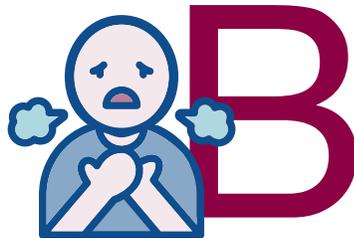


# Be Prepared: Palliative Care Emergencies in the Home

Navigating Home Emergencies with Care and Compassion



Your Conversation Guide

**BREATHING**

(Dyspnea)

## 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.

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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 hemorrhage)
-  **B** Brain (seizures)
-  **B** Bones (spinal cord compression)
-  **B** Blockage (superior vena cava obstruction)



**This Conversation Guide focuses on Breathing (dyspnea).**

**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 dyspnea 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 BREATHING (Dyspnea)



### 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 <b>purpose</b> and <b>importance</b> of having the conversation with empathy.</p> <p>b) Assess their <b>readiness</b> to have the conversation with sensitivity (i.e., ask for permission).</p> <p>c) Ask about their <b>fears and/or worries</b> and actively listen to their response(s).</p>	<p><b>PURPOSE/IMPORTANCE:</b></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><b>READINESS:</b></p> <p><i>“We need to talk about how your health may affect your breathing and the things you can do to help with your dyspnea and when it is time to get help. When do you think would be a good time to talk about it?”</i></p> <p><b>FEARS/WORRIES:</b></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 dyspnea and provide information on what they might see and/or hear, how they may feel, and what they can do	<p><i>"Dyspnea can be frightening, 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>

For individuals receiving palliative care, dyspnea is one of the most common symptoms, with estimates suggesting that up to 70% of end-of-life patients experience some form of breathlessness. This makes it a major concern for healthcare providers and caregivers alike (Hsu et al. 2021).

## The Palliative Care Emergency–BREATHING (Dyspnea)



### What is Dyspnea?

#### Information for Nurses

Dyspnea, often termed as “shortness of breath”, is the subjective experience of breathing discomfort, frequently characterized by sensations such as “chest tightness” or “air hunger”. This sensation can arise from a multitude of causes ranging from cardiac and pulmonary conditions to neuromuscular diseases.

#### How to describe dyspnea to Patients and/or Caregivers

*“Dyspnea is when someone has trouble breathing. Imagine feeling like you are out of breath and there’s a sharp tightness in your chest. It can feel as if you’re gasping for air, battling for each breath, or on the verge of suffocation. This sensation can be extremely scary because only the person experiencing it can truly explain how intense it feels.”*

### Who may be at risk?

#### Information for Nurses

Patients with compromised lung function, due to current conditions or pre-existing diagnoses, like heart disease, lung ailments, or neurological conditions such as amyotrophic lateral sclerosis (ALS) or myasthenia gravis, face a higher risk of dyspnea. Be vigilant to ensure tailored care, early interventions and that plans for potential emergencies are in place for those at risk.

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

*“Someone with a history of heart disease, lung issues, or specific neurological disorders, like ALS (amyotrophic lateral sclerosis), may experience increased difficulty in breathing. Being aware that these conditions may impact someone’s ability to breathe will help you be better prepared.”*

# Pathophysiology

## Information for Nurses

The sensation of dyspnea arises from the awareness of a respiratory supply-and-demand mismatch. Such a mismatch can result from the perception of increased demand, decreased capacity, or a combination of both. Many aspects of the patient's situation affect the experience of their dyspnea – it's not just physical!

Psychological aspects such as anxiety, levels of coping, spiritual aspects (such as the degree of acceptance, meaning, and suffering), and social aspects, including relationships, family experience, and financial situations can all play a role. Dyspnea may not only be due to a lack of oxygen, and this is why reassurance, a calming and supportive presence, and other non-pharmacological strategies can be very helpful for the patient.

