

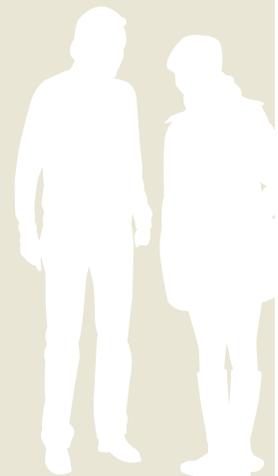


## Communicating as a **CAREGIVER**

### **COMMUNICATING WITH A LOVED ONE WHO HAS CANCER**

Communication is key when caring for a loved one who has a blood cancer. You and your loved one will need to be open and honest with each other from the start. Remember that you are both on the same team and hope for the best outcome. At some point, you will have disagreements and maybe even fight, but make it a priority to keep the lines of communication open and set boundaries and expectations early on to make things easier.

If you're not sure what to say to someone who has cancer, you are not alone. Sometimes the simplest expressions of concern are the most meaningful. And, sometimes, just listening is the best thing you can do.





## What to say

- **Speak from the heart.** For example:

*I don't know what to say, but I want you to know I care.*

*I'm here for you when and if you need me.*

*Let me know how I can help.*

- **Acknowledge this is a difficult time.** Listen to their fears, concerns or sad feelings.
- **Let them take the lead.** If you're familiar with cancer because you've been through it with someone else, let your loved one know and allow them to take the conversation from there.
- **Make room for humour.** Laughter can be a great way to relieve stress. If your loved one makes a joke about the situation, you can laugh with them. Make jokes only when your loved one can handle it and appreciate the humour.

## What not to say

### **"I know how you feel."**

While you do understand that your loved one is going through a difficult time, no one can know exactly how any one person with cancer feels.

### **"Always stay positive."**

While it's usually a good idea to be encouraging, it's also important not to tell people with cancer to "always stay positive." Saying this may seem to discount your loved one's legitimate fears, concerns or sad feelings.

### **"You look great."**

Be careful when bringing up your loved one's physical appearance. Cancer may bring with it a lot of physical changes—hair loss, weight loss, weight gain, skin changes, and swelling. They may struggle with body image and may be embarrassed or sensitive about the changes to their bodies. For example, weight loss is often a side effect of cancer and treatment, so a compliment on weight loss may come across as insensitive.

### **Sharing stories about other family or friends who have had cancer.**

Every person is different. Unless your loved one asks, avoid sharing stories of other family or friends who have or have had cancer even if they are doing well.

## Respect your loved one's privacy

As the caregiver, you may become your loved one's "gatekeeper" as friends and family members reach out to express concern or ask for updates. Ask your loved one who they plan to tell about the cancer diagnosis and how much they want to share. They may prefer to keep their diagnosis private, especially in the beginning. If your loved one does not want people to know, respect their wishes.

Be careful about what information you post on social media. Even if your loved one shares the diagnosis with friends or family, they may not want to share the diagnosis with acquaintances, coworkers or classmates. Even private social media profiles may not be as private as you think. Do not post on social media about your loved one's diagnosis without their approval.



### Be aware of cognitive issues

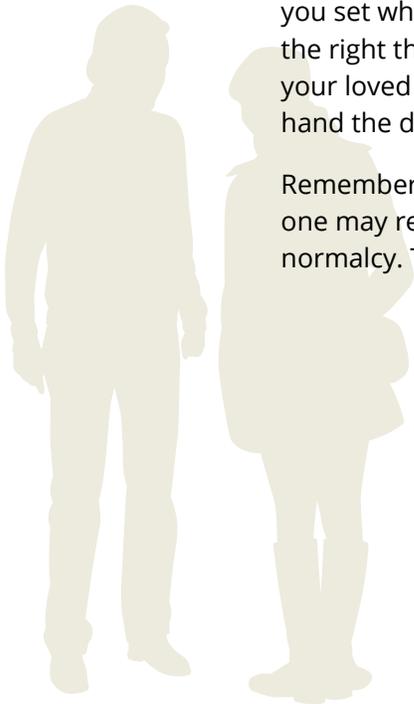
Your loved one may sometimes experience cognitive issues, often referred to as “chemo brain,” as a side effect of treatment. They may become forgetful, have trouble concentrating or seem confused at times. Be patient and understanding. If your loved one is struggling to remember things, suggest writing a to-do list, setting alarms on a mobile phone, or ask if it’s okay for you to remind them to take medication or carry out other tasks.

### Setting parameters and boundaries

Try not to make assumptions about what your loved one needs or wants. Find out what works best for both you and your loved one.

Keep the conversation ongoing. As treatment progresses, you may need to revisit the parameters you set when you first began providing care for your loved one. Don’t assume that something is the right thing to do. Ask if your loved one would like you to take over a responsibility. For example, your loved one may generally feel well enough to manage household chores but may need an extra hand the day after a chemotherapy infusion.

Remember, cancer may mean the loss of your loved one’s independence in many ways. Your loved one may resist your care at times and attempt to maintain his or her sense of independence and normalcy. Try not to take any resistance personally.



