

# Caregiving At the End of Life

Your role as a caregiver at the end of life is a complex one. You may observe your loved one going through physical, emotional, social and spiritual changes that are stressful and difficult for you as well.

Ask a member of your health care team to guide you in understanding the changes you see your loved one going through. Hospice programs are available to help prepare and comfort both the ill person and his or her caregivers. Your most important role is to provide comfort and support for your loved one.

**When someone you care for is at the end of life, here are some important things to consider.**

**Allow expression of emotion.** It is important to let the ill person express the full range of emotions he or she is experiencing. You may at times hear expressions of fear or sadness, particularly regarding death and pain. Your loved one may also fear separation from family or leaving behind unfinished tasks or responsibilities. Some of these emotions will be hard to listen to, but your presence and courage to listen will prevent feelings of loneliness or isolation.



It's possible that your loved one may experience visions of people, events or objects not visible to you. This may be an aspect of the pictures we carry in our memories. Your loved one may find these experiences soothing. If he or she is not distressed or made anxious by these images, there is no need for concern. If the person is upset by these images, your health care team can help you with ways to manage this issue.

**Attend to spiritual needs.** People who are at the end of life often have questions related to spiritual healing, the meaning of life, guilt and forgiveness, death, the afterlife, and their relationship with God or a spiritual entity. At times, your loved one may feel angry and abandoned by his or her faith or belief system. Other times, the person may embrace faith more intensely than before. Be patient and understanding if disagreements arise. For some, the assistance of a pastor or clergy person can be helpful.

**Accept help.** A home health aide or home attendant can assist you in the practical aspects of caring for someone at this time of life. Hospice programs, visiting nurse agencies, your health care team, and organizations such as CancerCare often have trained professional counselors to provide you with additional support. Telephone and online support group programs can give you a chance to talk with people going through similar experiences without having to leave your caregiving responsibilities.

**Don't forget humor.** Resist the idea that you need to be somber or solemn around your loved one. Doing so would ignore the richness, warmth, and other unique qualities that define your relationship.

**Understand silences and withdrawal.** People at the end of life may communicate less frequently or be less involved in the activities around them. This is not a sign of depression or rejection. It is normal for a person to become less engaged with family and friends at this stage.

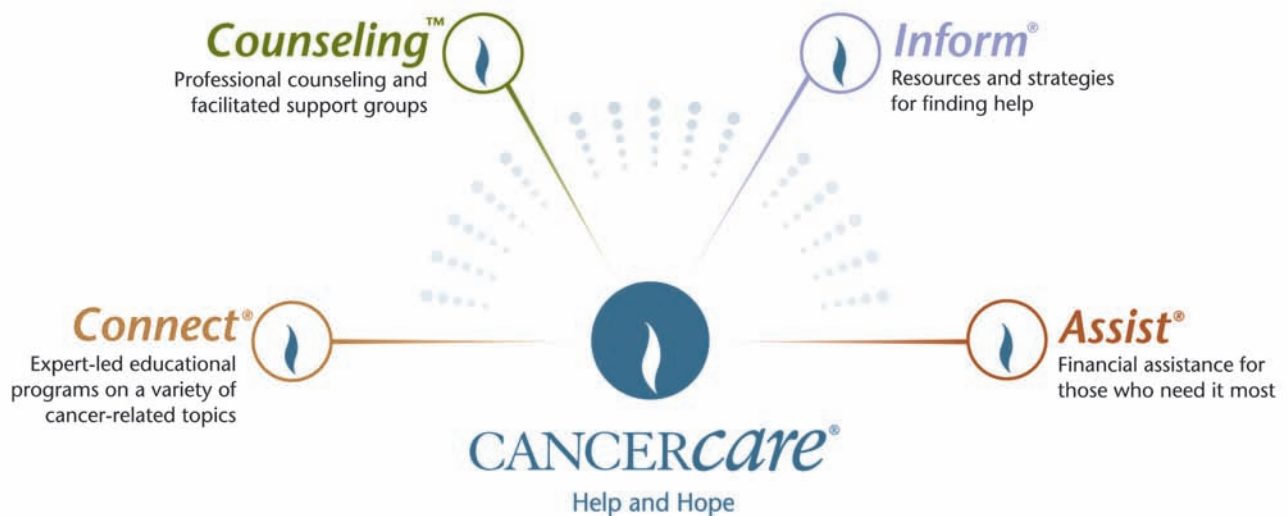
**Create a peaceful atmosphere.** When words are not enough to communicate how you feel, create a peaceful environment. You might play soft music or light scents, but avoid lighting candles or flames if using oxygen. In general, surround your loved one with your presence. Physical touch and reassurance can be powerful. Keep the person warm, clean and comfortable.

**Continue communication.** Keep in mind that your loved one's voice may weaken. He or she may talk less and avoid longer conversations. Continue to assume the person is still able to hear, even if he or she does not seem alert. Often, individuals are still aware of what is going on around them even if their eyes are closed.

**Expect a diminished appetite.** Providing food and nourishment is a basic way we show love and affection. As cancer progresses, your loved one's need for food can diminish. He or she may become unable or unwilling to eat or drink, and sometimes, a seriously ill person can choke on food or liquids. Your health care team can help you understand the best way to respond to your loved one's diminished appetite.

Caregiving at the end of life involves much more than the practical tasks of helping a person with cancer. It's also about how we communicate our love and commitment to the individual in verbal and non-verbal ways. It's about "tuning in" to the unique needs and experiences of your loved one and promoting an atmosphere of peaceful acceptance. This provides the person with the support he or she needs at this time.

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