



BACK TO LIFE CANCER SUPPORT

Support for anyone affected by cancer

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THE CAREGIVER GUIDE

Learning that someone you know has cancer can be difficult. If the person is close to you, it can be a shocking and stressful time for both of you. If you are not comfortable discussing cancer, you might not be the best person for your friend to confide in at this time.

It's okay to take some time to process your own feelings. You can let your friend know that talking about cancer is difficult for you. You can also help them find someone more comfortable discussing it by looking for support groups.

However, if you feel ready and willing to offer support, here is some guidance for listening to, talking with, and being around the person dealing with cancer. Effective communication and flexibility are key to offering successful support.

How do we adjust to the diagnosis?

With time, the patient and loved ones will start to adjust to the cancer diagnosis. This is a time of change and action – everyone is getting used to the unexpected and different situations that they now find themselves in. Despite all the activity, some individuals may feel emotionally numb and withdrawn, while others may experience feelings of sadness, anxiety, or anger. Emotions may fluctuate from minute to minute as everyone copes in their own way.

It's important to get accurate, reliable information in writing to be ready when you or others must ask questions or coordinate care:

- What is the exact name and location of the cancer?
- What's the stage of the cancer?
- What are the treatment plans? How are they done, and how long do they take?
- Will the patient need to be in the hospital? When and for how long?

Talking with someone who has cancer

When talking with someone who has cancer, the most important thing is to listen. Try to hear and understand how they feel. Don't make light of, judge, or try to change the way the person feels or acts. Let them know that you're open to talking whenever they feel like it. Or, if they don't feel like talking right at that time, that's OK, too. You can offer to listen whenever they're ready.

There may be times when the uncertainty and fear make the person with cancer seem angry, depressed or withdrawn. This is normal and is a part of the process of grieving what was lost to the cancer (things like health, energy, time). Over time, most people are able to adjust to the new changes in their lives and go forward. Some may need extra help from a support group or a mental health professional to help them cope with these changes.

It's common for someone with cancer to feel guilty about causing their illness, especially if others have made them feel that way (did they do things in the past that might have caused their cancer?).

This stigma can lead them to blame themselves for their illness or feel left out, isolated, depressed, and as if they don't have much support. It can even affect how they approach their treatment, affect their quality of life, and might make them avoid follow-up care. If someone feels they are to blame for their cancer diagnosis, be reassuring and show you care. Help them understand that they cannot change the past, but they can take control of their life and care while going through treatment and beyond.

Some individuals with cancer may discuss death, express concerns about their future or their family's future, or share their other fears. You don't always have to respond but be prepared to listen to their pain or the unpleasant thoughts they may want to share. If you are asked for your opinion about their illness, treatment, or other aspects of their cancer journey, be open and honest, but do not try to answer questions that you don't know the answers to.

If you are unsure of what to say to someone with cancer, remember that you are not alone. Your relationship with the person may vary. It can be more challenging in a work environment due to different types of relationships with co-workers. Whether you know the person well or have been close friends for many years, showing interest and concern through words of encouragement or offering support is crucial. Sometimes, the simplest expressions of concern or just listening can be the most meaningful things you can do.

How do I get over feeling uncomfortable around someone who has cancer?

Feeling sorry for them, or feeling guilty for being healthy yourself, are normal responses. Cancer can be very unsettling for people who haven't dealt with it before. Don't be ashamed of your fears or discomfort. It's important to be honest with the person about how you feel, and you may find that talking about it is easier than you think.

Cancer often reminds us of our own life experiences. If you are close in age to the person with cancer or if you are very fond of them, you may find that this experience creates anxiety for you. You might find yourself feeling similar emotions to the person with cancer, such as disbelief, sadness, uncertainty, anger, sleeplessness, and fears about your own health. If this is the case, you may want to get support for yourself from a mental health professional or a local support group.

Understanding the cancer experience when you are a caregiver

One of the first steps after being informed that a loved one has cancer is to understand their diagnosis. This will help you understand the disease process and get an idea of what to plan for. Some of the first questions that you and the person with cancer can think about asking the doctor and/or the cancer care team are:

- What kind of cancer is it?
- Where is it? Has it spread to other areas from where it started?
- What are the treatment options? Which do you recommend?
- What's the goal of this treatment?
- How long will treatment last? What will it be like? Where will it be done?
- What side effects should we expect?
- How will treatment affect everyday activities?
- What's the likely long-term outcome?

When a person has cancer, no one can predict the outcome. There's no way for them to know for sure, but the cancer care team can give you an idea of how things are likely to go. This will become clearer over time and as they get to know the person with cancer better.

How do we deal with the uncertainty?

When a person has cancer, they go through different stages. Your understanding and your care will change over time, too. There will be times when you will need to get more information about the processes of treating the cancer. You also will need to know about side effects of treatments and when to contact the cancer care team to let them know.

Some ideas that have helped others deal with uncertainty and worry and feel more hopeful are:

- Learn what you can do to keep the person with cancer as healthy as possible and find out about the services available to you. This can help you feel more in control.
- Share your feelings of worry or uncertainty with a friend or counsellor you trust. Being open and dealing with emotions can help reduce anxiety.
- Focus your energy on wellness and what you can do to stay as healthy as you can. Remember to take care of yourself, as well as the person with cancer.
- Find ways to help yourself relax and take time for yourself.
- Make time for regular exercise and be as active as you can.
- Control what you can. Keeping your life as normal as possible and making adjustments to your lifestyle are just a few of the things you can control.

You play an important role in the health of the person you are caring for, but you cannot control how they are doing physically or mentally. Your loved one may have good and not-so-good days. Uncertainties, highs and lows are part of dealing with cancer – no one, not even the best caregiver, can control them.

What should I know about new medicines?

If the patient gets a prescription for a new medicine, be sure you know the name of the drug, what it's for, and why they are getting it. Some other things you need to know are:

- How and when should the medicine be taken?
- What's the dose?
- Should it be taken with food, water?
- Are there side effects? (Like sleepiness, nausea, or dry mouth?)
- Will it get in the way of other medicines or supplements the patient is taking?
- Are there foods, vitamins, or medicines that should be avoided while taking this drug?
- What should you do if a dose is forgotten? Take another? Skip it?

What happens when treatment ends?

After treatment, most patients go into a stage of healing and recovery. Less time is spent at the hospital and there are fewer appointments with the cancer care team. During this time, patient stress may decrease, but caregiver stress may not. The caregiver becomes responsible for the day-to-day care and monitoring of the patient. The caregiver plays a key role during this time and there can be many responsibilities.

What if treatment doesn't stop?

Sometimes treatment doesn't end at the expected time. In some patients, cancer is treated as a chronic illness - a disease that people live with and manage on a day-to-day basis, much like diabetes or heart disease.

Some patients are able to go back to work during long-term treatment, though they may need extra help just after treatments. In other cases, less frequent treatments and better management of side effects mean that the caregiver can work a more normal schedule during long-term or maintenance treatment.

References: Cancer.org