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. 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.

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 to remain.

Expect an altered appetite. He or she 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. He or she may talk little 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, resist the idea that you need to be somber or solemn around him or her 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 that he or she needs.

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

EMOTIONAL CARE

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

• Encourage your loved one to make as many decisions as he/she can to maintain control in his/her life. As long as he/she is making safe decisions, let your loved one have the final say. For example, listen to his/her wishes about the following:
  - Pain control versus alertness;
  - Number of visitors;
  - Daily activities;
  - Type of food or drink.
• Touch the patient and offer comfort.
• Listen to your loved one and let him/her know that you hear what he/she is saying.
• Let him/her know what you are feeling, if he/she asks.
• Encourage the patient to think about the highlights of his/her life.
• Share a joyful memory or review a family album together.
• Ask the patient if he/she would like to speak to a professional (social worker or spiritual leader).
• Ask your loved one if there is anything he/she would like to speak about or anyone he/she would like to speak to but have been unable to.

DO I SPEAK WITH MY LOVED ONE ABOUT DYING?
Families must answer this question for themselves based on their values and beliefs. Many caregivers want to protect their loved one from these conversations. However, most patients are aware when their bodies are not responding to treatment and are weakening. Many patients are relieved when they are given the opportunity to talk about their changing condition—increased fatigue, loss of appetite, body slowing down, etc.

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 little or much he/she wants to discuss about his/her 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 from the patient how he/she wants to live the remainder of his/her life and 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 for a comfortable day that is free of pain; the company of family or friends; to be in familiar surroundings; a food that gives them pleasure or to have a view they enjoy.

CancerCare® Can Help
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