

Speaking With Compassion:

A Conversation Guide for the Last Days and Hours



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Speaking With Compassion: A Conversation Guide for the Last Days and Hours

Navigating Conversations with Care and Compassion

These conversations are not limited to the final moments of life—they are a vital part of palliative care from the moment of diagnosis onward. These discussions help patients and families prepare emotionally, make informed decisions, and feel supported throughout the journey.

Caring for someone in their final days and hours is a profound and sacred responsibility. As a healthcare professional, you are often the steady presence in an emotional time. This guide was created to support you in navigating end-of-life conversations with compassion, clarity, and confidence.

Families may feel overwhelmed, unsure of what to expect, or fearful of saying the wrong thing. Your ability to offer gentle guidance, honest information, and emotional reassurance can help bring comfort and understanding. This guide provides practical language to set the tone for these discussions, normalize the dying process, and explain the physical changes families might see in a way that is both respectful and accessible.

You will also find strategies to help caregivers feel more involved, offer comfort, and recognize the meaningful role they play as death approaches. Whether it's answering questions, managing uncertainty, or simply being present, your words and actions have a lasting impact.

*“People will forget what you said,
people will forget what you did,
but people will never forget how
you made them feel.”*

Maya Angelou

How the Conversation Guide Works:

1

A Conversation Checklist

A step-by-step framework to help healthcare providers navigate emotional conversations during a patient's final days. It provides practical phrasing, including the "Wish, Worry, Wonder" approach to open discussions, explore patient goals, share clinical information, and close conversations with empathy.

Purpose: To guide providers in delivering clear, and supportive communication during the final days and hours.

2

Pathophysiology Signs, Symptoms, and Treatments

What to expect as patients approach death. It explains physical, emotional, spiritual and behavioural changes in a way that is easy to understand. This guide covers systems such as respiratory, cardiovascular, neurological and more. Both medical and non-medical approaches to comfort care are outlined, with language that helps families understand the dying process without fear or confusion.

Purpose: To help providers normalize the dying process and explain it to families in plain, reassuring language while guiding symptom management.

3

A Toolkit for Caregivers

Designed to support caregivers, this section provides emotional guidance and actionable tips for providing comfort, maintaining connection, and practicing self-care. It includes sample phrases, supportive actions, and signs of caregiver burnout. The goal is to empower families to feel present and supported, while also acknowledging the emotional toll caregiving can take.

Purpose: To empower caregivers with knowledge, emotional support, and tools to provide compassionate care and preserve their own well-being.

1

CONVERSATION CHECKLIST: LAST DAYS AND HOURS

Having conversations with your patient and their caregiver(s) leading up to and during the last days and hours is a crucial component in ensuring patient-centered, compassionate care. These discussions, although sometimes difficult, help deliver holistic care, promote dignity, and reduce unnecessary interventions. Involving caregivers and the patient's support team acknowledges them and provides them with support during a very sensitive time.

This Conversation Checklist helps to better prepare healthcare providers in having these conversations.

Last Days and Hours Communication: Best Practice Tips



- ✓ Allow time for silence to support reflection and emotional processing
- ✓ Identify how much information the patient or caregivers want to know
- ✓ Recognize and explore emotions with empathy and openness
- ✓ Respect the autonomy of the patient in all decisions
- ✓ Offer support to families and caregivers throughout the process
- ✓ Maintain clear professional boundaries while remaining compassionate
- ✓ Provide reassurance that is honest and comforting
- ✓ Incorporate both medical and non-medical approaches to care
- ✓ Anticipate and guide challenging conversations with sensitivity
- ✓ Welcome diverse beliefs and perspectives without judgment
- ✓ Use plain, accessible language to ensure understanding
- ✓ When feeling unsure consult with an experienced colleague
- ✓ Plan for self care after an emotionally intense conversation

“Compassion is all-inclusive. Compassion knows no boundaries. Compassion comes with awareness, and awareness breaks all narrow territories.”

-Amit Ray

What to Include in Your Conversation

Helpful Phrases for Healthcare Providers



Setting the Tone:

Acknowledge the emotional weight. Ask about cultural, spiritual, or personal preferences.

- *“I understand this is a difficult time. I’m here to support in whatever way you need.”*
- *“Are there any spiritual, cultural, or personal practices you’d like us to honor?”*

Normalizing the Dying Process:

As appropriate, explain the signs of imminent death and use gentle, non-medical language.

- *“Some changes we see at this stage are caused by parts of the body naturally slowing down.”*
- *“You might notice less interest in food and water. That’s expected and okay. This is normal.”*
- *“These changes tell us that their body is preparing for the end of life.”*

Physical Care and Comfort:

Describe what the care team and family can do to ensure comfort as the patient is in the last days and hours.

