

## Communication And Decision Making In Palliative Care

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## Objectives

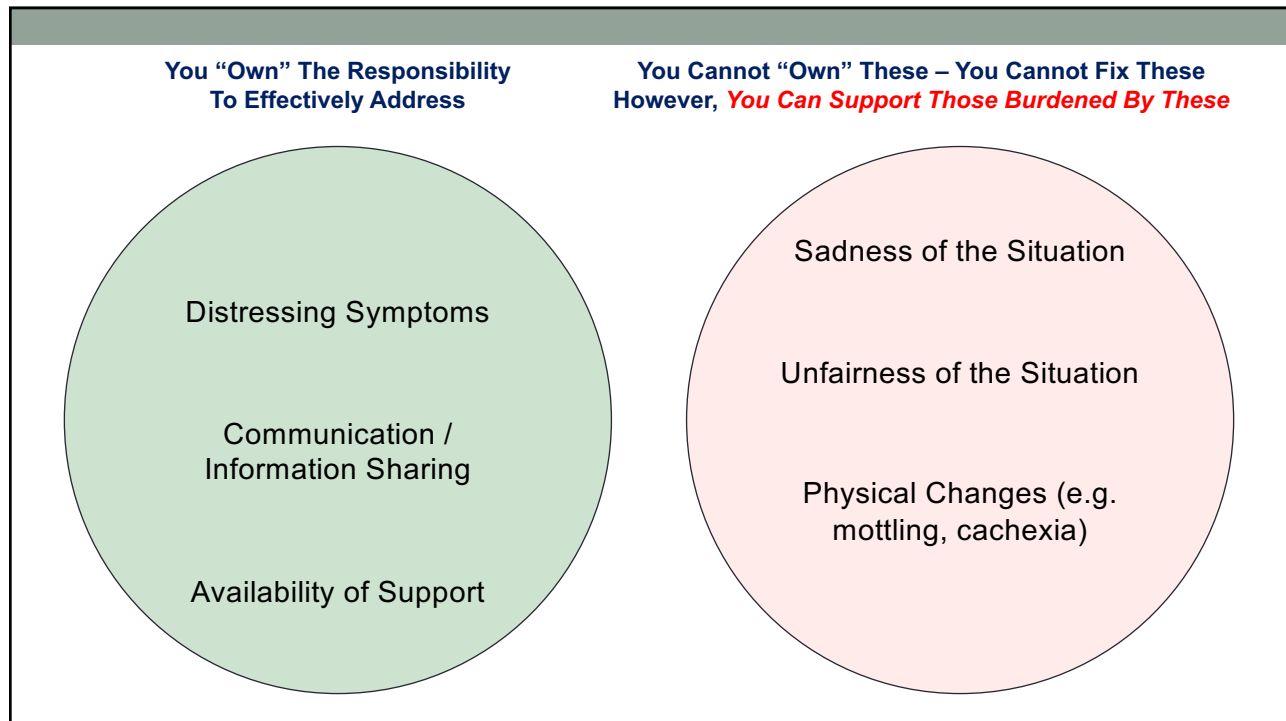
By the end this presentation, participants will:

- Realize that effective communication involves connection – one person to another – and we all have that fundamental skill and obligation
- Know that many – if not most – communication issues in palliative care arise foreseeably and can be approached proactively
- Realize that commonly encountered communication issues can be approached with a guiding framework
- Appreciate that how care options (and non-options) are discussed profoundly impacts care decisions and decision-maker burden



## Connecting – The First Step

- You're a person, your patient is a person
  - you almost certainly have thoughts/worries/fears about death and dying, as do they
  - you almost certainly have experienced loss, as they now are
- This is your foundational qualification for discussing death and dying with others; your "admission ticket" to the conversation; your credentials for having a role
- Your profession provides an added layer of technical information and skill, but without connecting as a person you cannot effectively provide support to a patient facing death and their family



Where possible: complex, sensitive discussions are  
*a process rather than an event*

## Seek Permission

- conversations about death & dying may be unexpected and not wanted – at least not at that time, or in that context, or with/without specific people present
- before you start into a very private and heavy conversation – who is everybody in the room? Don't assume they're family or should be in the room for all discussions (even if they *are* family)
  - introduce yourself and ask who the visitors are
  - is the patient OK with them being in the room?
  - are *they* comfortable being part of the conversation?
- even the person asking the question about their own illness might not realize where the discussion might lead
- keep checking to make sure it's still OK to carry on with the discussion

## Clarity Is Key

- when we don't like talking about something, we tend to talk around it with vague euphemisms
- clarity is achieved through paced titration of honest and accurate information
- may soften the delivery of the message by using progressive directness, e.g.:
  - “There is an area on the chest XRay that is quite concerning. In the left lung, there is a shadow that appears to be a growth. It looks as though there is a tumour there. Although we can't know for sure from an XRay, this is worrisome for possible lung cancer.”
- frequent checking with patient and family throughout discussion to make sure the information is understood

## Avoid Assumptions

We cannot make assumptions about...

