Listen With Your Heart

Talking With the Person Who Has Cancer

How do you talk to someone who has cancer?

When someone close to you has cancer and starts to talk about it, do you change the subject? Do you stand in silence, worried that you'll say the wrong thing? If so, you're not alone. Many people don't know what to say to a person who has cancer.

When talking with someone who has cancer, the most important thing is to just listen. Try to hear and understand how they feel. Don't make light, judge, or try to change the way the person feels or acts. Try to put your own feelings and fears aside. Let them know that you're 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 whenever they're ready.

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

You may find it helps to learn a little about cancer. Cancer touches people of all ages, races, and incomes. 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 each case is different.

The word "cancer" itself is upsetting. It often makes people think about death. But death is not the outcome for many people with cancer. Almost 14 million people who have had cancer are alive in the US today. And more and more cancers are being found early –

when they're small and 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 researchers are finding new and better ways to find and treat cancer every day.

Some people live with cancer for many years. This means they may have to "fit" cancer into their everyday lives. They also may have to adjust to different types of treatment and different stages of the disease. Family and friends must also adjust to these changes and try to keep giving support and hope along the way.

In many cases, cancer doesn't have a clear beginning, middle, and end. There may be a beginning and an end to a treatment plan, and maybe a time when there's no sign of cancer. But for some people, the cancer comes back after treatment. And sometimes treatment goes on for years just to keep the cancer under control – it never really goes away.

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Hearing the news

Waiting

When a lump or a symptom leads to a trip to the doctor, there may be many days of waiting to have tests done or waiting for test results. During this time you don't know what you might be dealing with. All kinds of thoughts can go through the patient's mind and through yours.

This is often a very scary time. If the person who might be facing cancer confides in you, it's probably because they need to share their worries. They may just need you to listen and try to help them hope 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 hear it from the doctor. Each person responds to a cancer diagnosis in their own 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 changes from day to day. Simply asking, "Would you like to talk about it?" is a direct and respectful way to find out what they need.

Finding out it's cancer

If cancer is found, the doctor should be the one who tells the patient. Is someone going to be with the patient for this visit? Do they want someone to go with them? Think about whether you should be there when the doctor gives the test results. Sometimes when the doctor talks with the patient and a family member or friend at the same time, it gives the patient a feeling of support – they know they're not facing cancer alone. But some people prefer to keep their talks with the doctor private. 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 affect how much information the doctor gives the patient, too. The doctor will also take the support person's cues and questions into account when family members or loved ones are there.

Most doctors will be honest about the diagnosis, treatment options, and treatment outlook. An honest approach from the start sets the stage for a trusting relationship among the doctor, patient, and family or friends. This allows for open, frank talks that help the patient make the best choices for their care.

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If you go with the patient to get test results

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 you are with the patient, try to pay close attention. You may even want to take notes on what the doctor says. Later on, you may be needed to help remember and explain what was said.

When you talk about the doctor visit later, if you sense that your loved one with cancer is having trouble taking in the information you're sharing, take it slow. Don't get into a lot of detail all at once. Ask what they're ready to know. Try to answer specific questions they may have. If the discussion is still too much for them, remind the patient that loved ones and the health care team are available, concerned, and ready to talk about the illness whenever the patient is ready.

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 them 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, not theirs. 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. Explain that you need some time to adjust, too.

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 website.

Ways people cope with a cancer diagnosis

Venting anger and frustration

People with cancer sometimes take out their anger and frustration on those around them. This can upset family members and friends. It may help to remember that people often vent their feelings onto those close to them. They do this because these people are safe outlets. They know you'll still be there for them, even if they behave badly or create tension.

In most cases, 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 out angry feelings on family, friends, or anyone who happens to be around at the time.

Acting passive

Sometimes a person with cancer seems to become childlike and passive, looking to others for direction. 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 how helpless and weak they feel. These are normal feelings to have when a person has cancer.

Though the disease may limit their ability to do some things, it's usually best for the person with cancer to keep living as normally as possible. Continuing to be a responsible adult can give them a sense of meaning, confidence, and control. Giving in to feelings of dependence may make the person with cancer feel even more helpless and out of control – more like a victim. You may feel the need to overprotect them, but in the long run that probably isn't helpful.

Fear and anxiety

The cancer diagnosis and treatment phase is usually an anxious and uncertain time. There's fear about the many changes that come with cancer – money and job changes, body changes, and even changes in personal relationships. Because they have so much anxiety in their lives, the person with cancer may seem upset or frightened for no reason that you can see. Sometimes this anxiety may come across as harshness or meanness. You may find that you have fights when you only want to help.

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 or you may blame them, too, and you may express this by changing the way you act toward the person with cancer. Other family members may have these same feelings.

How you can respond to these ways of coping

Try to not react emotionally to the changes the person is dealing with. Understand that this will likely last only a short time, and it comes from all of the fear and anxiety that's part of having and dealing with cancer.

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. 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. Try not to live in the past, but focus on a hopeful future.

