

How To Be With Someone Who is Facing Death

*Terminal lung cancer hasn't changed who I am; I'm just the dying version of me. I'm remaining in character. In practical terms this means I'm still always learning and teaching. It would give me an all-body smile to know you're reading something that will help you be with someone who is dying. Starting from my closely held belief that there is no formula suitable for everyone, **here are my answers to the questions people have asked.** -- Dor Mullen*

1. What should I say or do?

Let your dying person set the tone.

What clues do you have to your dying person's priorities and values? This is your guide: If their brain is still working, my hunch is they will stay in character. Would they typically want to:

* talk sports * be touched * talk about pain and sorrow, relief or joy * let go * eat * listen to music * feel appreciated * avoid the subject * express love * do "bucket list" items * focus on pleasure * talk about what gives them a sense of purpose

Assume unless otherwise proven that your dying person will remain in character. Assume you will remain in character too. Support the dying person where he or she is. Let him or her set the tone; it's his turn.

2. How can I help? Red flags! Caution!

Think before offering help. Are you offering something you can deliver? It's tempting to comfort yourself in the moment by offering and not as easy to fulfill. Close that gap between what you offer and what you will deliver. For me, blanket statements like, "I'll do whatever you need," or "Ask me anything," sound like "I love you" or "I'm so sad". Nice to hear but hard to answer. I know how to respond to: "Can I bring chicken soup Thursday?"

3. How will I know if visiting is OK?

Does your dying person like visitors? Close care givers, if any, may help you decide. Know why you are visiting. Is it for your own comfort? This works if your dying person likes helping others and wants to support you. This works if your dying person also wants to say good-bye or share amends, or whatever is the mutual purpose. If you're not sure, let your dying person or close care givers take the lead. You could just write a note. I love notes. I reread them.

Some people use schedulers such as Caring Bridge patient websites to organize visiting and volunteering.

4. What if I'm bringing my own needs into the room?

Can your dying person handle your needs right now or does he or she need you to be with his or her needs? Are you there to manage your own anxiety? Process your own uncomfortable feelings? Is it possible to support everyone at the same time? Personally, I'm an inveterate care giver so I'm fine in the role of listener and mother confessor. That's not always the case. Back to #1.

5. Is this a good time to deal with unfinished business?

I'm certainly feeling the pressure to clean my heart, make amends, clear up unfinished business. I also want to be open to others who need to do the same, but I wouldn't be able to withstand somebody making me wrong or bad at this point. Back to #1, let your dying person set the tone. If you say, "I forgive you," for something they don't feel bad about, ouch! Probably all forms of, "You should have (could have, might have)" are bad.

6. What does a dying person like to hear?

I'm guessing we want to hear how we make a difference in your life, or what you'll remember us for (assuming we're in acceptance). But go back to #1: some people for personal or cultural reasons have a hard time accepting appreciation, or even the fact that they're terminal. Personally, I love end-game expressions of gratitude in all forms!

7. What if I say the wrong thing?

Back to #1. Let your dying person set the tone. For me, I'll be able to tell you are operating from a clean heart. If the best you can do is show up and awkwardly tell me that you don't know what to say, you get *full credit* for showing up. "I feel so sloppy. I'm scared. I don't know what to say to you," sounds like "I love you," to me; another person might just want touch or to be read a favorite passage.

8. Is it OK to ask for help directing the conversation?

For me, yes! Go back to #1. Assuming that your dying person acknowledges his or her terminal situation, you can ask questions like, "Is it OK for me to talk about what you want to happen with Fido," or "do you want help selecting the music for your memorial service?"

9. What are common mistakes?

Making assumptions.

What I want you to know about me is I'm not scared of death. I can help you with your fears and would enjoy that, but I'm not scared of anything but too much pain. I would love to be asked how I would like my final days to go. I need people to stay curious, not act on bad assumptions about how I feel or what I need.

Using language that tells a dying person how they feel based on what you're feeling

Does your language project your feelings onto your dying person, who may be feeling something completely different? If *you're* sad, say so. If *you're*, petrified, admit to your feelings. If you use phrases like "You're strong; you can beat this," "at this difficult time," or "you must take comfort in knowing..." you are projecting your own uncomfortable feelings on a dying person who may feel relieved, joyful or even sublime. Start with neutral language that doesn't put feelings onto a person. I can love everybody for trying, but this is probably the most common and annoying mistake people make around me.

I invited my hospice doctor to comment on messages he hears that just don't help his patients. Top of the list: "You can fight this." Next: "You'll be OK." A person who has agreed to hospice care is at a higher level of acceptance and needs loved ones to accept loss too.

Talking too much.

Sometimes touch or listening to a story or music, or simply sitting still is a completing experience.

Pressing someone to eat, treat, medicate or do something.

My hunch is people who enjoy self-determining will continue to want to make up their own minds and people who take direction will still take direction if their brains are still working. (#1 again.) For me personally, pressing me to do something is the worst offense. Nature prepares us beautifully for death. If my twitching, writhing or moaning make you uncomfortable, we shouldn't be together. These things are very comforting for me, not a sign that I'm suffering but a sign that my body is managing the pain. I expect to stop eating when I get the signal from my body that it's time to let go; I don't want anyone encouraging me to eat. I will ask for morphine if I need it, as long as my brain is still working.

My hospice nurses report seeing loved ones press a dying person to eat: placing food in the mouth of an unresponsive person, leaving a feeding tube in a person whose brain is more tumor than brain. In my mind, pressing nourishment on a dying person is another way for loved ones to not deal with reality and to soothe themselves instead of the soothing the dying one.

Doing things they could do themselves.

For me, this is unwanted. It's infantilizing.

10. How can I protect myself?

Don't take anything personal. Us dying people can be cranky, smelly, demanding, irritable, uncomfortable, demented, or angry. Or meek, poised, sweet, or weak. If you're a visitor, you get full credit for showing up. You get full credit if being together is too much and you leave a note. If you're a care giver, ask for help. We should write a document on how to support care givers too.

11. Is silence good?

Sure! Sometimes. Go back to #1. Personally, I want all visitors to place their hand on my chest. You'll be within an inch of my heart and my tumor.

12. What about when the end is near, there's greater weakness, less communication?

Assume unless proven otherwise your dying person can still hear and is aware of what's happening in the room. Personally, I've put up a sign telling people to look for signs that I'm trying to communicate, the press of a finger, a blink.

13. What's a good read?

Atul Gawande: *Being Mortal*. It poses the question: What's a good day? How will we know if you want more time and treatment? The answer might be for one person: "life is worth living if I can eat ice cream and watch football." That's not what I'd want, but you get the idea.

Naomi Feil: *Validation Therapy*, if you're dealing with someone who has dementia or Alzheimer's. This made me a wanted and comforting visitor for a loved one through advancing Alzheimer's.

Final Note

In hard times, I observe, we remain intensely in character. The runners run. The hiders hide. The cooks bring food. The prayers pray. And the pushy people assert themselves. To the extent that someone's dying is stressful for loved ones, we may expect people to do more of what they're already good at, regardless of the need. It's on you – the visitor – to allow the dying person to set the tone.