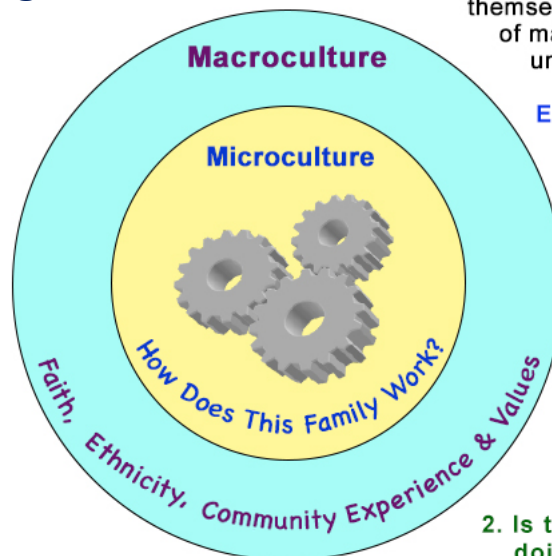
- what the patient/family understands about the illness
- what the patient/family might be experiencing (even if we think we've "been through the same thing")
- goals of care
- the meaning of a silent pause
- the implications of faith/culture

**be respectful, curious – ask**



## Considering Culture...

Families are microcultures unto themselves, reflecting influences of macroculture plus their own unique way of functioning



Exploring the unique family culture - be:

- respectful
- observant
- curious
- where possible - unhurried (paced)

Helpful Questions:

1. Is there anything that we can be doing that would be helpful or meaningful at this time?
2. Is there anything that we are doing that you find unhelpful or is a problem/concern?

## “Don’t Tell Him He’s Dying...”

- Sometimes families strive to protect a loved one from being told that they are dying
- there may be cultural considerations involved
- more common if patient is very elderly – even if they are competent
- complex - don’t simply respond with “It’s their right to know”
- rather than a “right to know”, people have the right to accept or decline information – to dictate the nature and pace of information sharing; they may indeed want to defer to family
- ultimately, may need to check with patient:

“Some people want to know everything they can about their illness, such as results, prognosis, what to expect. Others don’t want to know very much at all, perhaps having their family more involved. How involved would you like to be regarding information and decisions about your illness?”

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## Responding To Difficult Questions

### 1. Acknowledge/Validate and Normalize

*“That’s a very good question, and one that we should talk about. Many people in these circumstances wonder about that...”*

### 2. Is there a reason this has come up?

*“I’m wondering if something has come up that prompted you to ask this?”*

### 3. Gently explore their thoughts/understanding

- *“It would help me to have a feel for what your understanding is of what is happening, and what might be expected”*
- *“Sometimes when people ask questions such as this, they have an idea in their mind about what the answer might be. Is that the case for you?”*

### 4. Respond, if possible and appropriate

- If you feel unable to provide a satisfactory reply, then be honest about that and indicate how you will help them explore that

## Discussing Prognosis

1. Confirm what is being asked – often question is vague
2. Acknowledge / validate / normalize
3. Check if there's a reason that this has come up now
4. Explore “frame of reference” (understanding of illness, what they are aware of being told)
5. It would be helpful if they could describe how the last month or so has been for them (“momentum of decline”)
6. How would they answer that question themselves?
7. Answer the question

“First, you need to know that we’re not very good at judging how much time someone might have... however we can provide an estimate.

We can usually speak in terms of ranges, such as months-to-years, or weeks-to-months. From what I understand of your condition, and I believe you’re aware of, it won’t be years. This brings the time frame into the weeks-to-months range.

