



CANCERcare®

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fact sheet

CAREGIVING AT THE END OF LIFE

Caregiving at the end of life involves much more than the practical tasks of helping a person with cancer. It's also about letting your loved one know, through your words and actions, of your love and commitment. It's about promoting an atmosphere of peaceful acceptance. Your role as a caregiver is a challenging one. You will need support, too, as you do the important work of comforting and supporting your loved one through this difficult time.

HERE ARE SOME THINGS TO CONSIDER WHEN YOU ARE CARING FOR SOMEONE WHO IS NEAR THE END OF LIFE:

Create a peaceful atmosphere. Sometimes words are unnecessary. Keep your loved one warm, clean and comfortable. Play soft music, as hearing is thought to be the last sense.

Expect an altered appetite. Your loved one may decline food or be unable to eat or drink. Talk with the health care team about the best way to respond to changes in your loved one's appetite.

Understand silences. Keep in mind that your loved one's voice may weaken. They may talk less and avoid long conversations. This is normal as the end of life nears.

Be a good listener. Your loved one may speak of sadness and fear of pain or death. Your presence and courage to listen will lessen your loved one's anxiety and fear.



Attend to spiritual needs. Many people find support from a pastor or clergy person helpful in coping with these issues.

Don't forget humor. If your loved one has always enjoyed humor, don't think that you need to only be somber or solemn around them now.

Look after yourself. Being a caregiver requires strength and stamina. You need to care for yourself so that you can give your loved one the support and care they need.

Get help with practical tasks. A hospice nurse or home health aide can assist with the practical aspects of care.

EMOTIONAL CARE

As the primary caregiver, it will be up to you and the health care team to make sure that all of your loved one's needs are met.

- Encourage your loved one to make as many decisions as they can to maintain control in their life. As long as they are making safe decisions, let your loved one have the final say. For example, listen to their wishes about the following:
 - Pain control versus alertness
 - Number and frequency of visitors
 - Daily activities
 - Type of food or drink
- Listen to your loved one and let them know that you hear what they are saying.
- Let them know what you are feeling, if they ask.
- Encourage them to think about the highlights of their life.

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- Share a joyful memory or review a family album together.
- Ask your loved one if they would like to speak to a professional, such as a social worker or spiritual leader, for emotional support or spiritual guidance.
- Ask your loved one if there is anything they would like to speak about or anyone they would like to speak to but have been unable to.
- Even if you disagree with the wishes your loved one expresses, respect their right to decide.

DO I SPEAK WITH MY LOVED ONE ABOUT DYING?

Each family must answer this question for themselves based on their values and beliefs. Many caregivers want to protect their loved ones from these conversations. However, most people living with cancer are aware when their bodies are not responding to treatment and are weakening. Many people are relieved when they are given the opportunity to talk about their changing condition, such as increased fatigue, loss of appetite and so on.

Here are some tips for talking with your loved one:

- Take your cue from your loved one. Your loved one will let you know how much or how little they want to discuss their illness. For example, comments such as “I don’t seem to be getting better” or “The treatment doesn’t seem to be working” can be openings for discussion about end-of-life concerns. You may respond with “How do you understand what is happening?”
- Use this conversation to learn how they want to live the remainder of their life and how they would like to be cared for.

Does speaking about dying mean that I have given up hope?

No. Hope changes over time. While they no longer hope for a cure, people often hope instead for a comfortable day that is free of pain, the company of family or friends, the safety of familiar surroundings, a food that gives them pleasure or a view they enjoy.

CancerCare® Can Help

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by master’s-prepared oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercares.org or call **800-813-HOPE (4673)**.

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HOW DO I CARE FOR MYSELF DURING THIS DIFFICULT TIME?

You need to make sure that you are caring for yourself so that you have the strength and energy to give your loved one the best care possible.

- Watch for signs of emotional distress: constant sadness and/or fear, panic or extreme anger. If any of these symptoms make it difficult for you to accomplish your daily tasks, speak to a doctor, nurse or social worker.
- Listen to friends or family if they notice changes in your mood.
- Maintain contact with friends and family. Social isolation can increase emotional distress.
- Try to give yourself a half-hour to an hour each day outside the house.
- Remember to eat three meals every day. Even if the meals are small, they will give you energy to take care of your loved one.
- Drink water regularly.
- Try to get uninterrupted sleep (6–8 hours). This might require that you get some assistance in caring for your loved one at home.
- Take time to exercise.
- Allow yourself time each day to have quiet restorative time.



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