

# Communicating With Your Health Care Team

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# Communicating With Your Health Care Team

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## EDITOR

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*Your team of doctors, nurses and social workers are valuable sources of support as you cope with a cancer diagnosis.*

When you first heard the word “cancer,” you may have felt shocked, scared or numb. You may have felt disbelief. Reactions to a diagnosis are unique; there is no wrong or right way to respond to this news. Many newly diagnosed people face similar challenges: you may want to obtain information about the diagnosis and treatment options, ask questions to understand how the treatment plan will affect your life and find out what resources may be helpful throughout the process.

The relationship you have with your health care team can make a big difference in how you cope with these challenges. Research shows that people who have good communication with their health care team are more satisfied with their medical care than those who do not. They also tend to fare better emotionally and better manage symptoms such as treatment side effects and pain.

This booklet discusses ways to develop good communication with your health care team so you have access to the best possible care. It also explores ways you can take an active role in your care as a key member of that team. After all, you are the person who best knows how your treatment is affecting your quality of life and what issues are most important to you.

## Meet the Members of Your Team

**Today, cancer is treated through a “multidisciplinary” approach—that is, many different health care providers come together as a team to care for you. Some of the professionals with whom you may work with are:**

- Medical oncologists
- Surgical oncologists
- Radiation oncologists
- Oncology nurses
- Oncology social workers
- Registered dietitians
- Psychologists and psychiatrists
- Pain specialists (anesthesiologists, neurologists and others)
- Plastic surgeons (for reconstructive surgery)
- Rehabilitation specialists (physical therapists, occupational therapists and speech therapists)
- Pharmacists
- Home health aides

Other important professionals include financial specialists, case managers and patient navigators. You and your caregivers are also key members of your team.

# Making the Most of Your Medical Appointments

Your doctors' appointments will provide the best opportunity to speak with members of your health care team.

It is normal to feel nervous or anxious when going in for an appointment; you might worry that you will forget to ask important questions or that your doctor may be too busy to listen to your concerns. Such fears are normal, and good preparation can improve how comfortable you are during your appointments. It can also make you more satisfied with your appointments overall. Here are some tips for communicating with your health care team during appointments:

**Write down your questions.** Bring a written list of any questions you may have. Number your concerns in order of importance and ask the most important questions first. Let your doctor know you have a list so they can set aside some time during the appointment to go over it with you.

**Take notes or ask your doctor if the appointment can be voice recorded.** Write down your doctors' answers to your questions. Take down any other important information you want to remember; for example, the names of the members of your health care team, places you were referred to, dates and times of future appointments and when and how to take any medications you were prescribed.

**Keep everything in one place.** It may be helpful to have a binder where you can keep all the notes and papers you are receiving. This way, nothing gets lost and you always know where to look for the information.

## Questions to Ask Your Doctor about Your Diagnosis

**Getting as much information as you can about the goals of your treatment and how it will affect your life will help you feel more satisfied with your care. Some questions you may want to ask your doctor include:**

- What is my type and stage of cancer?
- Where can I learn more about my diagnosis and treatment options?
- What is the recommended treatment?
- How often will I receive treatment?
- What are the possible side effects?
- What are the possible benefits and risks of this treatment?
- If I have questions during my treatment and my doctor is not available, who can I ask? For example, is a nurse, social worker or other specialist available?
- Is there any information I can read about this treatment or procedure?
- Is there anything else I should know?
- Who should I call in case of an emergency?

**Bring someone with you.** Let the person know ahead of time how they can be most helpful to you during your appointment. In addition to giving you moral support, they can:

- Provide another set of ears to catch key points you may have missed.
- Take notes for you as you talk with your doctor.
- Remember important information about your cancer or other symptoms that you may have forgotten.
- Advocate on your behalf, especially if something is unclear to you.

**Make sure you understand.** If you don't know what something means, ask. Make your questions specific and brief. Other tips include:

- Use “I” statements whenever possible—saying “I don't understand” is more effective than “You're being unclear.”
- Try repeating the information back to your doctor—“So you mean I should...?”
- If you understand better with visual aids, ask to see the X-rays or slides, or ask your doctor to draw a diagram.

