
CANCER FACTS

National Cancer Institute • National Institutes of Health
Department of Health and Human Services

Follow-up Care: Questions and Answers

It is natural for anyone who has completed cancer treatment to be concerned about what the future holds. Many people are concerned about the way they look and feel, and about whether the cancer will recur (come back). They wonder what they can do to keep the cancer from coming back. They also want to know how often to see the doctor for follow-up appointments, and what tests they should have. Understanding what to expect after cancer treatment can help patients and their loved ones plan for follow-up care, make lifestyle changes, and make decisions about quality of life and finances.

1. What does follow-up care involve, and why is it important?

Follow-up care involves regular medical checkups that include a review of a patient's medical history and a physical exam. Imaging procedures (methods of producing pictures of areas inside the body); endoscopy (the use of a thin, lighted tube to examine organs inside the body); or lab tests may be part of follow-up care for certain cancers. Physical therapy, occupational or vocational therapy, pain management, support groups, or home care may also be included in the follow-up care plan.

Follow-up care is important because it helps to identify changes in health. The main purpose of follow-up care is to check for the return of cancer in the primary site (recurrence), or the spread of cancer to another part of the body (metastasis). Follow-up care can also help to identify the development of a second cancer, unknown or unusual treatment side effects, and late effects of cancer treatments (side effects that develop months or years after treatment).

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 problem.

2. How are follow-up care schedules planned?

Ongoing health needs are not the same for everyone. Follow-up care is individualized based on the type of cancer, the type of treatment received, and the person's overall health. In general, people return to the doctor for follow-up appointments every 3 to 4 months during the first 2 to 3 years after treatment, and once or twice a year after that.

At these follow-up appointments, the doctor may recommend tests to check for recurrence or to screen for other types of cancer. In many cases, it is not clear that follow-up tests improve survival or quality of life. This is why it is important for the doctor to help determine what follow-up care plan is appropriate. The doctor may not need to perform any tests if the person appears to be in good physical condition and does not have any symptoms. It is important for the patient to talk with the doctor about any questions or concerns related to the follow-up care schedule.

When planning a follow-up care schedule, patients should consider who will provide the follow-up care and other medical care. They should think about selecting 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 can 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. Some insurance plans pay for follow-up care only with certain doctors, and for a set number of visits. Patients may want to check their medical coverage plan to see what restrictions, if any, apply to their follow-up care.

3. Do some doctors or clinics specialize in follow-up care?

Very few comprehensive cancer centers and academic medical centers have clinics devoted to the follow-up care of adult cancer patients. However, a number of clinics provide follow-up care for pediatric cancer survivors. Patients can contact local comprehensive cancer centers or academic medical centers to see if follow-up care clinics exist in their area. A list of National Cancer Institute (NCI)-designated cancer centers is available in the fact sheet *The National Cancer Institute Cancer Centers Program*. This fact sheet is at http://cis.nci.nih.gov/fact/1_2.htm on the Internet. The Association of Cancer Online Resources (ACOR), a cancer information system that offers access to electronic mailing lists and Web sites, provides a list of long-term follow-up care clinics for children and adolescents treated for cancer. This list is on ACOR's Pediatric Oncology Resource Center Web page at <http://www.acor.org/ped-onc/treatment/surclinics.html> on the Internet.

4. What questions should people ask their doctor about follow-up care?

People may want to ask the doctor these questions about follow-up care:

- How often should I have a routine visit?
- What follow-up tests, if any, should I have?
- How often will I need these tests?
- What symptoms should I watch for?
- If I develop any of these symptoms, whom should I call?

Many patients find it helpful to write these questions down and take notes, or tape their discussions with the doctor to refer to at a later time.

5. How can patients deal with their emotions during follow-up care?

It is common to experience stress, depression, and anxiety after cancer treatment. Many people find it best to talk about their feelings with family and friends, health professionals, other patients, and counselors such as clergy and psychotherapists. Being part of a support group may be another effective outlet for people to share their feelings. Relaxation techniques such as imagery and slow rhythmic breathing can also help to ease negative thoughts or feelings. Reaching out to others by participating in volunteer activities is also an effective way for a person who has completed cancer treatment to feel stronger and more in control. However, people who continue to experience emotional distress should talk to their doctor about a referral for further evaluation of what may be causing or contributing to their distress, and how to deal with it.

6. What kinds of medical records and information should patients keep?

It is important for people to keep records of their health history. Patients may not always see the same doctor for their follow-up care, so having this information available to share with another doctor can be helpful. It is important to keep track of the following types of information:

- Specific type of cancer (diagnosis)
- Date(s) of cancer diagnosis
- Details of all cancer treatment, including the places and dates where treatment was received (for example, type and dates of all surgeries; names and doses of all drugs; sites and total amounts of radiation therapy)
- Contact information for all doctors and other health professionals involved in treatment and follow-up care
- Complications that occurred after treatment
- Information on supportive care received (for example, pain or nausea medication, emotional support, and nutritional supplements)

7. What other services may be useful during follow-up care?

Other services that may be helpful during follow-up care include financial aid and housing for patients receiving follow-up care. Information about services after cancer treatment is available from national cancer organizations, hospitals, local churches or synagogues, the YMCA or YWCA, or local or county government agencies. To get the most from any of these services, it is important to think about what questions to ask before calling. Many people find it helpful to write out their questions, and to take notes during the conversation. It is also important to find out about eligibility requirements for services.

8. Does the NCI have guidelines for follow-up care?

No, the NCI does not have such guidelines. However, some organizations do have these guidelines for some types of cancer.

The American Society of Clinical Oncology (ASCO), a nonprofit organization that represents more than 21,500 cancer professionals worldwide, has published clinical practice guidelines on a variety of topics, including follow-up care for breast and colorectal cancer. These guidelines, called Patient Guides, are available on the ASCO Web site at http://www.asco.org/ac/1,1003,_12-002132,00.asp on the Internet.

The National Comprehensive Cancer Network (NCCN), which is also a nonprofit organization, is an alliance of cancer centers. The NCCN provides Patient Guidelines, which include follow-up care information for several types of cancer. Most of the guidelines are available in English and Spanish versions. The Patient Guidelines are on the NCCN's Web site at http://www.nccn.org/patients/patient_gls.asp on the Internet.

The Children's Oncology Group (COG) is an NCI-supported clinical trials cooperative group devoted exclusively to childhood and adolescent cancer research. COG develops and coordinates cancer clinical trials conducted at the 238 member institutions. COG developed a resource for health care providers called *Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent and Young Adult Cancers*. These guidelines are available on the COG Web site at <http://www.childrensoncologygroup.org/default.htm> on the Internet.

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Related Resources

Publications (available at <http://www.cancer.gov/publications>)

- Cancer Facts 7.47, *How To Find a Doctor or Treatment Facility If You Have Cancer*
- Cancer Facts 8.1, *National Organizations That Offer Services to People With Cancer and Their Families*
- Cancer Facts 8.8, *Cancer Support Groups: Questions and Answers*

- *Facing Forward Series: Life After Cancer Treatment*
- *Facing Forward Series: Ways You Can Make a Difference in Cancer*

National Cancer Institute (NCI) Resources

Cancer Information Service (toll-free)

Telephone: 1-800-4-CANCER (1-800-422-6237)

TTY: 1-800-332-8615

Online

NCI's Web site: <http://www.cancer.gov>

LiveHelp, NCI's live online assistance:

<https://cissecure.nci.nih.gov/livehelp/welcome.asp>

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