From what we’ve seen in the way things are changing, I’m feeling that it might be as short as a couple of weeks, or perhaps up to a month or two”





## Navigating Health Care Decisions

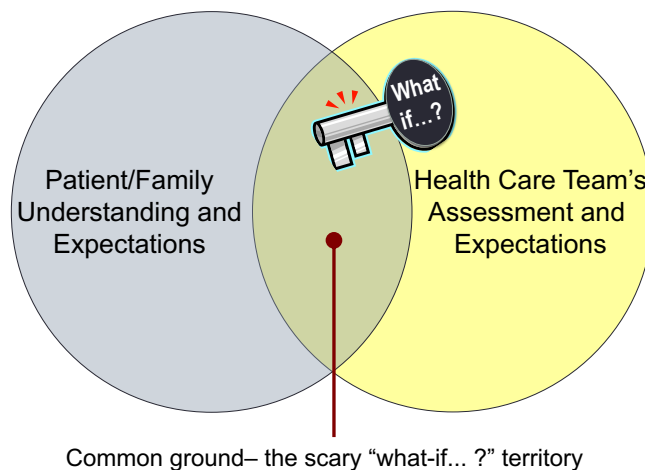
### Approach To Health Care Decision Making

- Be informed about the issues being considered
  - *Information is the foundation for decisions*
- Determine the goals for whatever is being considered
  - *Goals focus our deliberation about options*
- Determine whether the hoped-for goals are possible to achieve and plan an approach accordingly

## Role of the Health Care Team In Planning For Care

1. **Anticipate** changes and challenges: most issues are predictable
2. **Communicate** with patient/family regarding foreseeable potential concerns / issues
3. **Formulate** a plan for addressing predictable issues, including Health Care Directive / Advance Care Plan
4. **Reevaluate** goals of care when a significant change occurs – do not make assumptions about the implications of previous discussions
  - Levels of care designations are foundations for discussions when changes occur – they are starting points rather than end points

Sometimes it seems that the health care team and patients/families are in two separate rooms – the patient/family in the “don’t get it” room and the health care team in the “we know what’s coming” room



*“I know it’s been a difficult time recently, with a lot happening. I realize you’re hoping that what’s being done will turn this around, and things will start to improve... we’re hoping for the same thing, and doing everything we can to make that happen.*

*Many people in such situations find that although they are hoping for a good outcome, at times their mind wanders to some scary ‘what-if’ thoughts, such as what if the treatments don’t have the effect that we hoped?*

*Is this something you’ve experienced? Can we talk about that now?”*

Where possible: complex, sensitive discussions are  
a *process* rather than an *event*

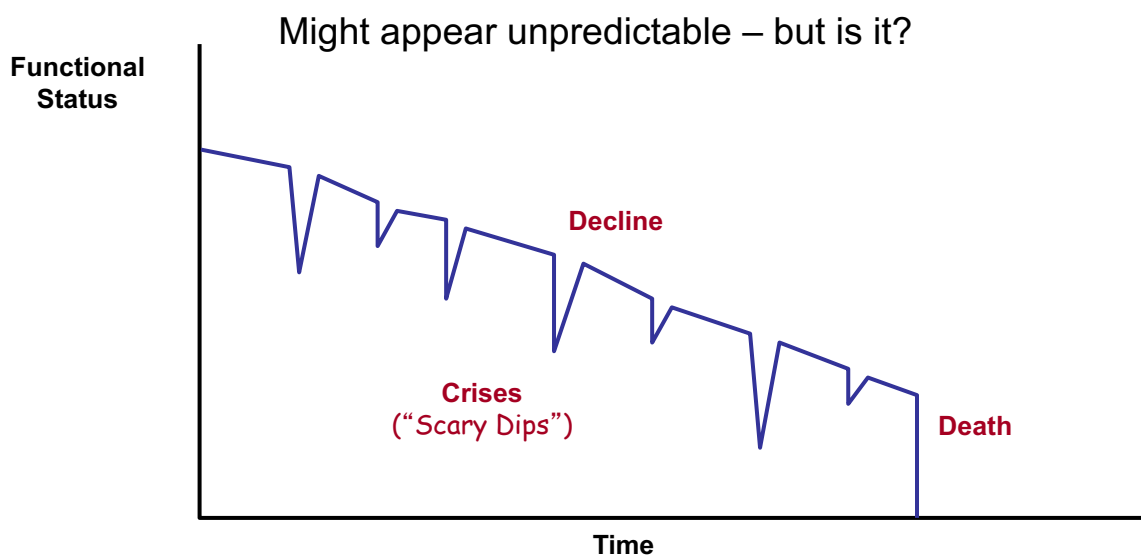
Most communication issues in palliative care relate to foreseeable challenges