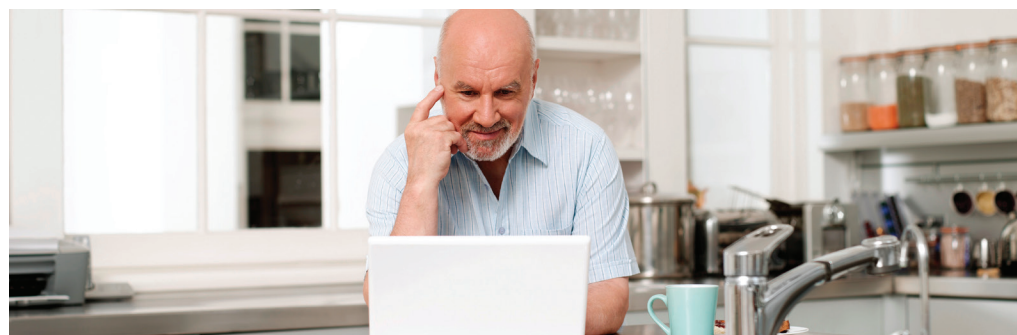
**Ask for a contact.** Important questions may come up between appointments. Find out whether there is someone you can talk to if you have an important issue or emergency. If your doctor is unavailable, is there someone else, such as a nurse or social worker, whom you can call? Is there another means of communication you can use? Sometimes, doctors may provide an email contact or patient portal for questions that arise in between appointments.

## Understanding Your Treatment Options

One of the best ways to begin making decisions about your health is to educate yourself.

Members of your health care team are very knowledgeable about the different aspects of cancer and will likely be your main source of information about your diagnosis and treatment. Here are some tips for communicating with your health care team about your treatment options:

**Do your research.** Once you know the type and stage of cancer, find out what the standard of care is for someone with your diagnosis. Ask your doctor or nurse to suggest reliable organizations, publications or websites that focus on the diagnosis or the recommended treatment. If you are unable to use the internet yourself or feel overwhelmed with the amount of information you are finding, ask a family member, friend, patient navigator or local librarian to help you. Use the internet with caution; there is a multitude of information online about various types of cancer and cancer treatment. It is important to educate yourself with credible sources and information that is specific to your diagnosis.



## Keeping a Side Effect Journal

**To help you get relief from side effects, your doctors and nurses need to know specific details about your symptoms. By keeping a side effect journal and bringing it with you to medical appointments, you can have this kind of information ready to share with them. Some of the things you may want to write down in your journal include:**

- The date and time the side effect occurs.
- How long the side effect lasts.
- How strong the side effect is—for example, if you experience pain, how strong is it on a scale from 0 to 10, where 0 equals no pain and 10 is the worst pain possible?
- What impact the side effect has on your daily activities—for example, does the pain keep you from sleeping, eating, walking, working or exercising?
- You may also want to include any non-urgent questions or concerns that come up.

**Work with a specialist.** Doctors who specialize in treating cancer are called oncologists. For the best medical care, it's important to work with an oncologist who specializes in treating your type of cancer. This is especially important if you have been diagnosed with a rare cancer. To find a specialist, you can:

- Ask your primary care physician for a referral.
- Get recommendations from friends, family members or other patients.

- Call your health insurance company's customer service line and ask a representative for a list of local specialists in your network.
- Search online—many professional and cancer organizations provide searchable listings of cancer specialists. For example, the American Society of Clinical Oncology has a database of oncologists. Go to [www.cancer.net](http://www.cancer.net) and type “oncologist” in the search box.

Another option is to choose a cancer center known for providing high-quality patient care and then select a specialist at that hospital. Many patients choose this option even if they need to travel long distances for appointments. For a list of some recommended centers, see the National Cancer Institute's list at [cancercenters.cancer.gov](http://cancercenters.cancer.gov) or call 1-800-4-CANCER.

