



Listen With Your Heart

How do you talk to someone who has cancer?

When someone close to you who has cancer starts to talk about the disease, do you change the subject? Do you stand in silence, worried that you'll say the wrong thing? If so, you share these feelings with many others.

When talking with someone who has cancer, it is important to listen. Try to hear and understand how they feel. Don't make light, judge, or try to change the way the person is feeling or acting. Try to put your own feelings and fears aside. Let them know that you are open to talking whenever they feel like it. Or if the person doesn't feel like talking right now, that's OK, too. You can offer to listen again later.

Here we will share some ideas on how to be supportive and helpful when you talk with someone who has cancer. You can learn how to make the person with cancer know that you are someone they can truly count on. We call this kind of communication "listening with your heart."

About cancer

Cancer touches people of all ages, races, and incomes. This means that, at some time in their lives, everyone will talk with a person who has cancer. There are no rules to follow when talking with them, because each person and situation is unique.

The word "cancer" itself is upsetting because it often makes people think about death. But death is not the outcome for many people with cancer. Almost 12 million people who have had cancer are alive today. And more and more cancers are being found early -- when they're easier to treat. So the fear you might feel when you learn that someone you care about has cancer can and should be mixed with hope. Most cancers can be treated, and research is constantly finding new and better ways to find and treat cancer.

Some people live many years with cancer. This means that they may have to adjust to different types of treatment at different stages of the disease. Family and friends must also adjust to these changes and provide emotional support and hope along the way.

In many cases, having cancer doesn't mean there is a clear beginning, middle, and end to the experience. There may be a beginning and an end to a treatment plan. And perhaps a time when there is no sign of the cancer. But for some people, there may be a time when cancer returns. And sometimes treatment can go on for years just to keep the cancer under control -- it never goes away.

Hearing the news

Waiting

When a lump or a symptom means a trip to the doctor, there are often several days of waiting for test results to come in and not knowing what you might be dealing with. All kinds of thoughts can go through the person's mind and through yours. This can be a very scary time. If the person who might be facing cancer confides in you, it is probably because of the need to share that anxiety. This is when you should listen and try to help your loved one keep hoping for the best. Waiting is always hard, but having someone to wait with eases the burden.

Some people may sense that they have cancer before they get the diagnosis from their doctor. Each person will receive and react to the diagnosis in a different way. Some may want to talk about what the doctor said in detail. Others may not want to talk about it at all. Sometimes, the person's need to talk will change from day to day. Simply asking the person, "Would you like to talk about it?" is a direct and respectful way to find out.

Finding out it's cancer

If cancer is found, it should be the doctor who tells your loved one about the diagnosis. Think about whether you should be there when the doctor discusses test results. Sometimes when the doctor talks with the patient and the family at the same time, it gives the patient a feeling of support to have others in the room. But some people with cancer prefer to keep their talks with the doctor private. Just ask the patient whether you should plan to go along for the test results.

How the doctor shares the news with the person who has cancer depends on the doctor's personal style and sense of the patient's needs and feelings. These factors also influence how much information the doctor gives the patient. The doctor will also take the family's cues and questions into account when family members or loved ones are with the patient. Most doctors make it a policy to be honest about the diagnosis, treatment options, and treatment outlook. Having an honest approach from the start sets the stage for a trusting relationship among the doctor, patient, and loved ones. This allows for talks to be open, and allows for give and take between the doctor and patient or family.

People are often shocked when they first hear the word cancer. It may be hard for them to hear or remember anything else after that. Many people can take in only small amounts of upsetting information. If a family member or friend is there, they should pay close attention. Later on, they may be needed to help remember and explain what was said.

If you sense that your loved one with cancer is having trouble taking in information and you are sharing what you heard from the doctor visit, don't get into a lot of detail all at once. Ask if you've given too much information or if you should stop talking for a while. If the discussion is too much at the time, you can assure the patient that loved ones and the health care team are available and concerned. Remind your loved one that these people will be ready to talk about the illness in the future, if that's what is needed.

