

## Introduction to Long-Term Follow-Up after Cancer Treatment

**Congratulations!** You are transitioning to long-term follow-up after completing treatment. In long-term follow-up, the goal is to support your physical and emotional health, provide education about your diagnosis and treatment, and facilitate your success at home, school and work.

Even though you may not have seen a primary care provider during treatment, it is important to reestablish your relationship with a primary care provider for regular medical care. In some cases, your long-term follow-up care may continue at the same hospital or clinic where you received your treatment, but you may be seen by different doctors and nurses in a special long-term follow-up or survivorship program. In other cases, you may receive cancer follow up care from a healthcare provider who is closer to your home. No matter where you receive your care, it is important that you learn about your treatment, its impact on your long-term health and the follow up care you need so that you can stay in the very best health possible.

### Your cancer treatment summary

When you transition to long-term follow-up care, it is important that you get a record of the cancer treatment that you received. This record, known as a **Summary of Cancer Treatment**, should contain the following information:

- Name of the **disease** that you had, the date when you were diagnosed, and the site/stage of the disease
  - Date(s) and description(s) of any relapses
  - Name, address, and phone number of hospital(s) or clinic(s) where you received your care
  - Name, address, and phone numbers of your cancer doctor (oncologist) and other health team members responsible for your care
  - Date that your cancer treatment was completed
- Names of all the **chemotherapy** medicines that you received and specific information about certain chemotherapy drugs as follows:
  - Total doses of anthracycline chemotherapy (such as doxorubicin, daunorubicin, idarubicin, epirubicin, and mitoxantrone)
  - Total doses of alkylating chemotherapies (such as cyclophosphamide, procarbazine, BCNU, melphalan, nitrogen mustard, ifosfamide, chlorambucil, CCNU, Thiotepa, and busulfan)
  - For cytarabine and methotrexate: How they were given (such as by mouth or into the vein), and if into the vein, whether you received “high dose” (1000 mg/m<sup>2</sup> or more in any single dose) or “standard dose” therapy
  - For carboplatin: Whether or not the dose was myeloablative (given during preparation for a bone marrow, cord blood, or stem cell transplant)
  - Total doses of other chemotherapy agents and how they were given should be included, if available
- **Radiation** therapy summary, including:
  - Part(s) of body that received radiation (radiation site or field)
  - Total radiation dose (including any boost doses) to each field
- Name and dates of any treatment-related **surgeries** that you had
- Whether or not you received a **hematopoietic cell transplant** (bone marrow, cord blood, or stem cell transplant), and if so, whether or not you developed chronic graft-versus-host disease

- Names of any other **cancer treatment(s)** that you received (such as radioiodine therapy or bioimmunotherapy)
- Names and dates of **any significant complication(s)**, and treatments received for the complication(s)

Keep a copy of your cancer treatment summary in a safe place, and give a copy to each of your healthcare providers.

## Your follow-up schedule

Most cancer survivors need long-term follow-up visits about once a year. During these visits, it is important to talk about your progress and check for problems that can happen after treatment for cancer. Talk with your healthcare provider about your individual situation and determine a schedule for follow-up care that best meets your needs.

## Between visits

Once you transition to long-term follow-up care, you will usually need to identify a local healthcare provider that you can visit or call if you are injured or sick. Make an appointment for a check-up with this healthcare provider so that they can get to know you before an illness arises. If a problem comes up that may be related to your cancer treatment, your local healthcare provider can discuss this with your long-term follow-up team.

## Late effects after treatment for childhood, adolescent, or young adult cancer

Problems that happen after treatment for cancer are known as “late effects.” Fortunately, most long-term survivors don’t have serious late effects, but it is important to catch any problems early. You may have already learned about some of the possible late effects that can happen after treatment for cancer. Some of the more common ones are reviewed here.

### Growth

Treatment for cancer during childhood, especially radiation to the brain or spine, can sometimes slow or stunt growth. Yearly measurements help to predict whether you will reach a normal height. If you are “at risk” for being short as an adult, your healthcare provider may also recommend other specialized tests and treatments.

### Heart

A small percentage of survivors treated with chest radiation or certain chemotherapy drugs known as “anthracyclines” (such as doxorubicin or daunomycin) have problems with the heart. This is most likely to happen in people who received higher doses of anthracycline chemotherapy or chemotherapy combined with radiation affecting the heart. Your healthcare provider may recommend tests to check your heart function, and may arrange for a cardiologist (heart specialist) to see you if the tests show any sign of problems.

### Fertility

Radiation to the reproductive organs or brain and certain chemotherapy drugs can affect sexual development and reproduction. Some survivors may be at risk for delayed puberty, infertility (inability to have children), or premature ovarian insufficiency (early menopause). Check-ups and certain blood tests can help determine if you have any of these problems. These issues are important, and if you have any concerns, you should be sure to discuss them with your healthcare provider. If there is a problem, arrangements may be made for you to see a specialist.

### Thyroid

Head or neck radiation can sometimes cause the thyroid gland to stop working properly. This gland helps regulate

growth, weight, and the balance of body chemicals. Blood tests can be done to check thyroid hormone levels. Low thyroid levels are easily treated with oral medication.