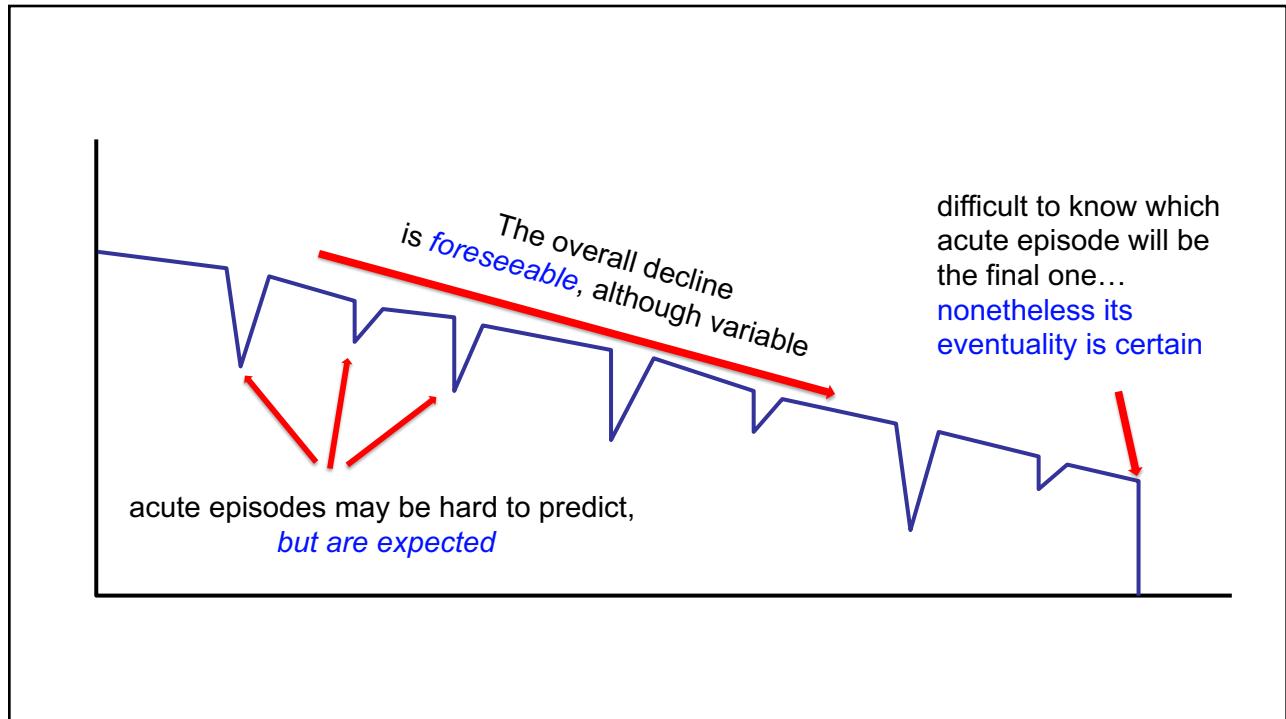
Foreseeable problems lend themselves to preemptive conversations

E.g.:

- Progressive weakness – challenges in mobility & care provision, risk of falls
- Challenges with intake – food, fluids, medications
- Increased sleepiness – concerns about contribution of medications to the decline
  - *“You might be wondering about...”*
  - *“In my experience people facing these decisions often wonder about...”*

### Non-Cancer Illnesses – An Overall Decline Punctuated By “Scary Dips”

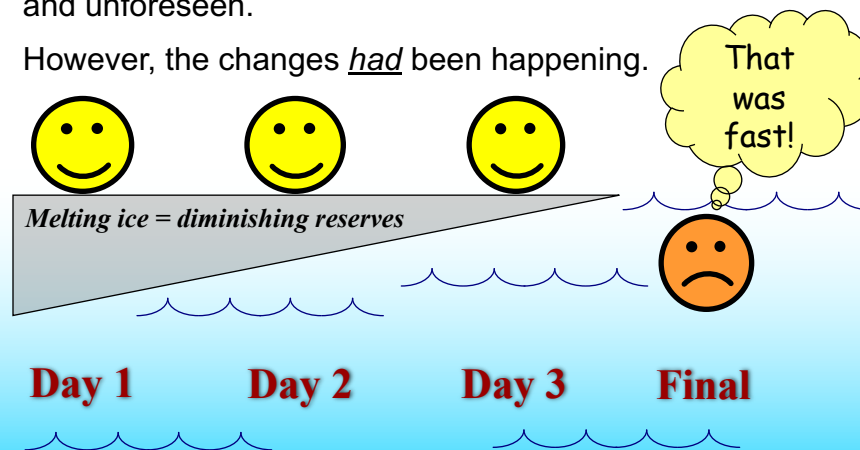




### The Perception of the “Sudden Change”

When reserves are depleted, the change seems sudden and unforeseen.

