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Printed January 29, 2015 from <http://www.cancer.net/navigating-cancer-care/children/managing-late-effects-childhood-cancer>

Managing Late Effects of Childhood Cancer [1]

This section has been reviewed and approved by the [Cancer.Net Editorial Board](#) [2], 07/2013

 *Watch the Cancer.Net Video: Late Effects of Childhood Cancer Treatment, with Lisa Diller, MD* [3], adapted from this content

Long-term side effects, also called late effects, are side effects of cancer treatment that occur months and years after treatment. Not all children treated for cancer will experience late effects, but it helps to learn about the ones your child could experience and how the health care team will help manage, treat, and/or prevent them.

Before treatment begins

Parents of a child diagnosed with cancer should discuss the possibility of late effects with a pediatric oncologist (a doctor who specializes in treating children with cancer) before treatment begins, if possible. A pediatric oncologist can help patients and families understand and weigh treatment risks. If it has been many years since you or your child were treated for cancer, you will likely focus on watching for symptoms and finding appropriate follow-up care.

These questions may be helpful when you talk with your child's doctor about late effects:

- What are the potential late effects of the treatment you recommended?
- What can be done to lower risks for late effects during and after treatment?
- What symptoms of late effects should I look for?
- What do I do if I notice a late effect?
- Do you have experience with treating cancer survivors?
- Can you recommend a follow-up clinic that specializes in late effects?

During treatment

If your child is being treated for cancer, work with your child's doctor to create and regularly update a detailed summary of treatment information. This document can be used to create a personal plan for late effects screening and check-ups. It is also important for other health care specialists who treat your child to have a copy. Once treatment is complete, your child should keep a copy of the treatment summary to carry into adulthood.

A treatment summary should include:

- Patient's name and birth date
- Date of cancer diagnosis and date of any recurrence (return of the cancer)
- Type of cancer, including details such as tissue or cell type and stage or grade
- Place of treatment and name and phone number of the primary oncologist
- The dates that treatments started and ended
- Specific drugs used for chemotherapy and the total dosage (if applicable)
- Radiation treatment field and dose (if applicable)
- Other treatment information, such as whether the child had a stem cell/bone marrow transplant and the type (autologous or allogeneic), and any transfusions
- Treatment-related complications
- Possible long-term effects based on treatment
- Recommendations for late effects screening tests and check-ups

One way to create the document is by using [ASCO's cancer treatment summaries](#) [4], which provide a convenient way to store information about your child's cancer, cancer treatment, and follow-up care. Even if it has been many years since finishing treatment, it is important to try to gather and recall any information you can.

After treatment

After a child finishes treatment for cancer, he or she will need regular follow-up screening to confirm the absence of cancer and diagnose any potential late effects. Long-term follow-up care, which should continue throughout adulthood, helps ensure that survivors of childhood cancer stay healthy.

Check-ups and screening tests. Most childhood cancer survivors need to see their doctor at least once a year for a check-up, even if they feel healthy. Depending on the treatment received, a survivor may also need specific screening tests that can help detect late effects early. Screening tests may include imaging tests, such as x-rays or computed tomography (CT) scans; blood tests; and physical examinations. Screening recommendations are available from the [Children's Oncology Group](#) [5]. Recommendations vary based on a patient's treatment and health history, so talk with your child's doctor to determine which screening tests are needed and how often.

Follow-up clinics. Many hospitals and health facilities now offer follow-up clinics or services for survivors of childhood cancer. Follow-up care generally begins two years after treatment and focuses on monitoring late effects and general wellness. Survivors should also continue to see their oncologist for check-ups aimed at detecting potential recurrence (return of cancer). Staffed by health care providers familiar with the possible late effects of childhood cancer, follow-up clinics provide a number of services:

- Education on potential late effects for a survivor's specific diagnosis and treatment
- Late effect screening and monitoring
- Referrals to doctors who specialize in areas of the body affected by late effects
- Help with treatment-related school and work difficulties

- Support for emotional issues of survivors and family members
- Wellness education and programs
- Education on reducing health risk-taking behavior, such as tobacco use
- Information on reproductive health
- Transition to adult health care
- Assistance with health insurance and financial issues

Some clinics will see survivors until they are 18 years old, while others will see patients of any age. Ask your child's doctor to help you locate an appropriate follow-up clinic, or review the lists of follow-up clinics provided by the [Pediatric Oncology Resource Center](#) [6] and the [National Children's Cancer Society](#) [7]. If you cannot find a clinic near you, some clinics are willing to see a survivor for a thorough, one-time evaluation to develop a long-term health care plan for late effects.

Coping with late effects

After undergoing cancer treatment, survivors may be reluctant to continue to receive follow-up care because they fear finding additional health problems. Or, they feel that they have had enough experience with illness and do not want to continue to see doctors and get tested. However, it may help to know that serious late effects are rare and there are ways to lower your risk.

Minimizing risk of late effects

Survivors of childhood cancer can minimize severity of late effects and reduce the risk for second cancers and other diseases by following these tips:

- Do not smoke or chew tobacco, and avoid secondhand smoke.
- Protect skin from sun exposure.
- Limit alcohol consumption.
- Do not use illegal drugs
- Eat a healthy diet low in fat and high in fiber.
- Exercise regularly.
- Get recommended vaccinations, such as a flu shot.

Find more information about all of these topics at www.cancer.net/prevention [8].

More Information

[Late Effects of Childhood Cancer](#) [9]

[Survivorship: Next Steps to Take After Treatment](#) [10]

[Guide to Childhood Cancer](#) [11]

Additional Resources

[Children's Oncology Group: Survivorship Guidelines](#) [12]

National Cancer Institute: Late Effects of Treatment for Childhood Cancer [13]

Links:

[1] <http://www.cancer.net/navigating-cancer-care/children/managing-late-effects-childhood-cancer>

[2] <http://www.cancer.net/about-us>

[3] <http://www.cancer.net/node/27136>

[4] <http://www.cancer.net/node/25394>

[5] <http://www.survivorshipguidelines.org>

[6] <http://www.acor.org/ped-onc/treatment/surclinics.html>

[7] <http://www.beyondthecure.org/page.aspx?pid=783>

[8] <http://www.cancer.net/node/24868>

[9] <http://www.cancer.net/node/24571>

[10] <http://www.cancer.net/node/25400>

[11] <http://www.cancer.net/node/18689>

[12] <http://www.survivorshipguidelines.org/>

[13] <http://www.cancer.gov/cancertopics/pdq/treatment/lateeffects/Patient/page1>