- *“Our team is here to make sure your loved one is as comfortable as possible at every step.”*
- *“If you notice anything that concerns you - changes in breathing, restlessness, or discomfort - please let us know right away.”*
- *“You can help just by being here. Holding their hand, speaking softly, or creating a calm and familiar environment.”*

Emotional and Spiritual Support:

Encourage family presence and saying goodbyes. Validate mixed feelings and offer supportive care services.

- *“Are there any particular worries or fears you’d like to talk about?”*
- *“You can talk to them, share memories, or simply sit quietly - whatever feels right to you .”*
- *“It’s completely normal to feel a mix of emotions. There is no right or wrong way to feel right now.”*

What to Expect Around the Time of Death:

Describe final moments. Reassure family that their presence is meaningful and talk about what to do after death.

- *“Even if they are not speaking, hearing is believed to be one of the last senses to go - so keep talking to them if you’d like.”*
- *“In their final hours and moments, it is normal to see changes in breathing, skin color, and responsiveness. These are expected and do not mean that your loved one is experiencing discomfort.”*

After-Death Support:

Provide clear next steps and provide information about grief resources.

- *“Everyone processes loss uniquely. Some may cry, others may stay quiet or focus on practical tasks. All reactions are valid.”*
- *“You can take as much time as you need. There is no rush.”*
- *“You don’t have to go through this alone - there are people ready to support you whenever you’re ready.”*

WISH, WORRY, WONDER FRAMEWORK

The Wish, Worry, Wonder framework is a compassionate communication tool designed to support meaningful, honest, and valuable conversations—especially during serious illness or end-of-life care. It helps clinicians express empathy, acknowledge uncertainty, and invite dialogue in a way that respects the patient’s values and emotions.

Wish statements express a shared hope or desire, even when outcomes are uncertain or unchangeable.

Worry statements gently introduce concerns, helping to prepare patients and families for what may come.

Wonder statements open the door to collaborative planning, reflection, and emotional exploration.

This framework encourages authentic connection, emotional validation, and shared decision-making, while avoiding false reassurance or overly clinical language. It is especially helpful when navigating difficult topics such as prognosis, dying, or the final days and hours of life.



The patient states, *“I don’t want to die”*

The family or caregiver, states, *“I’m not ready for them to leave us”*

WISH

“I wish I could give you more time.”

“I wish we had more time.”

WORRY

“I worry that you may not have as much time as we thought.”

“I worry that if we don’t talk about what is coming you won’t be prepared.”

WONDER

“I wonder if we could talk about what is important to you right now?”

“I wonder if we could talk about what the coming days may look like. Would that be ok?”

2

Pathophysiology

Signs, Symptoms & Treatment Options

Effective symptom management and treatment in end-of life-care are critical in ensuring that an individual's last days and hours are as comfortable, dignified, and as peaceful as possible. The dying process can bring about a wide range of potentially distressing symptoms such as pain, dyspnea, agitation, and nausea. If left untreated, the symptoms could cause unnecessary suffering.

The following document explains some available options to manage these symptoms.

Pain

In the last days and hours, the patient's experience of pain may change even if the overall level of pain does not increase. These changes are often due to the body's natural decline and does not necessarily indicate worsening pain. However, any pain should be assessed and treated.

Watch for signs such as:

- Wincing and/or facial grimacing
- Stiffening
- Clenched teeth
- Restlessness



- *“Their pain should not increase at this stage, but if it does we will do whatever possible to treat the pain.”*
- *“We want them to be as comfortable as possible. Here is what we can do to achieve that.”*

Treatment Options

Pharmacological:

- Consider current medication regime (ie. methadone, transdermal patches).
- Morphine: opioid analgesic that helps treat moderate to severe pain.
- HYDROmorphine (Dilaudid): opioid analgesic that helps treat moderate to severe pain.



Non-Pharmacological

- Encourage caregiver to monitor for signs of pain.
- Reposition patient to relieve pressure points and discomfort.
- Provide soothing and comforting touch.

Respiratory

In the last days and hours, changes in respirations are common:

- Breathing may become fast, shallow or irregular (Cheyne-Stokes), and there may be long pauses between breaths.
- Breathing may stop for extended intervals (apnea), occurring more frequently and lasting longer than before.
- Noticeable shifts in breathing patterns may happen, which may alternate between slow and fast, or shallow and deep.
- Secretions in the airway can lead to loud, rattling or gurgling sounds during breathing.
 - Avoid suctioning as it stimulates more secretion production.
- Open mouth-breathing is common.