It's important that you feel comfortable with and trust your doctor. If your preferred oncologist does not specialize in treating your diagnosis, they can still consult with a specialist about your treatment options.

**Agree on the treatment goals.** When your doctor recommends a treatment or procedure, make sure you understand the reason(s) why. For example, if you are getting chemotherapy or another cancer drug, is the goal to cure the cancer, control the cancer (shrink the tumor or keep it from growing) or relieve symptoms caused by the cancer? Let your doctor know if you have certain wishes or preferences with regard to treatment so these preferences can be taken into account. Your lifestyle and daily activities may also influence treatment recommendations.

**Discuss the cost of your care.** Research shows that many patients do not feel comfortable asking their doctors how much

treatment is going to cost and many doctors do not normally bring it up either. If possible, it is important to find out the cost of your medications before starting treatment. Consider asking your health care team the following questions to better understand the cost of treatment:

- How much will my treatment cost?
- Is there a co-pay for each doctor visit and for each individual treatment? If so, how much is my co-pay?
- What does my insurance cover?
- Does my health insurance company need to approve my treatment plan before I begin?
- Do you offer payment plans?
- Can you refer me to financial assistance resources?
- Will my medication require a co-pay?
- Is there a less expensive option for my medication?
- Will my prescription cost be an ongoing or a one-time expense?

Your doctor may not know the answer, but they should be able to refer you to a social worker, pharmacist or hospital financial specialist who can help. If you can't afford the treatment you need, financial assistance may be available to you. Some financial assistance resources are listed on the 'Frequently Asked Questions' chapter of this booklet.

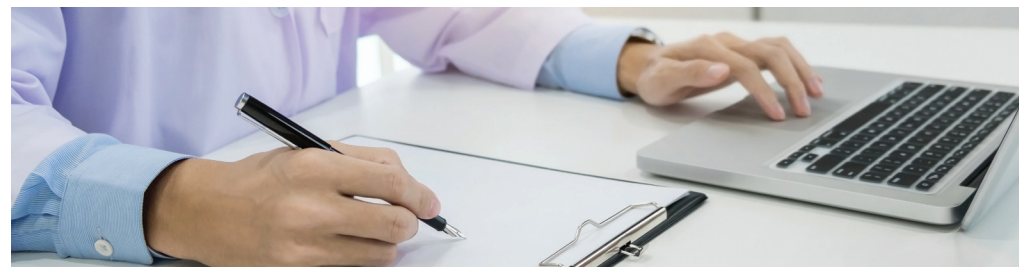
**Get a second opinion.** Before you begin treatment, you may want to make an appointment with another oncologist to review treatment recommendations. No member of your health care team will mind if you seek a second opinion. In fact, many specialists encourage it and may even provide a referral.

If you are nervous about letting your doctor know you want a second opinion, tell them that you are very satisfied with the care you are receiving, but just want to make sure you are aware of all your options. It is important that you feel comfortable with any decisions made in regard to treatment options and getting a second opinion may help you make decisions about your medical care.

### **Find out how the treatment plan will affect your daily life.**

Cancer treatments are often given at a doctor's office or hospital. However, many of today's treatments can also be taken at home. Find out where you will be treated, how often you will receive treatment and for how long. Will you need someone to accompany you to appointments or to help care for you at home? Will you be able to continue your usual activities, such as working or going to school? Knowing such information ahead of time will allow you to prepare for changes to your routine.

**Ask about possible side effects.** Find out what side effects you can expect from your treatment and how your health care team plans to manage them if they occur. See if there is anything you or your health care team can do to prevent or reduce the chances that you will develop certain side effects. There are effective ways to prevent side effects such as nausea, vomiting, diarrhea, constipation and pain. It is important to advocate for yourself if side effects do arise during treatment. Do not be afraid to ask your doctor about the best ways to manage them.