### How to explain why dyspnea may occur to Patients and/or Caregivers

*"You may feel short of breath when the amount of oxygen you breathe in is not enough for what your body and mind need."*

*"Did you know that feeling stressed, anxious, or moody can increase someone's breathing and/or heart rate? It's important to know that intense emotions and how they manage them can affect someone's physical well-being."*

# Signs and Symptoms

## Information for Nurses

When assessing a patient for dyspnea, watch for gasping, increased breathing rate, and visible distress. Note any wheezing, skin colour changes around the mouth or on the fingernails, and grunting on exhalation. Also, observe if the patient leans forward for deeper breaths or if their chest sinks unusually with each breath. These are critical signs to promptly address potential respiratory issues.

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

*"Look for these signs if you think someone might be struggling to breathe:*

*The way they breathe will change:*

- *Gasping for air*
- *Breathing rate or frequency increases*
- *Wheezing or breathing loudly*
- *Grunting sounds when breathing out*
- *Nose flaring while breathing*
- *Chest sinking in just below the neck or under the breastbone with each breath*
- *Leaning forward to take deeper breaths*

*The way they look may change:*

- *Looking distressed and anxious*
- *Colour changes around the mouth, lips, or on the fingernails or skin*
- *Sweating*

*Sometimes it's not easy to recognize if someone is struggling to breathe. They may be experiencing dyspnea, but not seem to be out of breath, or they might seem out of breath, but feel fine. It's important to ask them how they are feeling."*

# Treatment Options

## Information for Nurses

When addressing dyspnea in patients receiving palliative care, it's vital to adopt a comprehensive approach, focusing on both the physiological aspects and the emotional well-being of the patient. Here are the main treatment strategies:

### Pharmacological interventions

- **Opioids:** While there's debate in some circles, opioids are proven to be both safe and effective for pain and dyspnea management, notably in conditions such as malignancies, end-stage cardiopulmonary diseases, and ALS. These agents not only address dyspnea symptoms, but also provide an anxiolytic effect, usually at minimal therapeutic doses.
- **Benzodiazepines:** For patients displaying signs of heightened anxiety or panic, benzodiazepines can act as an effective anxiolytic, mitigating the psychological factors that exacerbate dyspnea.
- Other relevant medications include:
  - **Diuretics:** Particularly prescribed for patients with symptoms of congestive heart failure.
  - **Bronchodilators:** These are useful for patients experiencing bronchospastic episodes or other obstructive pulmonary conditions.
  - **Corticosteroids:** These can be beneficial in conditions characterized by inflammation.
- **Oxygen supplementation:** Oxygen therapy may be recommended if a patient's oxygen saturation is low or if clinical judgement indicates it could relieve their dyspnea symptoms.
- **Acute respiratory distress protocol:** In emergent situations, where rapid intervention is required, a combination of a benzodiazepine (typically midazolam), an opioid, and scopolamine is often administered.

