



What Do I Say?

By: CVH Team

You may be nervous about talking to someone who is not expected to live much longer. The big question is often whether to be up front and talk about the illness or try to ignore it. The best advice is to be yourself. Be open to talking about whatever the person brings into the discussion. Trying to ignore the illness altogether is probably going to feel awkward, but not every conversation needs to be about the illness or its progression. Most people will provide cues as to what they're comfortable talking about.

Fear of saying the wrong thing

Although people worry they will say the wrong thing and upset the person, there really are no special words for talking to people who are seriously ill. There is nothing wrong with talking about your day, a movie you've seen, or even the apples that are on sale at the corner store. If you restrict yourself to subjects that seem important enough to mention, you may never say anything at all.

Think about what you would have talked about together before the person was diagnosed with illness and start from there. If that doesn't help, try starting out with "I'm really sorry you have to go through this." Likely, feelings of discomfort about what to say will fade as you spend more time with the person.

In an effort to protect the person who is ill, people may hesitate to talk about the seriousness of the illness. Although shielding the person from sadness or worry may seem like a good idea, avoiding the topic of the illness may make the person feel isolated and lonely. If the person is raising fears about the future, acknowledge those fears and encourage discussion. Instead of changing the subject or telling someone not to worry, you might say "Tell me more about that," to open up discussion.

Couples sometimes protect each other from their worries, trying not to add to each other's burden. In a close relationship, however, the two people probably have similar concerns about what will happen when the other is gone, and find great relief in knowing they are going through similar emotional challenges. Instead of burdening each other, they may find that through open discussion, they are able to support each other.

Even though people should try to be themselves at the person's bedside, there is still a need to be sensitive to the difficulties the person is facing. Certain discussions may be better held away from the person's bedside. For example, there may be tension among family members as they try to sort out what the person's death will mean to them, or what life will be like after the person is gone. If family members are arguing or strongly disagreeing with each other about an issue, you might consider holding these discussions out of reach of the person's hearing, since they may add unnecessary stress to the person's life.

However, if your family has always held intense discussions when you get together, changing your normal pattern may leave the person feeling left out or more isolated. A good thing to do is check with the person. You might say something like "We're talking about some pretty intense feelings. We don't want to burden you with this, but at the same time, we don't want to exclude you if you want to participate." Deciding when to include the person who is ill is a bit of a balancing act because difficult discussions may require a lot of the person's energy.

Listening carefully

People tend to lead conversation away from subjects that make them uncomfortable. Let the person control where the conversation is heading and recognize the hints they may give that signal they no

longer want to talk. They may say things such as "I'm feeling tired," or "I think I'd like to rest now." Not everyone will be able to put their experience with illness into words, and people who seem hesitant to explore their feelings should not be pushed into doing so.

Visitors who can't make sense of what the person says may want to share the words that have been spoken with other family members or friends. Family and friends can sometimes find significance in what the person has said, and these words may come to hold great meaning later.

Someone who is nearing the end of their life may want to talk about what they've seen or accomplished over a lifetime. Listening carefully sends a message to the person that their words still hold value and that people still care about them. Sometimes the person's words or meaning are not clear, and it's alright to say something like "I'm trying to understand, but I'm having trouble right now," so that the person knows you are taking care to listen. If the person is becoming frustrated because you cannot understand, family and friends can help by offering to bring up the subject again later, when things might become more clear.

Sometimes people who are ill may make comments about things they see in the room that are not really there. They may talk about what they are seeing or even speak to their <u>hallucinations</u>. If the person is not upset by the hallucinations, there is no need to abruptly correct them or point out there is nothing there.

Sometimes people who are very near death make reference to people who have previously died, saying things such as "My father is waiting for me." In such cases, it is helpful to acknowledge this with supportive words rather than doubting or questioning the person. It is important, however, to tell the health care team if you notice that the person is becoming confused, since confusion can sometimes be helped with treatment.

See also: Confusion

Providing reassurance

People commonly experience confusion as serious illnesses progress. Clocks or calendars can be brought in to help a person remember what day and time it is, but the person may still be unsure of where they are or who visitors are, even if those visitors are sons and daughters or life-long partners. This can be very difficult for family members and close friends -- it may feel as though you have already lost the person, even before they have died. If you can manage it, try to calmly reassure the person that everything is alright. You can continue to provide support to the person and take part in conversation, even without being recognized.

Visitors can often be alerted to how a person may be feeling by watching the person's face or body language. If the person seems anxious or in other ways uncomfortable, there is no need to wait for the person to put that anxiety into words before offering gentle reassurance or acknowledgement. "How are you doing? You seem different today," might be one way to approach a person who seems stressed and in need of support.

Sometimes people who are nearing death seem to want reassurance that it is okay for them to die. "It's okay, you can go now," or "We are going to miss you terribly, but we will be alright" are words that may lead to a sense of calm or acceptance in the person who is dying.

People who have been interviewed about dying sometimes say they feel they cannot die – not while a family member is still convinced they will come home one day. Sometimes the dying person may feel that they are the glue holding the family together. Letting them know that the family will continue to stay together can provide needed reassurance and a sense of peace. If the health care team says that death is very near, but the person seems to be hanging on, you might consider providing reassurance that it is alright for them to die.

In the hours before death, the person may be no longer conscious. Family and friends should feel free to speak to the dying person in any case. No one can be sure whether the words will be heard or not, but even the act of speaking them can provide comfort to family and friends who wish to say goodbye.

See also: Living with Limited Time: Exploring Feelings; Rituals for Patients and Families as well as Rituals to Comfort Families

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