

TALKING WITH YOUR HEALTH CARE TEAM: FOLLOW-UP CARE

During cancer treatment, you had a lot of practice in getting the most out of every medical care visit. These same skills now apply to you as a survivor and are especially helpful if you are changing doctors or going back to a family or primary care doctor you may not have seen for a while. You have a team of professionals who take care of you in addition to doctors: nurses, social workers, psychologists, pharmacists and others who care for your physical and mental wellbeing. It is important to be able to talk openly with your team. All of you need information to manage your care. Be sure to tell your providers if you are having trouble doing everyday activities, and talk about new symptoms to watch for and what to do about them. If you are concerned that the treatment you had puts you at a higher risk for having health problems, be sure to discuss this with your doctor as you develop your follow-up plan.

WHAT SHOULD PATIENTS TELL THEIR DOCTOR DURING FOLLOW-UP VISITS?

During each visit, patients should tell their doctor about:

- Any symptoms that they think may be a sign that their cancer has returned.
- Any pain that bothers them.
- Any physical problems that interfere with daily life or are bothersome, such as fatigue; difficulty with bladder, bowel, or sexual function; difficulty concentrating; memory changes; trouble sleeping; and weight gain or loss.
- Any medicines, vitamins, or herbs they are taking and any other treatments they are using.
- Any emotional problems they are experiencing, such as anxiety or depression.
- Any changes in their family medical history, including any new cancers.

It is important to note that cancer recurrences are not always detected during follow-up visits. Many times, recurrences are suspected or found by patients themselves between scheduled checkups. It is important for patients to be aware of changes in their health and report any problems to their doctor. The doctor can determine whether the problems are related to the cancer, the treatment the patient received, or an unrelated health issue.

When planning a follow-up care schedule, patients should consider who will provide the follow-up care and who will provide other medical care. They should select a doctor with whom they feel comfortable. This may be the

same doctor who provided the person's cancer treatment. For other medical care, people should continue to see a family doctor or medical specialist as needed.

Some people might not have a choice in who provides their follow-up care, because some insurance plans pay for follow-up care only with certain doctors and for a set number of visits. In planning follow-up care, patients may want to check their health insurance plan to see what restrictions, if any, apply to them.

WHAT OTHER SERVICES MAY BE USEFUL DURING FOLLOW-UP CARE?

Other services that may be helpful not just during cancer treatment but also as part of follow-up care include support groups, couples counseling, genetic counseling, fertility/sexual counseling, home care services, nutrition counseling, physical therapy, pain management, and occupational or vocational therapy. Some patients may also need financial aid or assistance with transportation to and from appointments. Information about these and other services is available from local and national cancer organizations, hospitals, local churches or synagogues, the YMCA or YWCA, and local or county government agencies. Patients can also ask their doctor, nurse, or social worker how to find these services.

To get the most from these services, it is important to think about what questions to ask before calling. Many people find it helpful to write down their questions and to take notes during the conversation. It is also important to find out about eligibility requirements for these services. Organizations providing many of these services are listed in the "Resources" section of the National Cancer Institute (NCI) booklet *Facing Forward: Life After Cancer Treatment*, which is available at www.cancer.gov/cancertopics/life-after-treatment/page9#h2.

HOW CAN YOU GET THE MOST FROM YOUR FOLLOW-UP VISITS?

Here are some ideas that helped others with their follow-up care:

- Ask someone to come with you to your doctor visits. A friend or family member can help you think about and understand what was said. He or she also may think of new questions to ask.
- Make a list of questions ahead of time and bring it with you.
- Take notes or ask if you can tape-record the answers.
- Ask your most important questions first, in case the doctor runs out of time.
- Don't be afraid to ask for more time when you make your next appointment or ask the doctor to suggest a time when you could call and get answers to your questions.
- Ask to talk with the doctor or nurse in a private room with the door closed.

- Express yourself clearly.
- Describe your problem or concern briefly.
- Tell the doctor how your problem or concern makes you feel.
- Ask for what you want or need, for example, “I am tired most of the time each day. I’ve tried napping, but it doesn’t help. My fatigue gets in the way of my daily life. What can be done to help me with this problem?”
- Tell your doctor if you need more information.
- Ask for booklets or other materials to read at home.
- Ask the doctor to explain what he or she said in terms you understand.
- Repeat back in your own words what you think the doctor meant.
- Ask your doctor or pharmacist about the best way to take your medicine and about possible side effects.

National Cancer Institute (NCI) Fact sheet 7.48, Follow-up Care After Cancer Treatment: Questions and Answers (www.cancer.gov)
NCI, Facing Forward: Life After Cancer Treatment (www.cancer.gov)