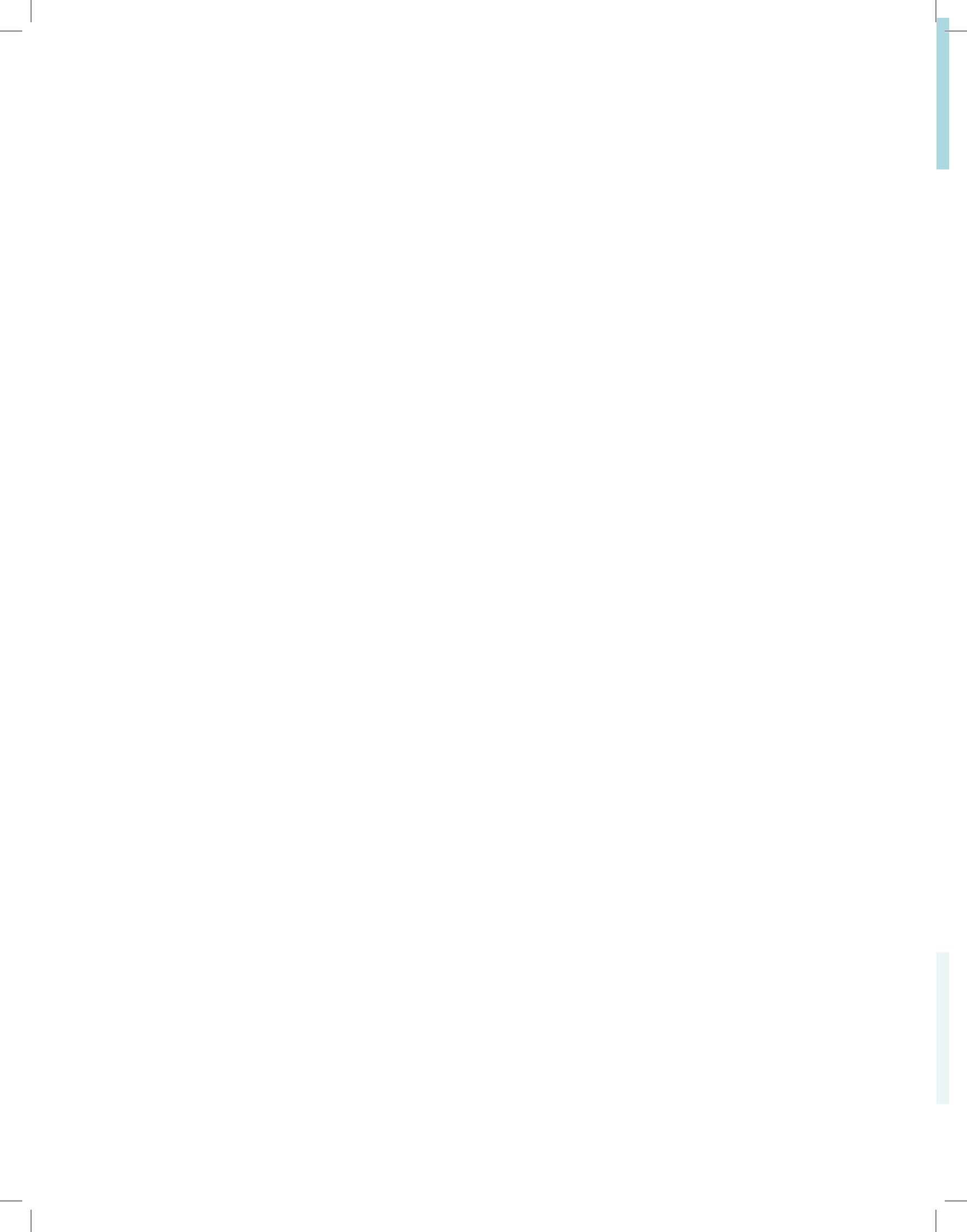
It's crucial to recognize the intertwined nature of dyspnea and anxiety. A holistic approach considering both clinical signs and the patient's subjective experience, ensures that comprehensive and empathetic care is provided.

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

*"If someone has trouble breathing, the doctor or palliative care specialist may prescribe medications like opioids for pain relief or benzodiazepines to calm any anxiety. Occasionally, they may prescribe oxygen."*

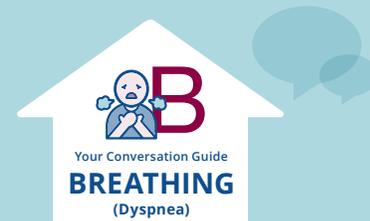
*"If breathing gets really bad, the healthcare team will follow a specific protocol. If you'd like, I can provide you with more information on this."*

*"Always remember, understanding how someone feels is just as important as addressing their physical symptoms. It's all about ensuring they're as comfortable as possible. Your top priority is to keep them calm."*



# 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 having difficulty breathing. Your healthcare provider will review the actions with you.

