p> 	<p><i>"It seems like you are having some trouble breathing. Let's use these pillows (or move the head of the bed) to raise you up. Does this help?"</i></p>
<p>Give medication</p> <p>If prescribed, administer dosage (only if you were shown how to do so). If there is a prescription for OXYGEN, put on the oxygen mask or nasal cannula.</p> 	<p><i>"This medication will help you. The nurse has shown me how to administer it."</i></p> <p><i>"Let me put on your oxygen mask. It will help you breathe easier. Can you let me know if it helps?"</i></p>
<p>Stay calm and be present</p> <p>Remain calm and stay with your loved one. Be there to provide comfort and safety. Some of the symptoms of SVC obstruction can be scary for your loved one to experience.</p> 	<p><i>"I'm here with you" or "I won't be leaving" or "We are taking care of you" rather than telling them, "Please calm down" or "Don't worry".</i></p> <p><i>It is important to keep talking to them and letting them know what you are doing, "I am going to keep you comfortable."</i></p>
<p>Make the person as comfortable as possible</p> <p>Loosen any tight clothing. Use pillows to support upper arms and be as comfortable as possible.</p> 	<p><i>"Do you feel tightness or pressure anywhere on your body?" or "How does it feel when you take in a breath?"</i></p>
<p>Call your healthcare team</p> <p>Contact the medical team to assess the patient's symptoms. They may arrange further tests if they feel they can make the patient more comfortable and prevent further physical problems.</p> 	<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 superior vena cava obstruction.
 - ✓ you have questions about what to do.



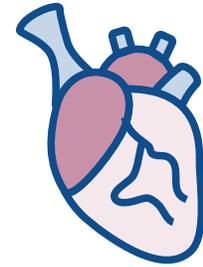
Call your Healthcare Team

Day time: _____

Evening: _____

Night time: _____

5 things you should know about Superior Vena Cava Obstruction



1 What is superior vena cava obstruction?

Superior vena cava obstruction is when a large blood vessel in your upper body, called the 'superior vena cava', gets blocked or squished.

This vein usually carries blood from your head, neck, and arms back to your heart. When it's blocked, it can cause problems.

2 What causes a blockage of the superior vena cava?

A blockage in the superior vena cava, an important vein carrying blood from the upper body to the heart, can happen when tumours grow and put pressure on it, or a blood clot blocks the vein.

As this blockage continues, it creates a lot of pressure, so the body makes new pathways for the blood to reach the heart. These pathways help blood flow better by going around the blockage. It's how the body deals with the problem and keeps the blood moving. However, these new pathways can lead to swelling, trouble breathing, and visible swollen veins.

3 What signs and symptoms should I look for?

The signs and symptoms of a blockage include:

- Swelling in the face, neck, and arms is an early sign of a possible blockage.
- Shortness of breath, especially when lying down or being active.
- A dry cough that won't go away can be caused by irritation in the airways.
- Increased pressure from the blockage may make it difficult to swallow or lead to feelings of chest pain or increased headaches.
- The skin might turn bluish in the lips, hands, or the face, and neck might look really red.

4 How can we treat a blockage of the superior vena cava?

Treatment options focus on comfort and managing the symptoms. They include:

- Medicines that can help with pain, breathlessness, and anxiety, making it easier to breathe and feel calmer. Steroids can be used to reduce pressure from anything blocking the vein.
- A prescription for oxygen can ease shortness of breath and improve oxygen levels in the blood.
- Other treatments that can help with symptoms are chemotherapy (that may reduce the size of the tumour) or surgery (insert a tube into the vein to keep it open and let blood flow). The goal of these treatments isn't to cure the disease but to help with symptoms and make the individual more comfortable.

5 When should I call the healthcare team?

When helping someone with a blockage in the superior vena cava, keep an eye out for these symptoms and situations. If you notice any of them, it's essential to contact your healthcare team right away to make sure the person feels as comfortable as possible:

- **Trouble breathing:** If the person suddenly has a lot of trouble breathing that doesn't get better with rest or changing position, it could mean the blockage is getting worse.
- **Pain that can't be controlled:** If the person has new or worse pain, and the medicines or treatments they usually use aren't helping, tell the healthcare team immediately so they can find a better way to ease the pain.
- **Mental changes:** If the person's thinking suddenly gets confused, they seem disoriented, or they lose consciousness, it's important to let the healthcare team know right away.
- **Swelling and skin colour changes:** If you see fast and significant swelling in the face, neck, or arms, and their lips or fingertips turn bluish, it could mean the blockage is getting worse and needs immediate attention.
- **Bleeding or blood clots:** If there's bleeding that won't stop, like from the mouth or nose, or if you notice strange bruises or heavy bleeding, it's crucial to contact the healthcare team right away.