During this time, you will need to overlook some of these types of behavior and be ready to offer extra forgiveness, understanding, and support. Give the person with cancer time to adjust. Try to put yourself in their 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.

Communication

One of the key ways to help keep open lines of 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're digging a little deeper. Asking this helps the person feel like you want to know how they're really doing.

When you ask, “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 family. Maybe the person will tell you they’re afraid they won’t live to see their kids grow up. Be ready to really listen to whatever answer you get. You don’t have to reply, but you must be ready to hear the pain or unpleasant thoughts that the question might bring up.

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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 website.

Living with cancer

Cancer is often a disease that lasts a long time, and people may get treatment for many years. Sometimes, people close to the patient are very involved at first, but grow distant as the treatment goes on over months or even years. It’s understandable that you can become “burned out” when supporting a person with cancer. Still, people with cancer need emotional support through all of the illness.

Remember that encouragement and support can help a person with cancer regain hope, even when they feel beaten down by cancer and/or its treatment. Also, the support of family and friends helps the person with cancer have as normal a life as their illness allows. So, if you’re going to be a support person for someone with cancer, try to hang in there for the long term. Being there and then pulling back can be very painful for the person who needs you, and may even be worse than never being there at all.

It’s 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 often a part of cancer treatment. It helps people who have had cancer 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 problem-solvers that you and the person with cancer can turn to when problems come up.

Rehab can help a person return to day-to-day functions after going through a serious illness. Rehab can help with things like 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's often frustrating. Sometimes people feel their efforts are useless or that it's 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 with breast cancer), ostomy education (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 and information. It can help you learn more 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 help with transportation and can put you in touch with other sources of support. To find out about services where you live, contact your American Cancer Society.

Everyone, no matter how emotionally strong they are, can use support. Try to understand what the person is going through – by listening, offering a hand, and giving encouragement along the way. Encouraging and supporting someone does not mean you act like a cheerleader, or that you try to make them feel good when they're feeling bad. It's important to allow the person with cancer to express anger, frustration, and sad feelings. You can encourage them by saying things like, "I'm sorry you're feeling so bad. I can't imagine how you feel, but I am here to listen anytime you need to talk." Or maybe, "You have one more round of chemo. Maybe when that's over, you'll start feeling a little better."

Everyone, no matter how emotionally strong they are, can be helped by support.

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 these things with the best of intentions, the person may feel like you really don’t understand and decide that it doesn’t help 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. You need people to get you through it.” 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 to stay emotionally and physically fit and be able to help the person with cancer.

If you’re a caregiver, plan time for yourself. Ask friends or other family members for help. Tell them exactly what they can do to help. Many times they are just waiting to be asked. For more information, please see our document called *What You Need to Know as a Cancer Caregiver*.

If you’re not the main caregiver of the person with cancer, it helps to think about that person, too. Caregivers often focus most of their energy and time on the person 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’re not able to do this, the caregiver might be glad to have someone ask how they are doing. 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.

The caregiver is often overlooked. Ask how they’re doing. Caregivers need support and encouragement, too.

Help and information

It's hard to see a loved one in pain or suffering through side effects of cancer treatment. If you need help coping with your feelings about their illness, know that help is 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. They may be able to suggest support groups in your area for friends and families of people with cancer. Sometimes the hospital chaplain or your own clergy can help. Asking around to find good counselors can be another 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 able you'll 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 sick and looks very different, it can be shocking and upsetting. Sometimes just seeing a lot of medical equipment around someone you care about can be disturbing.

Remember that this is the same person you've always known. Try to relate to them in the same way you have in the past. The pleasure you give by visiting them will be appreciated. When words seem too little, a look or touch can say a lot. Our booklet called *How to Be a Friend to Someone With Cancer* gives you tips on things you can do to show you care.

If you find it hard to not cry, it's all right. Explain how much you care and how upset you are that they're 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's often too much for a patient to manage. 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 the person with cancer will not agree on decisions that are made. One of those times may be when they decide that treatment aimed at fighting the cancer is no longer worth the physical and emotional cost – they want to let the disease run its course. You may feel like they're giving up, and that can be very upsetting and

frustrating. You may feel sad or angry that they have decided not to seek further treatment. This is not the outcome either of you hoped for. You are both upset.

It's important that you give each other the right to feel the way you do. Try to understand that the patient is tired of getting treatment and tired of feeling sick without seeing any clear benefits. Even though you may not agree with the decision to stop cancer-fighting treatments, it would be sad if you let your disagreement change your relationship.

Once you stop and think about it, you may decide to let go of your wish for more time with this person and focus, instead, on the quality of time that you have left. This is probably best for both of you. You might even have to talk about how the two of you will "agree to disagree" but still love and care about each other.

> *Try to remember that this is the same person you have always known. This will help you relate to the person in the same way you have in the past.*

If your loved one refuses cancer treatment

There are people who choose not to get any cancer treatment. This can be very hard for family and friends 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 cares about and supports the person with cancer, you may wonder why they would make this choice. Maybe the person has health problems that make cancer treatment harder or more risky. Maybe they 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 reasons why people choose to not get cancer treatment.