If you are not comfortable talking about cancer, you may not be the best person for the patient to talk with at this time. You may need some time and an expert to help you work through your own feelings. You can even explain to your loved one that you are having trouble talking about cancer. Tell her or him that you would like to talk, but don't feel you are the best person right now. A social worker, counselor, or other friend or family member may be able to offer more support at this time. You can suggest that your loved one seek support from them. Make sure the person with cancer understands that your trouble talking is your issue, your problem. You may also want to mention that you want to be there for support in spite of this, and hope to be there in the future.

If you would like to find out more on living with cancer and its treatment, we have another booklet called *After Diagnosis: A Guide for Patients and Families*. You can get a copy by calling us, or you can read it on our Web site.

Ways of coping

Venting feelings

During their illness, people with cancer may express anger and frustration to those around them. This can upset family members and friends, but it may help to remember that people often displace their feelings onto people close to them. They do this because the people closest to them are safe outlets. They know you will still be there for them, even if they behave badly or create tension. Often, the person is really frustrated and angry about the cancer and the losses it brings, but this can be hard to put into words. So the person with cancer may take angry feelings out on family, friends, or anyone who happens to be around at the time.

Acting different

Some people with cancer can act like children and become needy during illness. It can be very hard for an adult child to see a parent act this way. Try to understand that this is one way of acting out feelings of helplessness or weakness. These are quite normal feelings to have during a cancer illness.

Though the disease may limit some daily activities, it is usually best for the person with cancer to keep living as normally as possible. Continuing to be a responsible adult can give the person with cancer a sense of meaning, confidence, and control. Giving in to feelings of dependence may make the person with cancer feel even more helpless and more like a victim. Sometimes we feel so sorry for people with cancer that we may try to overprotect them, but in the long run that probably isn't helpful.

The cancer diagnosis and treatment phase is usually an anxious time for people. There is fear about the changes that come with having cancer, such as possible pain or feeling sick, money and job changes, body changes, and even changes in personal relationships. Because they have so much anxiety in their lives, sometimes people with cancer may seem upset or frightened for no reason that you can see. Sometimes this anxiety may come across as a harsh attitude toward you. Or you may find that you have fights when you only want to be supportive. Try to not react emotionally to this type of attitude. Understand that it is only likely to last a short time and comes from all of the fear and anxiety that is part of having and dealing with cancer. During this time, you will need to overlook some of this type of behavior and be ready to offer extra forgiveness, understanding, and support. Try to put yourself in your loved one's shoes. Think about how scared you would be if this were happening to you. This can help you to let go of minor arguments and troubles and move on.

The "blame game"

Sometimes people with cancer blame themselves for getting the disease because of something they did or did not do. As a friend or family member, you may also feel guilty and express this by changing the way you act toward the person with cancer. Other family members may have these same guilty feelings, too. You may try to make up for what you see as your failures in the past.

Blaming yourself and each other can be barriers to a healthy relationship. Try not to play the "blame game." Encourage your loved ones and the patient not to blame themselves for what's going on. The time has passed for that anyway. Moving forward is the only option. If you feel guilty as a friend or loved one, it's OK to express your regrets, apologize, and move on, too. Try not to live in the past, but focus on a hopeful and positive future.

Communication

One of the most important ways to help communication is not only to ask "How are you feeling?" but also "What are you feeling?" If you think about it, "How are you?" is one of the most common questions we ask, but it can be a rather thoughtless one. The expected response is "Fine" or "Good." It doesn't allow for much discussion. When you ask, "What are you feeling?" you are digging a little deeper. Someone who is asked that question will get the impression you want to know how he or she really *is* doing.

When you ask the question, "What are you feeling?" be prepared to hear anything. The person may be thinking a lot about death or be worried about what the future holds for

their children. Or maybe the person will tell you about their fears of not living another year. Be ready to really listen and hear whatever answer you get. You do not have to have a reply, but you must be ready to hear the pain or harsh thoughts that the question might provoke.

