

Suggested responses to common questions patients/families may ask



NSMHPCN
North Simcoe Muskoka Hospice Palliative Care Network

PSW & Others

What will the end be like? *Explore whether the patient wants to discuss physical symptoms or more of a spiritual realm.*

"I'm just wondering if you are asking about how their body will change in the last days."

Exploring spirituality/religion: "What do you believe will happen at the end?"

Why is their skin so cold and turning purple?

"As the circulation of their blood is slowing down, often their arms and legs will feel cool and will have red or purple blotches, this is not painful" "They will most likely not feel cold, however, if you like we can put a light blanket on them"

I don't want to take away their hope

"We often hope for a cure or a miracle, but if that doesn't happen, we can hope for other things such as comfort" "When someone is ill, hope changes throughout their journey"

How could this be happening so fast? *(clarify: maybe they are waiting for someone to visit)* "This must be very difficult for you" is there something that's concerning you, or is there something you would like to talk about"

Why are they sleeping so much? Why are they so drowsy?

"As their body begins to shut down, they will be sleeping more. This is a natural part of the dying process"

Why aren't you turning them every 2 hours?

"At end of life, your _____ is in a very peaceful and serene state, it is not necessary to turn them side-to-side for comfort" "Making small adjustments with pillows, elevating their head/knees etc. will be just as comforting"

Why aren't you feeding them? They must be starving/thirsty!

It's important to have the nurse discuss with family about goals of care and the pros and cons of starting hydration.

"Loss of appetite is common and natural as the body begins to shut down" "Natural endorphins kick in and patient's don't feel hungry or thirsty"

"Remember when you had the flu..you didn't feel hungry as your body was adjusting to illness". "It's the same when our body is dying...it's adjusting and doesn't feel hungry"

"Our bodies are very smart...it knows what it needs to live and knows what it doesn't need when it's dying"

"Adding extra food and fluids puts extra stress on your body because it has to process it and can cause discomfort"

"It's just like a car sitting in the garage on blocks and you are pouring in gasoline/overflowing an engine that isn't moving"

"Maybe...you can moisten their mouth with their favourite beverage, i.e. coffee, ginger ale...I'm sure _____ would love to taste something that they always enjoyed"

"often just moistening the mouth will decrease the sensation of thirst, especially if they are mouth breathing"

I don't want them to be alone when they die (we've missed the chance to say good-bye)

"Some people prefer, consciously unconsciously to die alone...sometimes your loved one will wait until you leave to protect you from seeing them go" "you will always be connected in spirit/heart/soul even if you aren't physically present"

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PSW & Others

How do you know that the end is near?

“There are certain signs and symptoms that are experienced when someone is approaching death...would you like me to share some of them with you?” *explore if they would like to know what they are, i.e. sleeping more, not eating, change in breathing pattern etc..* Offer “Your nurse can provide you with more information about these symptoms and how the body is changing, would you like me to contact her/him for you?”

Why are they making that rattling sound?

“This gurgling sound is very common at end of life as they are unable to swallow their saliva” “they are not drowning...its just air passing over the saliva” “it might seem like they are uncomfortable, but it’s just like snoring, the person who is snoring is not in any distress”

“If you are concerned I can let the nurse know, in the meantime, I can reposition them on their side as that might help drain some of the secretions”

We treat animals better than this! *Usually people state this when they are thinking about “suffering”*

“Tell me more about why you feel this way” “Are you concerned about suffering?” “Are there symptoms that you are seeing that are concerning you?”

Can they hear us?

“I’ve learned that hearing is one of the last senses to go...so we encourage families to continue to communicate, share stories, reminisce etc..” “Even though they are unconscious, they can probably hear you and even sense your presence”

They look like they are struggling to breathe!

“I have learned/seen breathing patterns change at end of life, they may even stop breathing at times” “this is the natural progression towards death” “Its just like sleep apnea..the person who is sleeping is not in any distress” “If you are concerned about them being short of breath, we can ask the nurse to assess them”

Will there be pain?

” Not everyone has pain at end of life, however as we provide care for _____ we look for signs/symptoms of pain, i.e. moaning, groaning etc. ” “We work with the doctors and nurses that have the knowledge to help people stay as comfortable as possible, relieve suffering and to alleviate much of the physical pain as they go through the dying process”. “If you suspect that they are in pain, please let your nurse know”

“All of my care providers will work with me and my family to support our quality of life throughout this journey and respond to our needs in a coordinated way”

NW(LHIN) St. Joseph’s Care Group, Value Statement, 2018