**Get the facts about reconstructive and plastic surgery.** Some surgeries, such as those for head, neck and oral cancer, breast cancer or skin cancer, may affect your appearance. Therefore, you may want to ask your doctor about reconstructive/plastic surgery. Reconstructive/plastic surgery can often be done at the same time as your oncology surgery, so ask about this option as early as possible. A board-certified plastic surgeon can give you information about your options. To find a certified plastic surgeon, visit the website of the American Society of Plastic Surgeons at [www.plasticsurgery.org](http://www.plasticsurgery.org) and click on “Find A Surgeon.”

**Learn about fertility preservation options.** If you plan to have children in the future, or if you are unsure, find out whether the treatment your doctor is recommending could affect your ability to conceive. It is important to speak with your doctor about fertility concerns before you begin treatment. They may be able to select a treatment or technique that preserves your fertility or they may be able to refer you for sperm/egg banking prior to treatment. Doctors do not always discuss fertility preservation, especially if they want to begin treatment right away. If this is a priority for you, make sure to discuss your concerns with your medical team from the beginning.



## How Your Pharmacist Can Help

A pharmacist is a professional who is qualified to fill prescription medications ordered by a doctor. They often provide information on how to take medications, potential side effects, potential drug interactions and tips on taking prescription medication on schedule.

**If possible, use the same pharmacy for all your medications.**

Get to know your pharmacist so they can help answer your questions. If you are taking multiple medications for different health problems, your pharmacist can help you understand any potential drug interactions that may be harmful or make your medication less effective.

**You may also want to try your insurance company's or pharmacy's mail-order service.** This is a service that delivers your prescription to your home. In many cases, the co-payment for your medication may even be lower than if you pick up your refill in-person at your pharmacy. This is a good option if long waits at the pharmacy keep you from refilling or picking up your medication or if your local pharmacy does not carry your prescribed medication.

Regardless of the type of medication that a doctor prescribes, pharmacists help you by:

**Explaining how the medication works.** Your doctor or another member of your health care team may have reviewed the ins-and-outs of the medication when you received your prescription, but hearing the information more than once is helpful—especially at what can be a stressful time.



## Questions to Ask Your Pharmacist

**When starting a new medication, here are some questions you should ask to help you communicate with your health care team and to receive the best care:**

- What is the best way to take my medication?
- How does this medication work?
- What should I do if I miss a dose?
- How much will my prescription cost?
- What time of the day should I take my medication and how often?
- Should I take it with or without food?
- How much water should I drink when taking this medication?
- What are the possible side effects and what side effects require me to call the doctor?
- What type of co-pay assistance is available?

**Explaining what your insurance covers.** An insurer may require that a generic (or biosimilar) version of the drug be dispensed, if one exists. Your pharmacist can help you determine if this is the case and explain any differences between the original drug and the covered drug, including any out-of-pocket cost implications.

**Recommending financial resources.** There are a number of financial aid organizations and patient assistance programs available to help patients with their out-of-pocket expenses. Your pharmacist can be a good source of information about these resources.



# During Treatment and Beyond

The more you feel that you can openly discuss any matters of concern with your health care team, the better you are likely to feel about your care over the long term.

Don't be afraid or embarrassed to ask questions—always seek the care you need and deserve. Here are some additional topics to discuss with your health care team:

**Side effects.** Chemotherapy, surgery, radiation, targeted treatments, hormonal therapy and other cancer treatments may all result in different side effects. Most side effects can be prevented or managed with medications and other techniques. Some common and often manageable side effects include:

- Fatigue (feeling very tired)
- Nausea and vomiting
- Hair loss
- Diarrhea or constipation
- Mouth sores
- Pain
- Rash and other skin changes
- Neutropenia (low white blood cell count that puts you at risk of infection)
- Lymphedema (swelling, usually of an arm or leg)
- Neuropathy (nerve damage often resulting in periodic numbness in the hands and feet)

Talk with your doctor about any side effects or symptoms that come up. Some patients worry that if they bring up a side effect, their doctor will be distracted from treating the cancer; that is not true. Side effect management is an important part of comprehensive cancer care. Managing symptoms will make it easier for you to stick with your treatment plan.

