

Follow-up Care After Cancer Treatment

Key Points

- Follow-up cancer care involves regular medical checkups that include a review of a patient's medical history and a physical exam (see Question 1).
- A key purpose of follow-up care is to check for recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body) (see Question 1).
- Follow-up care visits may also be helpful for identifying and addressing treatment-related problems a patient may have, or checking for problems that continue or can arise after treatment ends (see Question 1).
- Follow-up care is individualized based on the type of cancer, the type of treatment received, and the person's overall health, including possible cancer treatment-related problems (see Question 3).
- There are a few clinics that specialize in long-term follow-up care after cancer for adult and pediatric cancer survivors (see Question 4).
- It is important for people to keep a copy of their cancer treatment records. 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 (see Question 7).
- The National Cancer Institute does not have guidelines for follow-up care, but some organizations do provide these resources (see Question 10).

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 what they can do to keep the cancer from recurring (coming back). They want to know which doctor will follow them, 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 important health-related decisions.

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

Follow-up cancer care involves regular medical checkups that include a review of a patient's medical history and a physical exam. Follow-up care may include imaging procedures (methods of producing pictures of areas inside the body), endoscopy (the use of a thin, lighted tube to examine the inside of the body), blood work, and other lab tests.

Follow-up care is important because it helps to identify changes in health. The purpose of follow-up care is to check for recurrence (the return of cancer in the primary site) or metastasis (the spread of cancer to another part of the body). Follow-up care visits are also important to help in the prevention or early detection of other types of cancer, address ongoing problems due to cancer or its treatment, and check for physical and psychosocial effects that may develop months to years after treatment ends. All cancer survivors should have follow-up care.

2. 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.

3. How are follow-up care schedules planned?

The frequency and nature of follow-up care is individualized based on the type of cancer, the type of treatment received, and the person's overall health, including possible treatment-related problems. 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 special 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 plan.

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.

4. Are there doctors or clinics that specialize in follow-up care?

There are a few clinics that specialize in long-term follow-up cancer care for adult and pediatric cancer survivors. A listing of long-term follow-up cancer care clinics is available on the National Coalition for Cancer Survivorship (NCCS) Web page at http://www.canceradvocacy.org/resources/guide/?cancerrelated_information=long-term-survival-clinics&essential_care=&cancer_type= on the Internet. In addition, 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 located on ACOR's Pediatric Oncology Resource Center Web page at <http://www.acor.org/ped-onc/treatment/surclinics.html> on the Internet.

5. What should patients talk to their doctor about once cancer treatment ends?

Every cancer survivor should request a comprehensive care summary and follow-up plan from their doctor once they complete their treatment. Patients should ask their doctor the following questions once cancer treatment ends. The answers can help inform the patient about their care and what to expect next. (See Question 7 for more information about plans for follow-up care.)

- What treatments and drugs have I been given?
- How often should I have a routine visit?
- Which doctor should I see for my follow-up cancer care?
- What are the chances that my cancer will come back or that I will get another type of cancer?
- 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?
- What are the common long-term and late effects of the treatment I received?
- What should I do to maintain my health and well-being?
- Will I have trouble getting health insurance or keeping a job because of my cancer?
- Are there support groups I can turn to?

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

6. How can patients deal with their emotions once cancer treatment is completed?

It is common to experience stress, depression, and anxiety during and after cancer treatment. Many people find it helpful to talk about their feelings with family and friends, health professionals, other patients, members of the clergy, and counselors or therapists. Being part of a support group can provide another outlet for people to share their feelings. Relaxation techniques, such as guided imagery and slow rhythmic breathing, can also help to ease negative thoughts or feelings. Reaching out to others by participating in volunteer activities can help people to feel stronger and more in control. However, people who continue to experience emotional distress should ask their doctor to refer them to someone who can help determine what may be causing or contributing to their distress and how to deal with it.

7. What kinds of medical information should patients keep?

It is important for people to keep a copy of their cancer treatment records. Ideally, this should include a comprehensive care summary and follow-up plan from your doctor. 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. In particular, it is important to keep the following information:

- Results of any diagnostic test.
- 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.
- Side effects and complications that occurred during and after treatment.
- Supportive care received (for example, pain or nausea medication, emotional support, and nutritional supplements).
- Identifying number and title of clinical trial (research study), if the patient participated in a clinical trial.

8. 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) publication *Facing Forward: Life After Cancer Treatment*, which is available at <http://www.cancer.gov/cancertopics/life-after-treatment/page9#h2> on the Internet.

9. What research is being done in regards to follow-up cancer care?

NCI, a component of the National Institutes of Health, funds the Childhood Cancer Survivor Study (CCSS). This study, which is coordinated by St. Jude Children's Research Hospital, has over 25 sites across the country at medical institutions with doctors specializing in long-term care for children and young adults. Information about the study, including a link to a list of participating institutions, is available at <http://ccss.stjude.org/> on the Internet. This study was created to gain new knowledge and educate cancer survivors about the long-term effects of cancer and cancer therapy, and to provide information about follow-up care.