However, the changes *had* been happening.



## Need to Explore: How do you want to approach the next dip?

Often see one of 3 general approaches:

1. “Of course I want you to do everything you can to turn it around – it’s always worked before”
2. “I know I’m dying. I just want to be comfortable, and I want to die at home – *but...*  
I’d still like you to see if you can turn things around – give it a try and do what you can. If it doesn’t work, that’s OK – just keep me comfortable.”
3. “I don’t want anything unless it’s needed for my comfort. I don’t want any more tests, and nothing to make me live longer”

## Displacing the Decision Burden

*“If he could come to the bedside as healthy as he was a month ago, and look at the situation for himself now, what would he tell us to do?”*

**Or**

*“If you had in your pocket a note from him telling you that to do under these circumstances, what would it say?”*

## Life and Death Decisions?

- Families may feel as though they are being asked to decide *whether* their loved one lives or dies – i.e. to *choose* life/death
- It may help to remind them that the underlying illness itself is not survivable – no decision they make can change that

*“I know that you’re being asked to make some very difficult choices about care, and it must feel that you’re having to make life-and-death decisions. You must remember that this is not a survivable condition, and none of the choices that you make can change that outcome.*

*We know that his life is on a path towards dying... we are asking for guidance to help us choose the smoothest path, and one that reflects an approach consistent with what he would tell us to do.”*

## Goal-Focused Approach To Decisions

What are the goals? Whose goals are they?  
How and when will success in achieving those goals be assessed?

Things that work

**Goals achievable and consistent with standard of medical care**

- Proceed if desired by patient or substitute decision maker

Things that don't work

**Goals not achievable, or inconsistent with standard of medical care**

- Discuss; explain that the intervention will not be offered or attempted.
- If needed, provide a process for conflict resolution:
  - ❖ Mediated discussion
  - ❖ 2nd medical opinion
  - ❖ Ethics consultation
  - ❖ Transfer of care

Things that might work

**Uncertainty RE: Outcome**

- Consider therapeutic trial, with:
1. clearly-defined target outcomes
  2. agreed-upon time frame
  3. plan of action if ineffective

## The Temptation of Treatability

- In general, in progressive illness it's the complications – pneumonia; sepsis; bleeding; organ failure; etc. – that result in dying rather than the illness specifically
- People may say that “We understand that he will die from this cancer, but we can't just let him die from pneumonia – people don't die from pneumonia these days.”
- You can find yourself being drawn in by the “temptation of treatability”, trying to micromanage a dying process that would have otherwise unfolded naturally, predictably, and usually calmly

## The Illusion Of Treatability – CPR In Advanced Multisystem Failure

- Simplistically, there are two main circumstances under which the heart stops:
  1. a primary cardiac problem – e.g. ischemic event, arrhythmia
  2. overwhelming irreversible multisystem failure related to progressive illness – the heart simply can't keep going due to relentless physiological compromise
- CPR might be effective in the 1<sup>st</sup> of the above situations – if ideal circumstances
- In the 2<sup>nd</sup> of the above situations, unless you can reverse the underlying problems that resulted in cardiac arrest, CPR cannot work and *should not be offered as an option*
  - Rather, it can be acknowledged that while CPR is something that they may have heard about and are hoping for, it cannot work when the reasons that the heart has stopped can't be fixed. Consequently, it won't be attempted.



- Advance Care Plans or Health Care Directives serve as *starting* points for conversation in the context of a significant change in health status. They are not end-points dictating an approach that must be followed.
- E.g. imagine a patient with an overwhelming burden of multiple comorbidities, each life-limiting on its own:
  - 98 yo man from a Personal Care Home with advanced dementia, widely metastatic lung cancer (liver, bone, brain), renal failure
    - presents to Emerg with septic shock, massive intracerebral bleed, and an acute MI.
      - i.e. this is a very sick patient who is expected to die soon regardless of interventions

**Imagine he has a clear Health Care Directive for comfort-focused care only**

In spite of the clear and appropriate directive, there is still a need to ensure that the family and health care team have similar thoughts about what “comfort care” entails.