- *“Their breathing may become uneven, with long pauses or faster and slower rhythms. This is normal.”*
- *“Their breathing may sound moist and gurgly, while it can be unsettling to hear, it does not cause them any discomfort.”*

Treatment Options

Pharmacological

- Morphine: Opioid analgesic with secondary use of relieving dyspnea.
- HYDROmorphone: Opioid analgesic with secondary use of relieving dyspnea.
- Scopolamine, glycopyrrolate, or atropine drops: Antimuscarinic medications used to decrease pharyngeal and pulmonary secretions.



Non-Pharmacological

- Reposition patient to relieve pressure points and discomfort.
- Humidify room if possible.
- Provide frequent mouth care.
- Provide a fan as needed.

“In the quiet moments of care, you are not just easing pain—you are offering dignity, love, and presence. What you do matters more than words can say.”

Author Unknown



Neurological

In the last days and hours, the patient may express awareness of impending death, making direct statements such as “I’m going to die”.

It is common for them to become fidgety, restless, disoriented or distressed as they approach dying.

- They may become decreasingly responsive. Level of consciousness can fluctuate.
- Episodes of restlessness, confusion, hallucinations or agitation may occur.



- *“Your loved one may sleep most of the time or may not respond at all.”*
- *“They might seem agitated, pick at sheets, or say things that don’t make sense.”*

Treatment Options

Pharmacological

- Haloperidol: Antipsychotic used to help with agitation, delirium, and provide sedation for comfort (less sedating option).
- Methotrimeprazine (Nozinan): Antipsychotic used to help treat agitation, delirium and provide sedation for comfort (more sedating option).
- Midazolam (Versed): Benzodiazepine used to help with agitation and delirium
- Lorazepam: Benzodiazepine used to help with anxiety and provide sedation. Use with caution.
 - *Be aware that benzodiazepines can increase delirium at the end of life.*



Non-Pharmacological

- Provide comforting words and minimize stimuli.
- Ensure there are familiar voices and objects.
- Provide calming light and sounds.

Cardiovascular

In the last days and hours as the heart continue to weaken, the pulse may become difficult to identify. The body can have difficulty with systemic circulation causing fluid build up.

- Edema to the extremities may be prominent.
- They may present with jugular vein distension.

Monitoring of vital signs is not common practice in the last days and hours.



- *“Their heartbeat may feel weak at this stage. That is normal.”*
- *“Their legs may appear swollen as their heart is not pumping as strong as it was before.”*

Treatment Options

Non-Pharmacological

- Reposition patient to relieve pressure points and discomfort.
- Asses skin to watch for development of reddened areas, edema or skin breakdown.

Integumentary

In the last days and hours there may be a change in skin color due to the decrease in circulation.

- Skin may appear pale, bluish, blotchy, or mottled.
- The skin may become dry and fragile.
- The arms, hands, legs, and feet may feel very cold to the touch.
- The body's ability to maintain a stable core temperature deteriorates and could cause higher than normal temperatures.



- *“You may notice their skin becoming pale, bluish, or blotchy.”*
- *“Their hands and feet may feel cold to touch. This is normal.”*

Treatment Options

Non-Pharmacological

- Reposition patient to relieve pressure points and discomfort.
- Apply lotion if appropriate
- Assess skin to watch for development of reddened areas, edema or skin breakdown.
- Control temperature of the room if the patient feels cold or hot.

Gastrointestinal and Genitourinary

In the last days and hours it is normal for patients to stop eating and drinking because their body can no longer process food and fluids.

- IV rehydration therapy is not indicated during the last days and hours, can be more harmful than beneficial.
- Complete loss of the ability to swallow.
- Noticeable reduction in urine output, with urine becoming much darker or taking on unusual colors like red and brown.
- New onset of bladder or bowel incontinence in a person who was previously continent.



- *“It’s normal for them to stop eating or drinking, the body no longer needs food or fluids.”*
- *“You may notice less pee, and it may be darker in color.”*

Treatment Options

Non-Pharmacological

- Provide mouth care can reduce nausea and limit nauseating stimuli.
- Keep the air and room fresh, avoid strong smells.
- Avoid pressuring the patient to eat or drink if they are uninterested or unresponsive.
- Provide incontinence care as required.

3

The Last Days and Hours:

What You Could See

When someone is in their last days and hours, it can be a very emotional time for families and friends. Making sure your loved one is as comfortable and peaceful as possible can bring comfort to everyone. As the body starts to slow down, your loved one may have symptoms like pain, trouble breathing, restlessness, or nausea.

The health care team can guide you through a variety of options to manage these symptoms.

Pain

- Your loved one might not be able to tell you if they are in pain.



