Health Link

Healthy living after treatment for childhood cancer

Intro to LTFU
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Introduction to Long-Term Follow-Up after Treatment for Childhood, Adolescent, or Young Adult Cancer

Congratulations! You have "graduated" to long-term follow-up. ***You can now think of yourself as a cancer survivor, not as a cancer patient!*** In long-term follow-up, the goal is to help you stay as healthy as possible—to stay well and to do well in school or at work.

Even though you are a cancer survivor, it is still important that you continue to have regular medical care. In some cases, your 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 Program. In other cases, you may receive care from a healthcare provider working in partnership with your treatment center, or from a provider who is closer to your home. No matter where you receive your care, it is important that you learn what you need to know about your treatment and the follow-up care that you need so that you can stay in the very best health possible.

Your cancer treatment summary

When you graduate to long-term follow-up, 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 or daunorubicin)
    - 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^2 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)

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  - 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 **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 (cGVHD)
- 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 the follow-up care that best meets your needs.

Between visits

Once you "graduate" 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 these medicines, and in those who received their treatment before their heart finished growing. Your healthcare provider may recommended tests to check your heart function, and may arrange for a cardiologist (heart specialist) to see you if the tests show any sign of these problems.

Fertility

Radiation to the pelvis and certain anticancer drugs can affect sexual development and reproduction. Some survivors may be at risk for delayed puberty, infertility (inability to have children), or 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.

Second Cancers

Some chemotherapy drugs and radiation can increase the risk of a second (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 jobs 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. But it is quite possible that you will NOT develop any serious complications. And if you do, it is best to catch them early, so that you can begin treatment right away. So don't let anxiety get in the way of taking the very best care of your health.

Being treated for cancer at a young age is always a difficult experience. Having survived that experience, you have learned many things. Most likely, you are a stronger person than you were before you were diagnosed with cancer. As you move forward into your future, use those strengths to your advantage. Make healthy choices. Keep your follow-up appointments. And always remember that YOU are the most important member of your healthcare team!

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Additional health information for childhood cancer survivors is available at 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.

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