People with cancer sometimes like to get the opinions of those closest to them about their illness, treatment, and treatment outlook. Be open and honest, but don't try to answer questions that you don't know the answers to. The person with cancer will sense your honesty and appreciate it. If you want to know more about this, please see our document called *When Someone You Know Has Cancer*. You can get it by calling our toll-free number or visiting our Web site.

Living with cancer

Cancer is often a disease that lasts a long time, and people may be treated for it for many years. Sometimes, people close to the patient who were very involved at first grow distant as the treatment continues over the course of months or years. It is understandable that you can become "burned out" when supporting a person with cancer. Still, people with cancer need emotional support throughout the entire course of the illness. Remember that the encouragement and support of those around them can help people with cancer get a new perspective and have hope, even when they feel beaten down by cancer or its treatment. Also, the support of family and friends helps people with cancer try to get on with their old activities and have as normal a life as their illness will allow. So if you are going to be a support for a person with cancer, try to hang in there for the long term. Being there and then leaving can be very painful for your loved one, and can feel even worse than not ever being there at all.

It is often hard to know if you are crossing boundaries or treating the person with cancer too much like a "cancer patient" and not like your friend or family member. Encourage the person with cancer to let you know if you cross this line. Every person with cancer appreciates the friend or family member who remembers that they used to be a person *without* cancer -- that they had, and still have, strengths and weaknesses, interests, and parts of life that have nothing to do with cancer. Sometimes being the person in the "cancer patient's" life who remembers the whole person is a special gift.

Rehabilitation

Rehabilitation (or rehab) is also a part of cancer treatment. It helps people who have had cancer to do as much as they can on their own. Among the many specialists who help with rehab are the patient's doctor, nurse, social worker, physical therapist, and occupational therapist. Think of these experts as helpful resources when problems come up.

The rehab process is designed to help a person return to day-to-day functions after going through a serious illness. The services provided by rehab specialists might include job

training, homemaker services, prostheses (such as a replacement of a limb or body part), or exercise programs.

Rehab can be a long process. Results may come slowly, and it is often frustrating. Sometimes people feel their efforts are useless or that it is just too hard. Encourage the patient to actively take part in any rehab program, and offer your support along the way. One way of putting your support into action would be to go with the patient to the appointments, or do the exercises with the patient. If rehab has not been suggested and you think your loved one might benefit from it, go ahead and discuss it with the doctor.

Sources of support

There are many sources of support for people facing cancer. These include visitation programs like the American Cancer Society Reach To Recovery[®] program (for women who have been diagnosed with breast cancer), ostomy rehabilitation (for patients with stomas on the belly), and laryngectomy clubs (for those who have lost their natural voice because of cancer surgery). The American Cancer Society I Can Cope[®] program is another good source of support. It provides information about cancer diagnosis, treatment, side effects, nutrition, and other topics of interest to people with cancer and those close to them. Some of our local offices may be able to assist with transportation and can put you in touch with other sources of support. To find out more about available services in your area, contact your American Cancer Society.

Everyone, no matter how emotionally strong they are, can be helped by support. Try to understand what the person is going through -- by listening, offering a hand, and giving encouragement along the way. Providing encouragement does not mean that you act like a cheerleader, or that you try to make them feel good when they are feeling bad. It is important to allow the person with cancer to express anger, frustration, and sad feelings. After the person has vented negative feelings, you can encourage your friend or family member by saying things like, "I'm sorry you are feeling so bad. I can't imagine how you feel, but I am here to listen anytime you need to talk. You have one more round of chemo. Maybe when that is over, you will start feeling a little better."

In fact, just listening and not talking is probably more helpful than saying the wrong thing. Some of the wrong things to say are "I know how you feel," when you clearly don't; or "It will be better tomorrow," when you can't be sure of that either. Even though you may say those things with the best of intentions, the person may feel that you really don't understand and that it just isn't helpful to talk to you. You must listen with your ears and your heart. As one person with cancer put it, "A long illness is so discouraging." But having a good support system means the person does not have to face cancer alone.

