



# Caring for the Terminally Ill

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When faced with the news that a family member has been diagnosed with a terminal illness, many people worry about what they should say and do. They want to help, but often don't because they are afraid they will say or do something that will further upset the loved one.

Dying persons have the same physical, emotional, and spiritual needs as everyone else. In addition to the typical needs, persons who are dying often fear "great pain, loneliness, depression and meaninglessness" (Staten, Shuy, & Byock, 2001, p. 173). What they need most of all is to be cared about, not just cared for.

Some of the terminally ill person's needs are special; they can only be met by individuals with special expertise. For example, prescriptions for pain medication must be written by a physician. However, many of the dying person's needs can be met by family members and friends.

It is important to be familiar with the various ways in which we can help those who are dying. Even when we cannot do something specific, all of us can listen to and be with the dying person and his or her family.

There are four "primary dimensions of care for those who are coping with dying: physical, psychological, social, and spiritual" (Saunders, 1967; Woodson, 1976 as cited in Corr, Nabe & Corr, 1997, p. 172). Each is described here. While the information applies directly to the dying person, it is also relevant to others who are coping with dying—the family members, friends, and associates of the dying person, as well as professional and volunteer caregivers.

## Physical Care

One of the biggest concerns of dying persons is the control of acute and chronic physical pain. Other symptoms that may be as distressing or even more so than the physical pain include constipation, diarrhea, nausea, vomiting, weakness, loss of appetite, shortness of breath, and dehydration. Those who place a high value on self-image

may be concerned about hair loss, dark circles around their eyes, and changes in their skin color. Effective care must address all of the dying person's physical symptoms. Physicians can help with pain management, while family members and other caregivers can be trained to provide physical care that will help them be more comfortable.

## Psychological Care

It is important to take seriously what dying persons are feeling. They are likely to express negative feelings including anger, sadness, anxiety, and fear. Their emotions are real, and they need to be identified, acknowledged, and expressed. When faced with these, many would-be helpers are uncomfortable, and they wonder what they should say and do. Unfortunately, there is no universal right thing to say or do; however, several things seem to be helpful. Some include being present, speaking the truth, and listening actively.

A gentle touch is often psychologically healing. Many dying persons are comforted when caregivers gently touch their wrist or arm, hold their hand, or hug them.

In his book *Head First*, Norman Cousins documents many research investigations that show how hope provides positive effects in dealing with sickness and terminal illness. The book provides convincing support for a link between a patient's strong confidence and beneficial physiological effects. Cousins tells of how he encourages patients to mobilize all their spiritual, emotional, intellectual, and physical resources to fight back. He shows patients how positive expectations can pull them in that direction physically.

## Social Care

Dying persons want to maintain relationships with the special people in their lives. They may be concerned about their roles within the family, in the work force, and in the community. Many worry about who will care for and sup-

port their survivors, who will continue their special project at work, and what will happen to their possessions.

They may want to take care of some very practical issues—like arranging their funeral, telling their spouse how to do the chores, organizing or passing down their material goods, and talking about the well-being of their loved ones in the future, for example, encouraging their spouse to pursue new relationships and not remain alone (Goldsteen et al., 2006, p. 382). Providing help with “any uncompleted tasks can be part of the assistance dying persons welcome” (Staten, Shuy, & Byock, 2001, p. 260).

Caregivers can help by allowing the individual to talk about his or her concerns, to think about options and ways to fulfill needs, and then by being an advocate for them. It is important to note that it is disempowering when caregivers take over the work of the dying person. It is sufficient to be present and to serve as a sounding board so that the individual can recognize options and think about ways to fulfill needs. Social workers, family therapists, counselors, and lawyers may also be of help with social concerns.

## Spiritual Care

Has my life made a difference? What is the meaning of life—to me, to those closest to me, and in the large order of things? Have I accomplished my goals? What will happen to me after death? Dying persons look for “a connection or continuity with some aspect of existence beyond the death of the body” (Staten, Shuy, & Byock, 2001, p. 239).

Dying persons “search for some tangible evidence of continuity with ongoing life after their own death. The implied question—‘Will something that I valued and cared about most in this world continue to exist and to be valued, after I’m gone?’” (Staten, Shuy, & Byock, 2001, p. 255). Reassurance may come through passing their prized possessions on to loved ones, receiving assurance that their life’s work will continue, seeing qualities of themselves in their offspring, and connecting to a transcendent realm.

Dying persons often bring up issues that are spiritual in nature. When they ask these questions out loud, they usually are not interested in our response, but rather, are articulating issues that are on their own minds. They verbalize the issues as a way of developing their own thinking. It is important for dying persons to work out their own answers to their questions.

Again, it is usually helpful for someone to be present, to be empathic, and to listen. It is beneficial to affirm that the dying one’s life has been and continues to be meaningful to others. Providing creative opportunities in music, literature, drama, visual arts, dance, nature, and other arts can be an important way of helping individuals with spiritual tasks.

## Enjoying the Time that Remains

What many dying persons want most is to participate in ordinary daily activities. “Being able to eat with someone; to walk to the bathroom and use it in private, unaided; to talk with a friend; to watch a favorite TV show; to hold a grandchild—these mundane activities of daily living at the end of life” (Staten, Shuy, & Byock, 2001, pp. 135–136) become important. The dying take comfort in eating their favorite foods, listening to their best-liked music, going for a ride to see cherished places, or simply watching the changes of nature through a window.

## Summary

Even though many feel uncomfortable and ill-qualified to say and do things that will enhance the quality of life of those who are dying, through attention to the specific physical, psychological, social, and spiritual needs of the patient, caregivers can support the terminally ill.

Just because an issue has been dealt with once does not mean that it is now settled. The questions and issues are likely to be raised again. There will always be more questions, needs, desires, and fears. Caregivers need to be ready to listen to the cares of the moment.

## References

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August 2007—3445