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PERSONAL HEALTH

## Art and Grace, When It's Time to Say Goodbye

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The end of life has become an alien experience for those of us living in countries where most people spend their final days in institutional settings. As a result, conversing with people fast approaching the end of life is foreign for many people, who may be reluctant to visit dying friends or relatives because they do not know what to say or do.

There is no better time to learn than now, when more and more people are dying of protracted illnesses in hospitals, nursing homes, hospices and, increasingly, at home with hospice care. While physicians may do an excellent job treating potentially curable illnesses, after modern medicine has no further treatment to offer, they often become tongue-tied and may even abandon their patients, leaving the task of emotional support to friends and family.

In his helpful book "I Don't Know What to Say: How to Help and Support Someone Who Is Dying" (Vintage, 1992), Dr. Robert Buckman, a medical oncologist at the University of Toronto, wrote, "One of the biggest problems faced by terminally ill patients is that people won't talk to them, and the feelings of isolation add a great deal to their burden." Talking and listening to a dying person can help relieve the patient's and the visitor's distress, fears and guilt.

Dr. Buckman, who practices at the Toronto-Sunnybrook Regional Cancer Center, reassures those who are concerned that talking about dying will create new fears and anxieties. "In fact," he says, "the opposite is true: not talking about a fear makes it bigger. Those patients with no one to talk to have a higher incidence of anxiety and depression. Bottled-up feelings may also cause shame. Many people are ashamed of their fears and anxieties."

Keep in mind, too, that dying is a lonely experience. Many people are more afraid of dying alone than they are of death itself. By knowing how to act and what to say when visiting a dying person, you can bring caring and comfort that eases the person's passage over this most momentous threshold.

Patients often take their cues from their visitors. If meaningful discourse is to occur, the

visitor has to be a good listener. Take off the coat, try to relax, sit down at eye level with the patient, if possible, and as close as you would to a healthy friend. Remove obstacles that create distance or block eye contact. If touching and kissing were appropriate before the person became ill, they are fine now, too.

If you deliver a monologue about what you are doing or what is happening to mutual friends and relatives, you immediately convey the impression that you are not interested in the patient's concerns. Instead, focus on the patient. Try to determine whether the patient wants to talk and what about, perhaps by saying, "Do you feel like talking?"

You might ask, "How are you feeling today?" or, "What can I get you?" or, "Can I make you more comfortable?"

### **Offering Encouragement**

Let the patient take the lead in talking about difficult topics and deep concerns, and encourage continued conversation by saying something like, "Yes, I understand," or, "Tell me more," or reflecting back to the patient what you heard.

If the patient starts talking about how bad things are or says he knows that he is dying, do not contradict him or change the subject. Instead, you might ask: "How can I help? Are there things you'd like to say or matters that worry you?"

Do not be afraid to say that you do not know what to say and do not become disturbed by lulls in the conversation. Often just being there and staying close says enough.

Avoid giving advice, unless it is asked for. Do not regale the patient with tales of patients you heard about who were saved by a particular doctor or took an alternative remedy and experienced a miraculous cure. If there really were miracles out there, they would be in use at every major medical center. And do not try to compare the patient's experience with that of anyone else.

If there were enjoyable experiences you once shared with the patient, you might reminisce about them, even if it makes you and the patient sad to realize they will never happen again. It is, after all, O.K. to cry when someone you love is dying.

It is also O.K. to laugh, if there are things that you both find amusing. Humor can lighten the patient's emotional and physical burden by putting things in perspective and raising the pain threshold.

### **Expect Fallout**

Dr. Buckman points out that, like those in mourning, people who are dying are likely to pass back and forth through a series of emotional states, including denial, anger and acceptance. Although some patients — often those who are deeply religious and believe in an afterlife — readily accept the end of life with grace and equanimity, others may, as

Dylan Thomas suggested, "Rage, rage against the dying of the light."

Anger is often the hardest stage to deal with for those close to the patient, for anger is often misplaced. As Dr. Buckman put it, "When somebody in your family or circle is facing a serious illness and death, the anger that she feels might really be directed at the illness; it comes out directed at you because you are the only person around. If you are aware of the fact that the anger isn't meant for you personally, then you might be able to respond in a way different from the typical family-argument style."

If, for example, the patient says, "I feel dreadful, and you're no help," instead of rising to the bait with, "This is no picnic, you know," or even, "I'm doing my best," (which might prompt a reply, "Well, that's not good enough"), you could respond with, "How bad do you feel?" or, "What's bothering you the most?"

You, the future survivor, may also experience anger. You may be angry about the disruption in your life, the anticipated loss of your companion or support system or the seeming unjustness of the illness. In such cases, the patient may become the target of your anger. Because that is of no help to either of you, it is best to find a sympathetic soul who will talk things through with you. By recognizing the cause of your anger, you may be able to dissipate or at least redirect your angry feelings.

Some terminally ill patients remain in denial to their dying day. They may ask repeatedly, "I'm getting better, aren't I?" or "When can I get out of here?"

There is little to be gained by agreeing with such optimistic thoughts or directly refuting them. You might respond with a vague, "Let's hope so," or try gently to redirect the patient's thinking by asking, "What have the doctors told you?" or: "What if you don't get better? Should we make some plans just in case?"

Finally, you may be faced with a patient in despair who has lost all hope. Avoid making promises that cannot be kept, like, "Surely you'll feel better tomorrow." Instead, try to counter despair by reassuring the patients that everything possible will be done to assure their comfort, including relief of pain, and that no matter how bad things get, you will always be there.