Concern for the family and caregivers

Just as people with cancer should not spend all their time thinking about their illness, neither should family members and friends spend every spare minute thinking about or being with their loved one. Caregivers need relief and rest if they are to stay emotionally

and physically fit and remain helpful to their loved one with cancer. If you are a caregiver, plan time for yourself. Ask friends or other family members for help. Tell them exactly what they can do to be helpful. Many times they are just waiting to be asked. For more information, please see our document called *What It Takes To Be a Caregiver*. If you are not the main caregiver of the person with cancer, it helps to think about that person as well. Caregivers often focus most of their energy and time on their loved one with cancer and may not have time to take care of themselves. You may be able to offer help so that they can have a much-needed break. Just a couple of hours may be a big deal for someone whose loved one is very ill. Even if you are not able to do this, the caregiver might appreciate hearing someone ask how he or she is doing. You can ask about the caregiver's feelings, too. It can be very lonely and stressful to be the main support person for a person with cancer. With everyone concerned about the person with cancer, it's easy for the caregiver to be overlooked.

Help and information

It is hard to see a loved one in pain or suffering through side effects of cancer treatment. If you feel that you need help coping with your feelings about a loved one's illness, there is help available. The social services department at the hospital or doctor's office may be able to help you or direct you to someone who can help. They may be able to suggest support groups for friends and families of people with cancer in your area. Sometimes the hospital chaplain or your own clergy can help. Asking around in your community for good counselors can be another good way to get the support and help you need. Helping yourself may be the best way to help your loved one.

You can also support the person who has cancer by learning more about the disease. Talk with an expert such as a doctor, nurse, or social worker, and call your American Cancer Society for information. The more you understand your loved one's cancer, the better prepared you will be to help them cope with it.

Visiting

Some people may have a hard time visiting people with cancer, especially those who look and feel very sick. When someone is very sick and suddenly looks very different, it can be shocking and upsetting. Sometimes just seeing a lot of medical equipment around a loved one can be disturbing. Try to remember that this is the same person you have always known and cared about. If possible, try to relate to the person in the same way you have in the past. Doing so will help both of you think about what's going on inside, not on the outside. The pleasure you give by your visit and the warmth you are able to communicate will be appreciated. When words seem too little, a loving look or touch can say a lot.

If you find it hard to not cry, it's all right. Explain to your friend or relative how much you care and how upset you are that he or she is going through such a hard time. Don't be afraid to show your feelings, but make sure the person with cancer doesn't have to

comfort you. That may be too much for most people to manage at this stage. You may need to make the visit short if you have trouble controlling your tears.

If your loved one decides to stop getting treatment

There are times when you and your loved one will not agree on decisions that are made. One of those times may be when your loved one decides that treatment aimed at fighting the cancer is no longer worth the physical and emotional cost. You may feel that your loved one is giving up and that can be extremely upsetting.

It is important that you give each other the right to feel the way you do. You can try to understand that your loved one is tired of getting treatment and feeling sick without seeing any clear benefits. You also may feel sad and upset that your loved one has decided not to seek further treatment -- letting the disease run its course. This is not the outcome either of you wanted. You are both upset.

Even though you may not agree with your loved one's decision to end cancer-fighting treatments, it would be sad if you let your disagreement interfere with the loving, supportive relationship you have shared. Once you stop and think about it, you may decide to let go of your dream of having more time with your loved one and focus on the quality of time that you have left. This is probably in the best interest of both of you. You might even have a discussion together where you "agree to disagree" but can still be loving and caring toward each other in your relationship.

If your loved one refuses cancer treatment

There are people who choose not to get any cancer treatment. This can be very hard for loved ones who may not agree with this choice. But for the most part, people who are able to make decisions for themselves have the right to refuse any and all treatment. As someone who loves and supports the person with cancer, you may wonder why she or he would make this choice. Sometimes, the person has health problems that make cancer treatment harder or more risky. Others may feel that with their age and life history, it's just "their time." Sometimes, the person's religious beliefs come into play. There are many different reasons not to get treatment.