Actions you can take	 Comforting Words
<p><b>Use a fan</b> Try directing a fan towards the face or cheek for relief.</p> 	<p><i>"Let's turn on the fan and see if it helps. Can you tell me if it improves your breathing?"</i></p>
<p><b>Change positions</b> Recommend changing positions (45 degrees).</p>   <p style="font-size: small; text-align: center;">Sitting leaning forward    Sitting with pillows</p>	<p><i>"It looks like you are struggling to breathe. Can I gently lean you forward to see if it helps?"</i></p>
<p><b>Breathing techniques</b> Try breathing through pursed lips.</p>  <p style="font-size: small; text-align: center;">1+2 Inhale    1+2+3+4 Exhale</p>	<p><i>"Let's try this breathing technique together. First take a normal breath in. Now, bring your lips together like you are blowing out a candle and breath out. Let's keep repeating that pattern and see if it helps."</i></p>
<p><b>Stay calm</b> Be present and help manage stress—focus on deep breathing.</p> 	<p><i>"Take a deep breath through your nose, letting your belly expand. Now exhale, pulling your belly in, and breathe out through your mouth." Consider saying, "I'm here with you" or "Let's breathe together" rather than telling them, "Please calm down" or "Don't worry".</i></p>
<p><b>Airflow</b> Ensure proper ventilation of the room and consider eliminating "irritants" (e.g., cigarette smoke). Ask them if there is anything in the air that might be bothering their breathing (e.g., smoke, dust, smells, etc.).</p>  	<p><i>"Sometimes things in the air can affect your breathing. Let me open the window (or turn on the fan) to see if that helps."</i></p>
<p><b>Give medication</b> (If prescribed)</p> <ul style="list-style-type: none"> <li>• MEDICATION – administer dosage (only if you were shown how to do so)</li> <li>• OXYGEN - Put on the oxygen mask or nose cannula</li> </ul> <p style="font-size: small;"><i>Note: Masks and/or nasal cannulas may cause skin irritation (e.g., redness) or can dry out the inside of the nose and mouth. Monitor pressure points and try padding the skin with gauze for comfort and to prevent skin breakdown. A humidifier can also be helpful.</i></p>  	<p><i>"This medication will help you breathe easier. The nurse has shown me how to administer it."</i></p> <p><i>"Let me check your oxygen mask. I want to see if it's irritating your skin or drying out your mouth/nose. It's important that this is comfortable for you."</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.
- ✓ you have questions about what to do.



**Call your Healthcare Team**

Day time: \_\_\_\_\_

Evening: \_\_\_\_\_

Night time: \_\_\_\_\_

# 5 things you should know about Dyspnea



## 1 What is Dyspnea (shortness of breath)?

Dyspnea is when someone has trouble breathing.

Imagine feeling like you are out of breath and there's a sharp tightness in your chest. It can feel as if you're gasping for air, battling for each breath, or on the verge of suffocation.

## 2 What causes someone to experience shortness of breath?

Shortness of breath can happen when the body doesn't get enough oxygen. For someone with a serious illness, this might be due to reasons like a worsening heart condition, fluid build-up in the lungs, tumours pressing on the airways, or infections like pneumonia. Emotions, such as stress or anxiety, can also raise breathing rates.

## 3 What signs should I look for?

Watch for these signs if you think someone is having trouble breathing:

- Taking quick, short breaths or gasping for air.
- Breathing faster than usual.
- Making a wheezing or loud noise when breathing.
- Making a grunting sound when breathing out.
- Their nose opens wide, or their chest pulls in below the neck or under the chest bone with each breath.
- Lips, mouth area, fingernails, or skin turning a different colour.
- Sweating a lot and looking worried or scared.

Sometimes it's hard to tell if someone is having trouble breathing. They might look like they can't catch their breath, but they feel okay, or they might seem okay but feel out of breath. Always ask them how they feel.

## 4 How can we treat shortness of breath?

When someone has trouble breathing, there are several ways to help.

Medicines can ease pain, improve breathing, and reduce anxiety. If someone isn't getting enough air, they might need a prescription for oxygen. In emergencies, a combination of medicines can provide quick relief.

It's vital to understand that anxiety can worsen breathing problems, so staying calm is very important.

## 5 When should I call the healthcare team?

In any of these situations, you should call your healthcare team immediately for guidance and assistance.

- **Sudden breathlessness:** If the person starts having a really hard time breathing out of nowhere, and it's much worse than before.
- **Increased pain:** If the person has new chest pain or if the pain gets worse when they're short of breath.
- **Change in behaviour:** If the person seems very sleepy, is hard to wake up, or acts confused when they have trouble breathing.
- **Blue or grey lips or nails:** If their lips or nails change to a blue or grey colour because they're not getting enough air.
- **Medicines not working:** If the things that usually help them breathe aren't working or if they keep having trouble breathing even after taking them.