Some may consider IV fluids to be comfort, or have strong concerns about opioids – you won’t know unless you ask.

*“With everything going on, I’m afraid he will likely die within the next few hours. I see that you’ve talked about this kind of thing before, and that he would want an approach focusing on comfort – that’s very helpful.*

*To me, this would involve using medications related to morphine to help ease any pain or distress in breathing, and perhaps something to help with restlessness. We don’t need an intravenous for fluids or medications, and he doesn’t need oxygen administered or antibiotics to be comfortable. Is that approach similar to what you were thinking?”*

### **Imagine the same patient has Health Care Directive indicating CPR**

In spite of this directive, there is no obligation for the health care team to provide medical treatment that cannot possibly meet its physiologic goals. Survival of the inevitable cardiac arrest is not possible for this patient, and CPR should not be offered. This needs to be explained to family / substitute decision maker.

*“I’d like to talk to you about what’s happening and what we’re able to do. I see that his Health Care Directive indicates a hope for aggressive measures – specifically for CPR when his heart stops and he dies from these many serious conditions.*

*Unfortunately CPR can’t work when the heart has stopped due to the various body systems having shut down from problems that can’t be fixed. We’re not able to reverse the problems that we know will soon lead to his heart stopping – I wish we could.*

*We can make sure he’s comfortable, not having pain or other distress. We won’t attempting CPR once his heart stops. I wanted to be clear about that with you, and be sure that you are aware of that”*

## **Helping Families With The Physical Changes Often Seen At End Of Life**

- mottling, cyanosis
- breathing patterns: rapid shallow breathing; apneic episodes followed by deep gasping breaths; using accessory muscles
- loss of skin turgor; may seem to become rapidly thinner
  - distinguish between what is happening to the person’s physical body (“shell”) vs who that person is and what is being experienced
  - these changes are part of the normal and natural way that our bodies shut down; they cannot be changed by medications
  - continue to ensure comfort, and reassure family about that

## Common Questions – Consider Addressing These Preemptively

- “Can he hear us?” Sample answer:

*We can't really be sure about whether people can hear at this time, however we do know that hearing tends to be pretty resilient. For example, people given an anesthetic for surgery sometimes describe the last thing they were aware of is the noise in the operating room.*

*If it feels right to talk, tell stories, say important things, then we suggest that you do so. However, this also means to be respectful at the bedside of what is said – if there are arguments or other unpleasant conversations they should not take place at the bedside.*

*Some people might want time alone – we suggest you check with each other to see if that's the case*

- “How do we know he's comfortable?” Sample answer:

*When someone is no longer responsive it can be difficult to assess comfort. We look for the same signs of distress that we may have seen previously when we knew for sure that he was uncomfortable, perhaps with procedures or care. This might be grimacing in his face, or restlessness and moaning.*

*As his family, knowing him so well, there are things that you will notice that we might not. Together, we'll be his team to make sure that he remains comfortable.*

*We mostly go by how he appears overall. If his face seems calm rather than grimacing and he is not restless, he is likely comfortable. If there's anything you're seeing that concerns you about his comfort, please let us know*

- “What about water? I don’t want him to die of thirst” Sample answer:

*Thirst isn’t something that people in his condition can experience. We know that even when we are simply sleeping, we are not aware of being thirsty – it’s only when we wake up that we become aware of thirst. He is much more deeply unconscious than simple sleep, and we feel confident that he will not be sensing thirst.*

*The most important factor related to thirst at end of life seems to be a dry mouth rather than the amount of fluids the person is taking in. We will be providing mouth moisturizing products, and we can show you how to administer them to him as well.*

- “I don’t want to leave – I don’t want to miss being here when he dies. I promised him I would be here” Sample answer:

*It’s very understandable that you would want to be there. It isn’t always possible for us to predict a time when someone will die.*

*However, just because you weren’t present, doesn’t mean you were absent – not in thought, emotion, spirit.*

*Instead of thinking of “being there” as strictly being physically near, I wonder if it might make more sense to think about your connection in emotion, thought, spirit. This is not diminished by physical distance, and is perhaps the more meaningful presence at this time. Whether you were in the same room, or in the hallway, or in a different city, you were no less connected in your heart.*

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