Chapter 7
Emotions, Spirituality and the Tasks of Dying
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Treating the Whole Person, Not Just the Illness

Physicians have a responsibility to treat each patient as a whole person. Symptoms of pain and physical distress can be largely relieved as outlined earlier. Addressing psychosocial and spiritual needs can be more challenging.

As death approaches, patients’ personal projects and social responsibilities have to be reconsidered. Depending on their individual situations, dying patients are likely to feel some frustration, sadness and perhaps anger at the way things turned out. And, depending on how much they value independence, they may fear—and be angry about—losing control over the ability to care for themselves or becoming dependent on others.

The end of life also brings a loss of relationships with others. Those surviving will be permanently changed. Family members, friends and physicians all may feel a mixture of anxiety, love, sadness and anger. Everyone involved needs to be sensitive to their own emotions and the emotional and spiritual needs of the others.

Focus on Living to the Fullest

Once the team of patient, family, physician and other health care professionals accept that death will occur in the foreseeable future, they are free to concentrate together on living fully until death occurs. Physicians can assure that any new medical treatments or procedures are designed to help the patient find comfort and peace.

Patients should be encouraged to concentrate on tasks they want to complete in the time they have left. Some may be mechanical, such as updating or completing a will or a durable power of attorney for health care. Some may be spiritual, such as finding and making peace with oneself or one’s god, and may require the assistance of clergy. Other tasks involve resolving old personal and emotional issues, hurts and animosities. This includes asking for and receiving forgiveness from oneself or others.

Depending on a patient’s comfort and strength, visits can be made to favorite places and friends to reminisce, give thanks and say good-bye. A written, audio or videotaped record can be created as a permanent legacy that contains statements of the dying patient’s values and lessons learned in life and while dying. Team members also may want to develop some unique practices and rituals, like setting times together to reminisce, laugh and cry, or share meditation or prayer.

The Physician’s Role

Physicians have multiple responsibilities in caring for a patient at the end of life. They must treat the whole person, not just the disease. It is critical that physicians assess their patients’ spiritual and emotional needs. These needs are important in their own right, and may contribute to physical symptoms as well. Physicians need not manage all of their patients’ psychosocial and spiritual needs themselves; they can call on hospice and other professionals for help.
Healthy Grieving

Healthy grieving is a long and complex process of emotional and spiritual recovery following the death of a loved one. It is best to begin the process before death. Healthy grieving begins when the entire team of patient, family, physician and other health care professionals work together to prepare for death.

In varying degrees, everyone involved with caring for a dying patient faces a spiritual crisis of personal redefinition and the need to grieve. The dying patient is challenged to find meaning in life and redefine his or her goals as death approaches. The family is challenged to begin to consider life without a loved one. The physician needs to grieve the impending loss of a patient whom he or she may have tried valiantly to save and who also may be a friend.

For families and friends, there are no shortcuts through the pain of loss and on to renewed emotional and spiritual health. Healthy grieving requires recognizing appropriate feelings of sadness and loneliness. For families that use them, hospices provide assistance with grieving for at least 13 months after the death of a loved one.

The same techniques that were useful for dealing with emotions surrounding approaching death also can help with healthy grieving. Visiting favorite places, reminiscing with friends, meditation and prayer can facilitate the grieving process. New rituals and ceremonies might be beneficial, such as having an imaginary conversation with the person who died and establishing memorial celebrations of the loved one’s life on important anniversaries.

While it may not seem possible at the time of death, families will eventually find new meaning in life and be able to have fun and laugh again.

Physicians also need ways to process their grief. Depending on the circumstances, a physician can grieve a patient’s death in a healthy manner by calling family members or sending them a note to express condolences, attending the visitation, funeral or memorial service.

Emotional Response to a Terminal Illness

After learning of a terminal illness and then dealing with its reality, patients tend to experience a range of emotions. It is important to ask how they are responding to the illness. Help them name their emotions—common ones include:

- Anger
- Grief
- Depression
- Fear

Actively listen to and acknowledge patients’ feelings. This normalizes their experiences and allows them to move toward acceptance.