**Your feelings and emotions.** Often, people need help coping with challenging emotions raised by cancer, such as sadness, anger or fear. While family members and friends are likely to be your main source of support, you may want to seek additional help. If so, your doctor or nurse can refer you to an oncology social worker, counselor or other professional who specializes in helping people cope with the emotional challenges of cancer.

Support groups connect you with others in a similar situation to share experiences and feelings and provide support. Ask your health care team if there are local support groups that would give you an opportunity to speak with other patients in a similar situation. CancerCare offers free support services such as telephone and online support groups. You may also want to explore peer-to-peer networks, which match you individually with someone facing the same (or similar) diagnosis.



**Practical matters.** Experts agree that the highest-quality care for people with cancer is care that addresses not just their medical needs, but their psychosocial needs as well. Psychosocial support refers to services that address emotional concerns, as described on the previous page, and practical issues that can interfere with completing treatment. It also includes providing support with day-to-day concerns so you can have the best quality of life during treatment. Some of the many practical issues your health care team may be able to help you with include:

- Getting transportation to and from treatment
- Talking to your children about your diagnosis
- Deciding whether you should, timing and how to talk with your employer about your diagnosis
- Adjusting a treatment schedule to attend a special event
- Finding financial help for medications or household bills
- Locating home care or other services

The members of your health care team can assist you directly with many practical matters and/or refer you to other support services as necessary.

**Resources for caregivers and family members.** A cancer diagnosis often causes a ripple effect, impacting loved ones and family members. To help ensure that the needs of your loved ones are met, ask your doctor about resources available to them. For example, CancerCare provides specialized support services for children and teens to help them understand and cope with a loved one's cancer diagnosis. Also, young adults (ages 20–39) that have a loved one with cancer can join an online support group led by an oncology social worker at CancerCare. CancerCare also provides free services including case management and support groups available by telephone and online throughout the country and individual counseling within New York and New Jersey.

**Your post-treatment survivorship care plan.** As you get close to completing treatment, it is important that you and your medical team discuss what your follow-up care will be like. In the months and years ahead, your doctors will continue to monitor you for any long-term side effects of your treatment. They will also check for symptoms of recurrence (a return of your cancer), spread or of new cancers developing.

To manage your follow-up care, ask your doctor to put together a written survivorship care plan. This document should include a summary of your diagnosis and all the treatments you received, as well as a follow-up plan of the steps you need to take to achieve the best health and well-being possible. For details about specific items to include in your plan, read CancerCare's booklet "After Treatment Ends: Tools for the Adult Cancer Survivor."





# CancerCare Can Help

It is very difficult to receive a cancer diagnosis, and adjusting to life changes can be challenging.

CancerCare can help. We are a national nonprofit organization providing free, professional services to anyone affected by cancer. Our licensed oncology social workers can provide case management, counseling, support and education, help navigating the complicated health care system and provide information on support groups and other resources. To learn more about how CancerCare helps, call us at 800-813-HOPE (4673) or visit [www.cancercares.org](http://www.cancercares.org).

You will likely also build your own personal support network, comprised of family and friends. In doing so, it's best to take some time to think about the people in your life and how they are best suited to help. Match the task to their strengths—ask a family member who loves to shop to pick up something for you at the store; ask a friend who's a good listener to come over for a chat.

## CancerCare's Online Helping Hand

**CancerCare's Online Helping Hand at [www.cancercares.org/helpinghand](http://www.cancercares.org/helpinghand) is a searchable, online database of financial and practical assistance available for people with cancer. This comprehensive online tool features up-to-date contact information and descriptions for hundreds of national and regional organizations offering financial help to people with cancer. You can search by diagnosis, zip code and type of assistance.**



# Frequently Asked Questions

## **Q: Where can I find a simple explanation of some of the complicated medical terms my doctor uses?**

A: The first and best place to turn to is your health care team itself. Whenever your doctor uses a term that you don't understand, ask what the word means. It is okay to tell your doctor, "I don't know what that word means. Could you please explain it to me?" Asking questions will help you better understand medical terms and what they mean for your treatment.