Several additional studies being supported by NCI, including the Experience of Care and Health Outcomes of Survivors of Non-Hodgkin's Lymphoma (ECHOS-NHL) study and the Assessment of Patients' Experience of Cancer Care (APECC) study, will provide data on how and where survivors of adult cancer receive their follow-up care and the special information and service needs they may have. Information about the ECHOS-NHL study is available at <http://outcomes.cancer.gov/surveys/echos-nhl/> and information about the APECC study can be found at <http://outcomes.cancer.gov/surveys/apeccc/> on the Internet.

In addition, a survey of physicians' attitudes and practices regarding appropriate follow-up care for survivors is under way. This work is being supported by NCI in collaboration with the American Cancer Society. The results will be available in late 2010. More information about this study can be found at <http://healthservices.cancer.gov/surveys/sparccs/> on the Internet.

10. Does NCI have guidelines for follow-up care?

No, NCI does not have such guidelines. However, some organizations do have follow-up guidelines for some types of cancer. Also, some organizations help patients and physicians develop individualized care plans based on a patient's treatment history.

The American Society of Clinical Oncology (ASCO), a nonprofit organization that represents more than 27,000 cancer professionals worldwide, has published information summaries for patients based on the *ASCO Clinical Practice Guidelines* for health care providers. The patient summaries provide information on a variety of cancer topics, including follow-up care for breast and colorectal cancer. These guidelines, called *What to Know: ASCO's Guidelines*, are available on ASCO's Cancer.Net Web site at <http://www.cancer.net/patient/Publications+and+Resources/What+to+Know%3A+ASCO%27s+Guidelines> 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. Clinical trials are conducted in the United States, Mexico, Canada, Europe, Australia, and New Zealand. 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 at <http://www.survivorshipguidelines.org/> on the Internet.

The Journey Forward is a program that was created by the National Coalition for Cancer Survivorship, the University of California, Los Angeles Cancer Survivorship Center, Genentech, and WellPoint, Inc. The program is designed for doctors and their patients who have recently completed cancer treatment. It promotes the use of a Survivorship Care Plan, which oncologists create using an online Survivorship Care Plan Builder. The Survivorship Care Plan is a full medical summary and recommendations for follow-up care to be shared with patients and their primary care providers. The Journey Forward also provides an electronic tool, the Medical History Builder Form, to help patients put together a summary of their medical history. The program can be accessed at <http://www.journeyforward.org> on the Internet.

The Livestrong Care Plan was developed by the Lance Armstrong Foundation and the University of Pennsylvania to provide cancer survivors with information regarding the health risks they face as a result of cancer therapies. An individual answers a series of questions in an online questionnaire, and the Livestrong Care Plan uses this information to provide a specific survivor care plan. The plan can be accessed at <http://www.livestrongcareplan.org> on the Internet. A version in Spanish is also provided.

The National Comprehensive Cancer Network (NCCN) is a nonprofit organization that is an alliance of cancer centers. The NCCN has a consumer Web site called NCCN.com. This Web site includes information about follow-up care for cancer, along with guidance on making formal survivorship plans. The Life Beyond Cancer: Follow-Up Care After Cancer Web page is available at <http://www.nccn.com/Life-Beyond-Cancer/WellnessArticles.aspx?id=486> on the Internet.

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Related NCI materials and Web pages:

- National Cancer Institute Fact Sheet 7.47, *How To Find a Doctor or Treatment Facility If You Have Cancer* (<http://www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility>)
- *Facing Forward: Life After Cancer Treatment* (<http://www.cancer.gov/cancertopics/life-after-treatment>)
- *Facing Forward: Ways You Can Make a Difference in Cancer* (<http://www.cancer.gov/cancertopics/make-a-difference>)
- National Cancer Institute-Designated Cancer Centers Database (https://cissecure.nci.nih.gov/factsheet/FactSheetSearch1_2.aspx)
- National Organizations That Offer Cancer-Related Services Database (https://cissecure.nci.nih.gov/factsheet/FactSheetSearch8_1.aspx)
- Resources for Financial Assistance for Patients and Their Families Database (https://cissecure.nci.nih.gov/factsheet/FactSheetSearch8_3.aspx)

How can we help?

We offer comprehensive research-based information for patients and their families, health professionals, cancer researchers, advocates, and the public.

- **Call** NCI's Cancer Information Service at 1-800-4-CANCER (1-800-422-6237)
- **Visit** us at <http://www.cancer.gov> or <http://www.cancer.gov/espanol>
- **Chat** using LiveHelp, NCI's instant messaging service, at <http://www.cancer.gov/livehelp>
- **E-mail** us at cancergovstaff@mail.nih.gov
- **Order** publications at <http://www.cancer.gov/publications> or by calling 1-800-4-CANCER
- **Get help** with quitting smoking at 1-877-44U-QUIT (1-877-448-7848)

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