It is OK to ask your loved one about their reasons for refusing cancer treatment. Even though the answer may be hard to hear, the choice to refuse treatment is the patient's. Often, the reasons make sense and give you a better idea of what's going on. It is also OK to tell the patient what you think. You may say something like, "I hadn't thought about it that way, and I'm glad you shared your point of view with me." Or, "I wish you would talk to a doctor about treatment options, but I will support your choice and help you through this time the best that I can."

Even after a person refuses cancer treatment, loved ones will want to make sure that the person with cancer fully understands their options. They may ask the person to talk with a

doctor about the decision and any possible treatments that may help. Some patients will agree to talk with the doctor, and others won't. But loved ones shouldn't be surprised if, after talking with a doctor, the person still refuses treatment. Again, this person has the right to feel this way, just as you have the right to feel the way you do. Try to see it from the point of view of the person with cancer, and continue to offer your support and friendship.

Palliative care can often help those people who are sure that they don't want to be treated for cancer. Palliative care helps to keep people with cancer from having severe pain, nausea, or other symptoms, whether or not they are getting cancer treatment. And the person who refuses cancer care may still want to enter hospice. Hospice workers use palliative care so that symptoms can be controlled as the cancer runs its course. They also try to help the family and the patient make the most of the time they have left. A patient who is competent to make decisions may elect to refuse this care, too. If that happens, loved ones usually work with the situation as best they can, but should keep offering hospice and palliative care as an option. This can be especially crucial as the patient's condition gets worse -- the time may come when the family and loved ones cannot manage without help.

Facing the final stage of life

Some people have cancer that no longer responds to treatment and must face the fact that they will probably die soon. This is scary for the person who is sick and for those around them. The person with cancer may be in pain, may be in bed, may be able to walk only a few steps, or may be confused. It is hard to watch someone you love go through this process of decline.

Being there

No matter how hard it may be, it is still important to try to be there for the person. The person with cancer may feel lonely even if there are people around. This is because the people nearby may not be really in tune with what is going on with the person. You can be the person who is in sync with your loved one every step of the way. Just by staying close and listening with a smile or gentle touch, you show you are there for your loved one. It takes courage and extra energy to be in this situation.

Sometimes the person with advanced cancer may pull away from people and seem to be withdrawing as death nears. This is usually a natural process and is one way of disconnecting from life. The best thing you can do if this happens is to take the person's cue, and simply stay in the background and be available. Try not to take this withdrawal personally or feel hurt when the person pulls away. It likely has nothing to do with you.

Talking about death and dying

Many people worry about what to say when a person talks about dying. But this is something that commonly happens. Some people want talk about different parts of the

dying process -- they want to know what to expect. Some want to know how they will die, and ask, "What will happen when I'm actually dying?" For answers to these questions, it will help to find experts in hospice care or care of the terminally ill. If you don't know the answers to specific questions, you can say, "I don't know, but we will call some people who can help us with those answers." These professionals can guide you and the person with cancer by explaining the things that might happen as death gets closer.

Hospice staff members are used to answering these questions, and they are skilled in doing it in a supportive, caring way. In many communities, hospice organizations give expert, compassionate care for people with advanced disease. If you would like to read more about end of life issues or about hospice care, please see our documents called *Nearing the End of Life* and *Hospice Care*. We also have information on advanced cancer and caring for the cancer patient at home.

You may be asked, "Why is this happening to me?" It is very hard to hear this question because there is no answer, and it is heart wrenching to feel the pain that lies within such a question. This is a question where the simple answer is "I don't know." Holding your loved one's hand and letting them cry or talk about their sadness and regrets is the best you can do. Allowing a person to do this is a true help because so many people avoid the topic of dying and won't allow themselves to feel this pain with their loved one.