It's 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 – no one else's. Often, the reasons make sense and give you a better idea of what's going on. It's 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'll support your choice and help you through this time the best that I can."

Even after a person refuses cancer treatment, it's important to make sure they fully understand their options. You may want to ask the person to talk with a doctor about the decision and whether any treatments might help. Some patients will agree to talk with a doctor, and others won't. But don't be surprised if, after talking with a doctor, the person still refuses treatment. Again, they have the right to make their own choices, 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.

Supportive care can help anyone with cancer – even those who are sure that they don't want treatment for the cancer itself. Sometimes called palliative care, supportive care helps keep people with cancer from having severe pain, nausea, or other symptoms. It's care that aims to treat symptoms, not cancer. It helps the person feel as good as possible for as long as possible.

The person who refuses cancer care may be open to hospice. Hospice workers give palliative or supportive 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 able to make their own decisions may choose to refuse this care, too. This can be hard on the family and loved ones, watching the person suffer while knowing that supportive care could ease the pain and other symptoms. If this happens, loved ones usually do the best they can, but should keep offering hospice and palliative care as an option. This care will be needed even more 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 soon die. This is scary for the person who is sick and for those around them. The person with cancer may be in pain, may be bedridden, may be able to walk only a few steps, or may be confused. It's hard to watch someone you love go through this process of decline.

Being there

No matter how hard it may be, it's still important to try to be there for the person with cancer. They may feel lonely even if there are people around. This is because the people nearby may not be really in tune with what's going on with the person. You can be the one 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. It takes courage and extra energy to do this.

Sometimes the person with advanced cancer may pull away from people and seem to be withdrawing as death nears. This is natural and is one way of disconnecting from life. This process and what you might expect at this time is described in our information called *Nearing the End of Life*. The best thing you can do at this time is take the person's cue – 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 a common topic when facing cancer. Some people want to talk about the dying process – they want to know what to expect. Some want to make sure that their wishes are followed when it comes to death – they want to be sure that machines are not used to keep them alive. Some want to know how they will die, and ask, “What will happen when I’m actually dying?” For answers to these questions and concerns, it helps 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 can call some people who can help us with those answers.” These professionals can guide you and the person with cancer by helping figure out things like living wills and advance directives and 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. Hospice gives expert, compassionate care for people with advanced disease. If you would like to read more about end-of-life issues or hospice care, please see our documents called *Nearing the End of Life* and *Hospice Care*. We also have information on living wills, advanced cancer, and caring for the cancer patient at home. (See the “To learn more” section.)

You may be asked, “Why is this happening to me?” It’s very hard to hear this question because there is no answer. And it’s heart wrenching to feel the pain that lies within questions like this. In most cases, 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 many people avoid the subject of dying and won’t allow themselves to share this pain.

Some people who know they’re going to die 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’re not proud of or that they regret. They may want to apologize for these things. They may want to give you advice about the lessons they learned or 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’s 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: Talking to the person with cancer

- Let them take the lead. If they want to talk, be a good listener. Listen to what’s said and how it’s said.

- Try to be OK with silence. It may help people with cancer to focus their thoughts. Talking because you are nervous can be irritating. Sometimes silence is comforting and allows them to better express 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 good advice is hard when you are not in the person's shoes. It's safer to ask questions or listen.
- Do not say, "I know how you feel." The person may get angry because you really don't know how they feel.
- If you're 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 don't always want to think or talk about the disease. This makes them feel like their only identity is "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 or watch movies together at home. Use your judgment about your loved one's energy level. Ask them if they need to take rest breaks. 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 often hard for even the person with cancer to know exactly what will help! Stay in touch.
- Most of all, be yourself. 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 right now.

To learn more

More information from your American Cancer Society

We have selected some related information that may also be helpful to you. You may order free copies of these materials by calling our toll-free number at 1-800-227-2345, or you can read them online at www.cancer.org.

More on relating to people with cancer

When Someone You Know Has Cancer (also in Spanish)

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

How to Be a Friend to Someone With Cancer

To learn more about cancer and what to expect

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

Coping With Cancer in Everyday Life (also in Spanish)

What You Need to Know as a Cancer Caregiver

What It Takes to Be a Caregiver

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

Advanced Cancer (also in Spanish)

Advance Directives

Nearing the End of Life (also in Spanish)

Hospice Care

National organizations and websites*

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

CancerCare
Toll-free number: 1-800-813-4673
Website: www.cancercare.org

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

Cancer Support Community
Toll-free number: 1-888-793-9355
Website: www.cancersupportcommunity.org

Has support groups for patients, caregivers, and loved ones, as well as open discussion groups that are available 24/7; all are password protected and led by trained professionals

Family Caregiver Alliance (FCA)/National Center on Caregiving
Toll-free number: 1-800-445-8106
Website: www.caregiver.org

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

National Cancer Institute (NCI)
Toll-free number: 1-800 422-6237 (1-800-4-CANCER)
TTY: 1-800-332-8615
Website: www.cancer.gov

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

**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
1-800-227-2345 or www.cancer.org