## Subsequent Cancers

Some chemotherapy drugs and radiation can increase the risk of a subsequent (different) cancer. Some survivors may have genetic changes that put them at risk for second cancers. Tobacco, excessive sun exposure, and other chemicals and behaviors can also increase this risk. Talk with your healthcare provider about ways to lower your risk and to detect common cancers at an early stage.

## School and work

Problems with schoolwork or job performance can occur as a result of some types of cancer treatment. Psychologists can work with your local school system to make sure that any special needs are met. Also, financial assistance for education and job training may be available through government programs. Social workers can help to explain these programs.

## Moving toward the future

Thinking about developing late effects after surviving cancer can be anxiety provoking. Your long-term follow-up program is here to help you navigate the emotional and physical challenges of cancer survivorship. Regular health checks and recommended screening and surveillance testing are meant to put you in control of your health and provide the best chance of early detection of problems, if they occur, before they become severe. Work with your health care team to develop a follow up plan that works best for you.

Make healthy choices. Keep your follow-up appointments. And always remember that you are the most important member of your healthcare team!

---

Written by Wendy Landier, PhD, CPNP, Children's Hospital of Alabama, Birmingham, AL. Portions adapted from "Introduction to the After Completion of Therapy Clinic," St. Jude Children's Hospital, Memphis, TN, used with permission.

Reviewed by Beth Fisher, DNP, APRN, CPNP, CPON, CHPPN; Christine S. Yun, MSN, PNP, CPON; and Kayla L. Foster, MD, MPH.

**Additional health information for childhood cancer survivors is available at**  
[www.survivorshipguidelines.org](http://www.survivorshipguidelines.org)

**Note:** Throughout this *Health Links* series, the term "childhood cancer" is used to designate pediatric cancers that may occur during childhood, adolescence, or young adulthood. Health Links are designed to provide health information for survivors of pediatric cancer, regardless of whether the cancer occurred during childhood, adolescence, or young adulthood.

### Disclaimer and Notice of Proprietary Rights

**Introduction to Late Effects Guidelines and Health Links:** *The Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers* and accompanying *Health Links* were developed by the Children's Oncology Group as a collaborative effort of the Late Effects Committee and Nursing Discipline and are maintained and updated by the Children's Oncology Group's Long-Term Follow-Up Guidelines Core Committee and its associated Task Forces.

**To cancer patients (if children, their parents or legal guardians):** Please seek the advice of a physician or other qualified health provider with any questions you may have regarding a medical condition and do not rely on the Informational Content. The Children's Oncology Group is a research organization and does not provide individualized medical care or treatment.

**To physicians and other healthcare providers:** The Informational Content is not intended to replace your independent clinical judgment, medical advice, or to exclude other legitimate criteria for screening, health counseling, or intervention for specific complications of childhood cancer treatment. Neither is the Informational Content intended to exclude other reasonable alternative follow-up procedures. The Informational Content is provided as a courtesy, but not intended as a sole source of guidance in the evaluation of childhood cancer survivors. The Children's Oncology Group recognizes that specific patient care decisions are the prerogative of the patient, family, and healthcare provider.

# Health Link

Healthy living after treatment of childhood, adolescent, and young adult cancer

CHILDREN'S  
ONCOLOGY  
GROUP

No endorsement of any specific tests, products, or procedures is made by Informational Content, the Children's Oncology Group, or affiliated party or member of the Children's Oncology Group.

**No Claim to Accuracy or Completeness:** While the Children's Oncology Group has made every attempt to assure that the Informational Content is accurate and complete as of the date of publication, no warranty or representation, express or implied, is made as to the accuracy, reliability, completeness, relevance, or timeliness of such Informational Content.

**No Liability on Part of Children's Oncology Group and Related Parties/Agreement to Indemnify and Hold Harmless the Children's Oncology Group and Related Parties:** No liability is assumed by the Children's Oncology Group or any affiliated party or member thereof for damage resulting from the use, review, or access of the Informational Content. You agree to the following terms of indemnification: (i) "Indemnified Parties" include authors and contributors to the Informational Content, all officers, directors, representatives, employees, agents, and members of the Children's Oncology Group and affiliated organizations; (ii) by using, reviewing, or accessing the Informational Content, you agree, at your own expense, to indemnify, defend and hold harmless Indemnified Parties from any and all losses, liabilities, or damages (including attorneys' fees and costs) resulting from any and all claims, causes of action, suits, proceedings, or demands related to or arising out of use, review or access of the Informational Content.

**Proprietary Rights:** The Informational Content is subject to protection under the copyright law and other intellectual property law in the United States and worldwide. The Children's Oncology Group retains exclusive copyright and other right, title, and interest to the Informational Content and claims all intellectual property rights available under law. You hereby agree to help the Children's Oncology Group secure all copyright and intellectual property rights for the benefit of the Children's Oncology Group by taking additional action at a later time, action which could include signing consents and legal documents and limiting dissemination or reproduction of Informational Content.