Some people who know they are going to die may feel the need to get some things off their chests. They may want to talk about some of the things they did in their life that they are not proud of or that they regret. They may want to apologize about these things. They may want to give you instructions about what to do for them in the future. Respectfully listening and, of course, offering forgiveness and a loving attitude are often all that is necessary. There are no magic words for the dying person, but often your presence is all that's needed, and having an open heart is priceless.

Summing up: Tips on talking to the person with cancer

- Let them take the lead. If they want to talk, be a good listener. Listen to what is said and how it is said.
- Try to be OK with silence. It may help people with cancer to focus their thoughts. Constantly talking because you are nervous can be irritating. Sometimes silence is comforting and allows them to express even more of their thoughts and feelings.
- Try to maintain eye contact. This gives the person a sense that you are really present and listening carefully.
- Touching, smiling, and warm looks can get past the barriers of the illness to the person you know and love.
- Try not to give advice. Giving advice is hard when you are not in the person's situation. It is safer to ask questions or listen.

- Do not say, "I know how you feel." The person may become angry because you really don't know how he or she feels.
- If you are feeling tearful, explain this to the person with cancer. Be brief in your explanation. Stay away for a time until you can be there without the patient having to comfort you.
- People with cancer do not always want to think or talk about their disease. That makes them feel like their only identity is as "cancer patient." Laughing and talking about other things are often welcome distractions.
- Try to do as many things together as possible. If you used to play cards -- play cards now! If you used to go to the movies together -- keep going to movies. Use your judgment about your loved one's energy level. Or ask about the need to take rest breaks in between activities. Try not to take the effects of the illness too lightly, but don't be overprotective. Keep inviting and urging the person to do things with you and others.
- Encourage other friends to visit. Maybe they would be willing to do errands, cook meals, or care for the children. If they can't visit, ask them to write, email, or call.
- Continue to visit. Put the person with cancer on your weekly "to do" list. Cancer can be a very lonely and isolating experience. Your loved one can't always ask for help because it's hard for even the person with cancer to know exactly what will help! Stay in touch.
- Most of all, be yourself and try not to worry about whether you are doing things the right way. Let your words and your actions come from your heart. Your compassion and genuine caring are the most important things you can express to your loved one right now.

Additional resources

More information from your American Cancer Society

We have selected some related information that may also be helpful to you. You may order these materials by calling our toll-free number at 1-800-227-2345.

Coping With Cancer in Everyday Life (also available in Spanish)

Advanced Cancer (also available in Spanish)

After Diagnosis: A Guide for Patients and Families (also available in Spanish)

Caregiving: How to Care for a Loved One With Cancer -- And Yourself

Caring for the Patient With Cancer at Home: A Guide for Patients and Families (also available in Spanish)

Hospice Care

Nearing the End of Life (also available in Spanish)

Talking With Friends and Relatives about Your Cancer

When Someone You Know Has Cancer (also available in Spanish)

When Someone You Work With Has Cancer (also available in Spanish)

Where to Turn -- Patient and Family Support Program Overview (pamphlet only; also available in Spanish)

National organizations and Web sites*

Along with the American Cancer Society, other sources of information and support include:

CancerCare

Toll-free number: 1-800-813-4673

Web site: www.cancer.org

Offers free professional support services to anyone affected by cancer, including things like telephone counseling, online support groups, workshops, and publications

Family Caregiver Alliance (FCA)/National Center on Caregiving

Toll-free number: 1-800-445-8106

Web site: www.caregiver.org

Provides information on caregiving topics such as guidelines for better communication and how to hold a family meeting, as well as online support groups

National Cancer Institute (NCI)

Toll-free number: 1-800 422-6237 (1-800-4-CANCER)

Web site: www.cancer.gov

For up-to-date information on cancer and many cancer-related topics

**Inclusion on this list does not imply endorsement by the American Cancer Society.*

No matter who you are, we can help. Contact us anytime, day or night, for information and support. Call us at **1-800-227-2345**, or visit www.cancer.org.

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For additional assistance please contact your American Cancer Society
1 - 800 - ACS-2345 or www.cancer.org