



Suggested responses to common questions patients/families may ask

Reg. staff

How could this be happening so fast?

"This must be very difficult for you. Is there something that's concerning you, or is there something you would like to talk about?"

Can they hear us?

"Many studies have shown that hearing is one of the last senses to go...so we encourage families to continue to communicate, share stories, reminisce etc."

Is there nothing more we can do?

"This must be very difficult for you...but there is always something we can do even if we can't cure the disease." "What do you understand about the disease process and what are you concerned about?" "What are your thoughts...what's going through your mind?"

I don't want to take away hope?

"Of course miracles may happen and I hope this happens...but in case they don't I wonder if we should be prepared for...."

"Given that a cure is not possible, I'm wondering if being as comfortable as possible may be an important goal"

"Hope can change in the course of the illness"

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 our body will change in the last days?"

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

Will there be pain?

"We 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"

Why aren't you feeding them? They must be starving? Can you start an IV?

"Loss of appetite is common and natural as the body begins to shut down."

"Natural endorphins kick in and people who are dying don't feel hungry."

"Remember when you had the flu and you may not have felt hungry as your body was adjusting to illness? When you are dying that lack of hunger is 10x more pronounced...our bodies know how to die naturally"

"Thirst can be alleviated by good mouth care and not by giving fluids"

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

"Adding extra food and fluids...puts added stress on the organs...your body has to work hard to process that food and fluid creating more discomfort"

"With extra fluid....and the circulatory system...shutting down...they may have more fluid buildup in their body that can cause pain/discomfort"

"Maybe you can moisten their mouth with their favourite beverage, i.e. coffee, gingerale...I'm sure your (mom/dad) would love to taste something that they have always enjoyed"

"Think about a car sitting in the garage on blocks and you are pouring in gasoline/overflowing an engine that isn't moving"

I don't want them to be alone when they die

"Some people prefer, consciously or 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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NSMHPCN
North Simcoe Muskoka Hospice Palliative Care Network

Reg. staff

How long do I (they) have?

"It must be an important question to you. Many patients/residents in the same situation have asked the same question"

We are very inaccurate at predicting life expectancy and are often wrong. Sometimes we overestimate and sometimes we underestimate.

Provide a rough estimate. What has the doctor told you?

"days to many days or weeks"

"many days to many weeks"

"many weeks to a few months"

"it is unlikely to be in the order of years any more"

"Just like in giving birth, we don't know how long labour will last...and it's the same in death...we don't know how long it will take before they take their last breath"

"There are certain signs and symptoms that are experienced when someone is approaching death...would you like me to share them with you"? Explore if they would like to know what they are, (i.e. sleeping more, not eating, change in breathing pattern etc)

"I want you to know that no matter what the time is we will get your loved one the best care." "No matter how much time is left, there is still living to be done."

Isn't that pain medication going to stop them breathing?

"When opioids are ordered for pain and symptom management, we always start with the lowest dosage possible to manage the symptoms...respiratory depression is virtually non-existent." "Towards the end of life their breathing pattern may change. It might become irregular or shallow or they may have periods where they stop breathing ...this is not caused by the medication...it's part of the dying process."

We treat animals better than we treat humans. They might be thinking about "suffering". "Are you concerned about suffering?" Reassure families about providing comfort.

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." You may want to add: "as death nears, the person may slip into a coma and become unresponsive". You might add some education on opioids when they are first initiated: "they might feel more sleepy for several days...until their body gets used to the medication...however, they will sleep more as their body is dying."

Helping Substitute Decision Maker(s) make decisions

Standing at the bedside ask the family member or other SDM
"If you had in your pocket a note from him/her telling you what to do in these circumstances, what would it say?"
"If he/she could come to the bedside as healthy as he/she was ___ months ago, and look at the situation they are in, what would he/she tell us to do?"