BE YOUR OWN ADVOCATE

As someone living with cancer, you are a consumer of services, and are entitled to the best care. Being a health care advocate means feeling comfortable with your health care team and satisfied that you are getting the best possible care. Here are few ways to express your wishes, questions and needs in a clear and direct way so that other people, like your health care team, are able to understand what it is you want and need.

BEING AN ADVOCATE

Educate yourself on your diagnosis. As someone living with cancer, it is important to remember that you are a consumer of health care. The best way to begin making difficult decisions about health care is to educate yourself about your cancer and who is on your health care team. CancerCare and other reputable organizations have helpful literature and user-friendly websites that provide detailed information about cancer treatments, side effects, and other related concerns.

Take advantage of resources and services. A cancer diagnosis raises a wide range of challenges and concerns. Fortunately, there are local and national resources to assist you with many of the issues that come up. Your health care team is one great resource for information about counseling, home care, transportation and child care. Another is CancerCare’s A Helping Hand at www.cancercare.org/helpinghand. This 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.

Understand your insurance policy. Understand ahead of time which treatments and medical services your insurance covers, and whether you are still responsible for any out-of-pocket expenses. A good first step is to contact your insurance company using the telephone number found on the back of your insurance card. Read CancerCare’s fact sheet titled “Understanding Your Insurance Policy” for more information.

COMMUNICATE WITH YOUR HEALTH CARE TEAM

The relationship you have with your health care team can make a big difference in how you cope with your cancer diagnosis. Doctors’ appointments are the main time you will speak with the members of your health care team. Good preparation can improve how comfortable you are during your appointments and can also make you more satisfied with your appointments overall.

Ask Questions. Bring a written list of any questions you have. Number your concerns in order of importance, and ask the most important questions first. Let your doctor know you have a list so he or she can set aside some time during the appointment to go over it with you. Write down your doctors’ answers to your questions. Take down any other important information you want to remember—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 medicines you were prescribed.

**Keep a Side Effect Journal.** To help you get relief, 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 a side effect occurs
- How long a 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—does the pain keep you from sleeping, eating, walking, working, or exercising?
- Any non-urgent questions or concerns that come up

**Make the Most of Your Medical Appointments.**

Bring someone with you. Let the person know ahead of time how he or she can be most helpful to you during your appointment. In addition to giving you support, he or she 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.
- Make sure you understand. If you don’t know what something means, ask. Make your questions specific and brief.
- 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 you can call?

**TAKE CARE OF YOURSELF**

Though you may have others around you who are supportive, you must make sure that you take the best possible care of yourself. The better you care for yourself, the better able you will be to cope with your diagnosis. Oncology social workers are licensed professionals that understand the complex issues that can arise by cancer. CancerCare’s oncology social worker can help you better understand your diagnosis and help find resources that fit your needs. To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

**CancerCare® Can Help**

Founded in 1944, CancerCare is the leading national organization providing free support services and information to help people manage the emotional, practical and financial challenges of cancer. Our comprehensive services include counseling and support groups over the phone, online and in-person, educational workshops, publications and financial and co-payment assistance. All CancerCare services are provided by professional oncology social workers and world-leading cancer experts.

To learn more, visit www.cancercare.org or call 800-813-HOPE (4673).

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