Use worksheet:

*Questions for Caregivers to Ask Their Loved Ones*



## Communicating with members of the healthcare team

The doctors, nurses, social workers and other members of the healthcare team can offer crucial support and encouragement as you help your loved one through cancer treatment. A good working relationship with the members of the healthcare team can make navigating the challenges of cancer treatment easier.

### Who makes up the healthcare team?

A number of healthcare professionals will be involved with your loved one's care. Based on your loved one's need, the team may include:

#### Doctors

<b>Hematologist-oncologists</b>	doctors who are specially trained to diagnose and treat patients who have blood cancers
<b>Oncologists</b>	doctors who treat patients who have cancer
<b>Radiation oncologists</b>	doctors who use radiation therapy to treat patients who have cancer
<b>Pathologists</b>	doctors who use microscopes and different techniques to study cells and tissues in order to identify diseases
<b>Hematopathologists</b>	doctor-pathologists who are board certified in both anatomical and clinical pathology and who examine blood, bone marrow and tissue samples
<b>General surgeons</b>	doctors who perform surgical procedures, such as splenectomies, lymph node biopsies and other tissue biopsies

Sometimes, your loved one's cancer care may also involve **specialists**, such as:

<b>Gastroenterologists</b>	doctors who specialize in treating patients who have digestive tract diseases
<b>Nephrologists</b>	doctors who specialize in treating patients who have kidney diseases
<b>Cardiologists</b>	doctors who specialize in treating patients who have heart disease
<b>Radiologists</b>	doctors who are trained to read and interpret imaging studies, such as a computed tomography (CT) scan or a magnetic resonance imaging (MRI) scan
<b>Psychiatrists</b>	doctors who can prescribe medication to help patients with mental health conditions



## Nurses

<b>Oncology nurses</b>	nurses who specialize in treating people who have cancer
<b>Nurse practitioners</b>	nurses who have advanced training in diagnosing and treating illness
<b>Oncology nurse navigators</b>	nurses who specialize in cancer and help patients overcome barriers to care and find resources

## Additional members of the healthcare team

<b>Physician</b>	medical professionals who diagnose illness, develop and manage treatment plans, prescribe medications, and often serve as a patient's principal healthcare provider
<b>Oncology pharmacists</b>	professionals who prepare chemotherapy doses, educate patients about side effects and perform safety checks (in hospitals); professionals who prepare oral cancer drugs and educate patients about the drugs' side effects (in community pharmacies)
<b>Radiology or lab technicians</b>	professionals who withdraw blood or take images of the patient's body
<b>Psychologists</b>	professionals who are trained to help patients with emotional and mental health conditions
<b>Social workers</b>	professionals who are trained to talk with patients and their families about their emotional or practical needs and to find them support services
<b>Child-life specialists</b>	healthcare professional who can help children and their families cope with serious illnesses, such as cancer
<b>Registered dietitians</b>	healthcare professionals who specialize in food and nutrition

Make sure you keep track of all the contact information for each member of your loved one's healthcare team. Not every person with a blood cancer will need support from every type of healthcare professional mentioned in these lists. The members who make up the healthcare team will depend on your loved one's needs.

Use worksheet: *Healthcare Team's Contact List* 





## At appointments

Your loved one's appointments are the best times to speak with members of the healthcare team. It's normal to feel nervous and worry that you and/or your loved one will forget to ask an important question during an appointment. Good preparation can improve your comfort levels and can make you feel more satisfied with doctor visits overall.

The following tips will help you to better communicate with members of the healthcare team during your loved one's appointments:

### Write down your questions.

- Number your concerns in order of importance, asking the most important questions first.
- Let the doctor know you have a list so that he or she can set some time aside during the appointment to respond to your questions.



Use worksheet:  
*Questions for the Healthcare Team*



### Take notes.

- Write down the doctor's answers to your questions.
- Ask the doctor to slow down or explain things in another way if you or your loved one is having trouble either following or understanding information.
- Notes can include the names of the members of the healthcare team, dates and times of future appointments, and when and how your loved one should be taking prescribed medicines.
- You can also ask the doctor if you can record the conversation so you and your loved one can listen to it again later.
- Ask for written information about the patient's diagnosis, treatment plan and lab results.



Use worksheet:  
*Appointment Details*



### Keep everything in one place.

- This way, nothing gets lost, and you always know where to find the information.
- Share this information with all the healthcare professionals your loved one sees for any health reason, and encourage the healthcare professionals to talk to each other to ensure the most comprehensive care.

### Watch for signs and symptoms or side effects.

- Encourage your loved one to tell the doctor about any signs, symptoms or side effects.
- Make sure you know who to contact in an after-hours or an emergency situation when you need immediate assistance.
- Ask what side effects, signs or symptoms require a trip to the emergency room and write them down.



**Keep medical records.**

- It's important to keep current copies of your loved one's medical information in an easy-to-find location.
- Take these records with you to any appointment, especially appointments with new doctors who will need to know the details of your loved one's diagnosis and treatment plan.

**Information check list**

- Your loved one's medical history
- The family medical history
- A list of current medications, supplements, and vitamins
- Immunization records
- Copies of recent imaging or scans
- Lab values
- A list of all doctors or specialists the patient sees



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