Nearly all patients have fears as they near the end of life. These fears are important to recognize. They include:

- Loss of control
- Loss of dignity
- Loss of relationships
- Physical suffering
Assessing the Spiritual Needs of the Patient

Most people have some spiritual component to their lives. For some, spirituality may play an important role in daily activities. For others, spirituality is not readily apparent, but is nonetheless important. It is valuable to determine a patient’s individual interpretation of spirituality. Spirituality is not always about “organized” religion—it really is about what gives meaning to life for an individual.

Christina Puchalski, MD, has designed a short spiritual history that can be used to assess a patient’s spirituality and related needs.

Taking a Spiritual History

1. Consider spirituality as a potentially important component of every patient’s physical well-being and mental health.

2. Address spirituality at each complete physical exam and continue addressing it at follow-up visits if appropriate. In patient care, spirituality is an ongoing issue.

3. Respect a patient’s privacy regarding spiritual beliefs. Don’t impose your beliefs on others.

4. Make referrals to chaplains, spiritual directors or community resources as appropriate.

Spiritual Assessment Tool

The acronym FICA can be used to help remember what to ask in a spiritual history:

F: Faith or beliefs
I: Importance and influence
C: Community
A: Address issues

Some specific questions you can use to discuss these issues are:

F: What is your faith or belief?
   Do you consider yourself spiritual or religious?
   What things do you believe in that give meaning to your life?

I: Is spirituality important in your life?
   What influence does it have on how you take care of yourself?
   How have your beliefs influenced your behavior during this illness?
   What role do your beliefs play in regaining your health?

C: Are you part of a spiritual or religious community? If yes, is this of support to you, and how?
   Is there a person or group of people you really love who are important to you now?

A: How would you like me to address these issues in your health care?

Source: Spirituality Assessment Tool, © 1999 by Christina Puchalski, MD. Reprinted by permission of the author.
Emotions and Spirituality Resources

Whole Person Care

- www.dyingwell.org—Dying Well is a website sponsored by Ira Byock, MD, a long-time palliative care physician and an advocate for improved end-of-life care. The site includes resources for people facing life-limiting illness, their families and their professional caregivers.

Spirituality

- Daniel P. Sulmasy. Spiritual Issues in the Care of Dying Patients: ...It’s Okay Between Me and God”. JAMA, Sep 2006; 296: 1385 - 1392.
- www.gwish.org—The George Washington Institute for Spirituality and Health supports clinical issues related to spirituality and health through research, education and policy work focused on bringing increased attention to the spiritual needs of patients, families and health care professionals.

Physician Self-Care

- Michael K. Kearney; Radhule B. Weininger; Mary L. S. Vachon; Richard L. Harrison; Balfour M. Mount. Self-care of Physicians Caring for Patients at the End of Life: “Being Connected...A Key to My Survival” JAMA.
- www.meaninginmedicine.org—Finding Meaning in Medicine offers the opportunity to speak openly with colleagues and to receive a level of support, understanding and insight that is unique to a physician group.
Finding Meaning in Your Life

People have found many ways to give meaning to their experiences at the end of life. Examples of things others have done to heal emotionally and grow spiritually are listed below.

Centering Yourself

There are many ways to center yourself and your thoughts, to quiet your mind and to see yourself as part of the whole world around you. You might ask a hospice or hospital chaplain or a social worker to help you find ways to meditate and reflect on your life. Talk with your spiritual leader about the benefits of prayer.

Gathering

Getting together with people you love and who are important to you can be very satisfying to you and to them. Organize a party and invite family and friends to share memories and stories. Such gatherings can be surprisingly happy and can give you a chance to say good-bye to people you have loved and enjoyed being with.

Giving

Some cultures prefer gift giving. Native Americans, for instance, give valuable keepsakes to signify the end of life. This activity allows the giver to show appreciation for the relationship shared with someone else.

Creating

You can give more than your material treasures to those you love. Making an audio or video tape of stories or memories—sharing your experiences with family members and friends—is a wonderful gift to you and your family. Discuss your values, hopes, insights, beliefs and wisdom, or just tell your story. This becomes both a cherished reminder of you and a way to continue your good will. A special photo album or a scrapbook also can help create memories of times you shared. Some people write letters to those who will survive them, particularly parents to their children.
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Dedicated to Isabelle and all other patients who died in pain.

To order additional copies

Send your request to Michigan State Medical Society, 120 W. Saginaw, East Lansing, Michigan 48823, fax us at 517-337-2490, or call us at 517-337-1351. Download the booklet at www.msms.org/endoflife.