

Caregiving

CARING FOR A LOVED ONE WITH LUNG CANCER

Caregivers are volunteers who provide physical and emotional care to a loved one with lung cancer. They may be spouses, partners, family members, or close friends. Many times, they may be the lifeline of the person with cancer. And they are often not trained for the caregiver job.

Caregiving may be the most difficult job you ever take on, but also one of the the most valuable. Remember that you're not in it alone—LUNGEvity has many resources to assist you. Visit www.LUNGEvity.org/caregiver to get started.



► TALKING TO THE PATIENT

Let let your loved one know you want to be there for him or her and want and need to be included in his or her care. Try something like:

"This is a scary time for both of us, but I want to be here for you to help you get through this. You are not alone."

"I will do whatever I can to help you through this. I might do the wrong thing sometimes, or not know what to do, but I will do my best."

"We can do this together. Let's try to be open with each other and work with each other no matter what happens."

It's good to set a goal of openness and sharing right from the start. Remind each other that you're "on the same team." Share your fears and worries. Sometimes it may be hard and you'll disagree, but openness will allow you to deal with the conflict. It will also help you to keep supporting each other and reduce distress and anxiety. Acceptance and sharing will help keep your relationship strong.

► COMMUNICATION LAYS THE GROUNDWORK

Good communication allows you to express yourself, help others understand your limits and needs, and help you understand the limits and needs of the person with cancer. You will need to be able to talk to the patient, the medical team, friends, family, and even people you barely know who are concerned about the patient. This can be hard to do. And when you need information from the medical team, it may not be possible to get it without signed permission.

A few tips to help you communicate clearly:

- Respect your own feelings, needs, and desires, as well as those of the patient.
- Speak up for your feelings while being sensitive to those of others.
- Try to use "I" statements rather than "you" statements. For instance, say, "I need a break" instead of "You never help me!"
- Focus on the present rather than bringing up old patterns or hurts.

► FOR THE PATIENT: CHOOSING AND COMMUNICATING WITH YOUR CAREGIVER

Start by selecting the person or persons you'd like to be included in your care. For example, you may choose your spouse to be your champion when it comes to emotional needs, and a different family member or friend to be in charge of your financial or health care needs. Usually one person is the primary caregiver.

Set your expectations with your caregiver. Let him or her know what your needs, hopes, and fears are, so that you can discuss openly your treatment options and any concerns you may have.

While you have a medical team caring for you, no one is caring for your caregiver. Keep this in mind; take "cancer breaks" *with* each other and *away from* each other.

- Remember the relationship you had before cancer.
- Do ask others for help—if someone you cared about was diagnosed with cancer, you'd want to help them. Give them the chance to help you.

Caregiving

COMMUNICATING WITH THE MEDICAL TEAM AND THE FAMILY

The caregiver is often the link between the patient, the medical team, and the family. You'll need to make sure you have the patient's written consent for the medical team to share information with you. And you'll need to be prepared to communicate that information to the family, answer their questions, and be understanding of their concerns.

► TALKING TO THE MEDICAL TEAM

First, ask the patient's permission to communicate with the health care team. Then talk to the doctor about what steps need to be taken so that the health care team can discuss the patient's care with you.



The patient can fill out a release form that allows the doctor to discuss care with you. Be sure there's a copy in the patient's records, and keep a back-up copy for your files.

When you call the doctor's office, you may need to remind them that they have the form on file.

There are different consent forms for different purposes. The type of form discussed here allows the doctor to share medical information with you; it does not give you permission to make decisions about the patient's care.

► KEEPING THE FAMILY INFORMED

It can be hard to keep everyone up to date on what is happening with the patient. Family members may feel frustrated and left out. They may not understand the medical condition, especially if the patient is having problems. They also may not know that their help and ideas are needed, or how best to help.

One way to keep everyone informed is to have a family meeting, in person and/or by conference call. It's important to include everyone who is or will be part of the home caregiving team. This may include a family friend, neighbor, or paid caregiver – and don't forget the patient!

Some of the things that may be covered are:

- The latest report from the doctor
 - How are things going?
 - What can we expect to happen next?
- Sharing of feelings and concerns
 - What does the person with cancer want and need?
 - How much time does each family member have to help out or visit?
 - Other ways each person can help. What other help might be available?
- Financial concerns about caregiving
 - How much will it cost?
 - How much work can family members afford to miss?
 - Is other financial help available?
- What sort of support does the main caregiver need?
 - A break from caregiving from time to time
 - Help with meals, shopping, cleaning, laundry, yard work, childcare, etc.
 - Emotional support by phone or email
 - Help with medical care, like taking the patient for treatment or to doctor's appointments
 - Help with sharing news and updates on the patient's condition so that the main caregiver doesn't have to spend time repeating the news each day.

Every family has a history that affects each person's role within the family, how members relate to each other, how they feel toward the person with cancer, and how they deal with illness. Be understanding of these individual differences.

There are unspoken rules about what can be expressed and what emotions are OK. It may be hard to hold family meetings if the patient's condition requires the group to discuss these taboo topics.

You may want to talk with a social worker or other professional about how to bring up delicate subjects.