Another valuable resource that provides simple explanations for complex medical terms and procedures is the National Cancer Institute's Dictionary of Cancer Terms, a resource with more than 7,000 terms related to cancer and medicine. This resource is especially helpful if you are doing research in between doctors' appointments. You can view the glossary at [www.cancer.gov/dictionary](http://www.cancer.gov/dictionary).

## **Q: I know my oncologist is focused on treating my cancer, but I wish she was more compassionate towards me. What can I do?**

A: Some doctors and health care teams may not have as much time as they would like to sit down and talk with you about your needs and concerns. It is also possible that some medical professionals lack training in regards to effective ways to communicate and cope with emotions. Some health care professionals are trying to change that and many medical schools now require coursework on doctor/patient communication. Many organizations, such as CancerCare, are also raising awareness of how important it is to address the full range of patients' concerns.

This booklet discusses many steps you can take to improve communication with the members of your health care team. You can also speak with a social worker at CancerCare for additional tips.

## **Q: I have tried to improve my relationship with my oncologist, but it's just not working. I really want to try another physician, but I'm scared to. Should I just stay with my current doctor?**

A: A strong relationship with your oncologist can make a tremendous difference in how you cope with your cancer and treatment. However, they are only one member of your medical team. If you are not able to communicate directly with this person, try talking to a nurse, nurse practitioner or social worker associated with your oncologist's practice. Someone else may be able to meet your needs.

If you have tried many of the tips in this booklet and nothing works, or you really believe changing doctors would improve how you feel about the care you are receiving, trust your instincts. You have a right to feel comfortable with your health care team and satisfied that you are getting the best care possible. Before selecting another oncologist or health care team, do your research. Ask other patients for recommendations, or contact diagnosis-specific cancer organizations for a list of recommended doctors or cancer centers. Many cancer centers and medical centers have physician referral services to help you.



In addition to being among the first to receive a new treatment, people who take part in clinical trials are closely monitored by their doctors and other researchers and help future patients by advancing the science of cancer. Your doctor can tell you whether there are any trials that may be right for you. There are also resources available online. For more information, see the resources listed on the opposite page.



## Resources

### Medical Information

#### American Cancer Society

800-227-2345  
[www.cancer.org](http://www.cancer.org)

#### Cancer.Net

888-651-3038  
[www.cancer.net](http://www.cancer.net)

#### National Cancer Institute

800-422-6237  
[www.cancer.gov](http://www.cancer.gov)

### Supportive Resources

#### CancerCare

800-813-HOPE (4673)  
[www.cancercare.org](http://www.cancercare.org)

#### Cancer Hope Network

800-467-3638  
[www.cancerhopenetwork.org](http://www.cancerhopenetwork.org)

#### Imerman Angels

877-274-5529  
[www.imermanangels.org](http://www.imermanangels.org)

#### Caregiver Action Network

202-454-3970  
[www.caregiveraction.org](http://www.caregiveraction.org)

### Financial Assistance Resources

#### CancerCare

800-813-HOPE (4673)  
[www.cancercare.org](http://www.cancercare.org)

#### CancerCare Co-Payment Assistance Foundation

866-55-COPAY (866-552-6729)  
[www.cancercarecopay.org](http://www.cancercarecopay.org)

#### Patient Advocate Foundation

800-532-5274  
[www.patientadvocate.org](http://www.patientadvocate.org)

#### Partnership for Prescription Assistance

888-477-2669  
[www.pparx.org](http://www.pparx.org)

#### Social Security Administration

[www.ssa.gov](http://www.ssa.gov)  
800-772-1213

### Clinical Trials

#### EmergingMed

877-601-8601  
[www.emergingmed.com](http://www.emergingmed.com)

#### National Cancer Institute

800-422-6237  
[www.cancer.gov/clinicaltrial](http://www.cancer.gov/clinicaltrial)

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