- Watch for signs like wincing, frowning, or clenching their jaw. These can mean they are not comfortable.
- Talk to the healthcare team about giving medicine that can help.

Breathing Changes

- Your loved one's breathing may change in speed or depth- it might be fast, slow, deep, or shallow.
- Sometimes, their breathing may pause, then start again.
- It may also sound wet or noisy.
- These changes are normal and do not mean they are uncomfortable.



- Talk to the healthcare team about giving medicine that can help to reduce secretions.
- Place pillows behind your loved one's back or side to help reduce secretions.

Feeling Weak and/or Sleeping More

- Your loved one may stay in bed and sleep more.
- This is normal. Their body is slowing down and can't work like it used to.



- Shift or adjust your loved one's position to help with discomfort and pressure on certain parts of the body

Confusion, Restlessness, or Agitation

- Your loved one may seem restless or confused.
- They might pick at the blankets or reach into the air.
- They could have a hard time getting comfortable.



- If your loved one is overwhelmed, consider keeping the room calm and quiet so your loved one can rest.
- Say your name clearly when you talk.
- Avoid disagreeing with them. It can make them feel more upset or scared.
- Talk to the healthcare team about giving medicine that can help.

Eating or Drinking Less

- Your loved one may not feel hungry or thirsty anymore.
- Their body might have a hard time swallowing food or drinks.
- Trying to eat or drink could make them feel sick to their stomach or uncomfortable.
- Giving fluids through an IV at this time is not helpful.
- They produce less urine.
- They will lose control over their bladder or bowel.
- These are all normal changes.



- Provide mouth care to keep their mouth moist.
- Provide a urinal, bedpan. Incontinence underwear or a catheter can also be used to help with loss of bladder or bowel control.

The Last Days and Hours:

What You Could Say



This page has ideas for things you can do and say to comfort someone you love when they are near the end of their life. These are only suggestions. You can change the actions or words to fit your own feelings and your special relationship. Everyone is different, so it's okay to do or say what feels right to you.

Actions you can take	Suggestions for comforting words
Continue talking with them	"I'm/We are here, you are not alone." "I'll read to you from your favorite book."
Reminisce on happy memories	"Remember when..." "Last year at ____, we had so much fun!"
Hold their hand	"Hi ____, it's ____, I'm here with you."
Embrace them experiencing seeing passed loved ones	"Your mom is here? That's so nice she came to see you."
Provide mouth care	"I'm going to wet your mouth with this sponge." "I have your favorite lip balm, I'll put some on for you."
Keep them comfortable	"I'm just going to adjust your pillows." "Your feet seem cold, let me get you a blanket."
Provide or ask for any medications needed	"I noticed you started frowning. I will see about getting you some medication."
Discuss any concerns with the healthcare team	"You seem unsettled. I am going to talk to the nurse to see what we can do."
Consider saying goodbye when you leave	"I am going to go get some food. I love you."
Respect your loved ones preferences and wishes	"I am going to brush your hair and do your makeup like you have always liked me to do."
Give them permission to go	"We will be okay. We love you." "You don't have to hold on for us, it's okay, you can rest now."
If you can't think of anything to say	"Thank you." "I love you." "I forgive you....." "Please forgive me....."

Helping Yourself

Taking care of your loved one can make you feel very tired and emotional. It's normal to feel things like worry, stress, sadness, comfort, or even relief. All these feelings are okay. Remember, taking care of yourself helps you take better care of the person who needs you.

Signs of Caregiver Burnout

- Feeling constantly tired or drained
- Changes in sleep—too much or too little
- Feeling sad, anxious, or overwhelmed
- Losing interest in things you used to enjoy
- Gaining or losing weight unexpectedly
- Getting irritated or angry more easily
- Using alcohol or substances to cope
- Feeling emotionally heavy or burdened

Tips & Tricks to Prevent Caregiver Burnout

- Eat well, drink water, and try to get enough sleep so your body and mind can rest.
- Take short breaks away from caregiving. Do something that helps you relax, like reading, walking, or listening to music.
- Spend time with people who care about you. Let them help when they offer.
- Talk to your own or your loved one's healthcare team if you feel scared, worried, or have questions.
- Ask about extra supports. This is when others can help care for your loved one so you can take a break.
- Try calming activities like deep breathing, writing in a journal, or gentle exercise.
- Create a routine that works for you, your loved one, and others helping out.



"Compassion for others begins with kindness to ourselves."

Pema Chödrön

If you are experiencing caregiver burnout:

- Notify your own healthcare team to inform them of your struggles
- Consider extra supports for your loved one to give yourself a break
- Contact 24/7 mental health phone lines
- Attend wellness and grief groups
- Reach out to community mental health services
- Be kind to yourself