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## Managing Late Effects of Childhood Cancer

**This section has been reviewed and approved by the Cancer.Net Editorial Board, 01/2016**

### video\_play\_icon.png



Watch the [Cancer.Net Video: Late Effects of Childhood Cancer Treatment, with Lisa Diller, MD](#) [1], adapted from this content

Late effects are conditions that continue or develop 5 or more years after a cancer diagnosis. Some late effects do not show up until many years after cancer treatment ends. Not all children who receive cancer treatment will experience late effects. However, 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 before treatment begins. A pediatric oncologist is a doctor who specializes in treating cancer in children. Talking with the doctor can help patients and families understand treatment risks.

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**

Work with your child's doctor to create and regularly update a detailed summary of treatment information. You can use this document to create a personal plan for late effects screening and check-ups. Other health care specialists who treat your child should also have a copy. Once treatment is finished, 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
- Type of cancer, including details such as tissue or cell type and stage or grade
- Place of treatment
- 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 area and dose (if applicable)
- Other treatment information, such as whether the child had a stem cell/bone marrow transplant and the type, and any transfusions
- Treatment-related problems
- Possible long-term effects based on treatment
- Recommendations for screening and check-ups for late effects

You can create this document by using [ASCO's Cancer Treatment and Survivorship Care Plans](#) [2]. They provide a convenient way to store information about your child's cancer, treatment, and follow-up care. Even if it has been many years since finishing treatment, it is important 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. The screening will confirm the cancer has not come back and it can diagnose any potential late effects.

If it has been many years since you or your child received cancer treatment, you should focus on watching for symptoms of late effects, finding appropriate follow-up care, and practicing health behaviors that can reduce the risk of late effects. Long-term follow-up care should continue throughout adulthood. It 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 to find early signs of late effects. Screening tests may include physical examinations, blood tests, x-rays and other imaging tests, and echocardiograms. Screening recommendations are available from the [Children's Oncology Group](#) [3]. Recommendations vary based on a patient's treatment and health history. Talk with your child's doctor to determine which screening tests are needed and how often.
- **Follow-up clinics.** Many hospitals and health care facilities now offer follow-up clinics or services for survivors of childhood cancer. Follow-up care generally begins 2 years after treatment and focuses on monitoring late effects and general wellness. Some survivors

may continue to see their oncologists for check-ups aimed at finding a potential recurrence. However, most survivors can visit follow-up care clinics. 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 person'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 behaviors, such as tobacco use
- Information on reproductive health
- Transition to adult health care
- Help 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](#) [4] and the [National Children's Cancer Society](#) [5]. 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 medical 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.

## **Lowering risk of late effects**

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

- Do not smoke or chew tobacco, and avoid secondhand smoke.
- Protect your skin from too much 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.

Learn more about [cancer prevention and healthy living](#) [6].

## **More Information**

[Late Effects of Childhood Cancer](#) [7]

[Life After Cancer](#) [8]

[Childhood Cancer](#) [9]

## **Additional Resources**

Children's Oncology Group: [Long-Term Follow-Up Guidelines for Survivors of Childhood, Adolescent, and Young Adult Cancers](#) [3]

National Cancer Institute: [Late Effects of Treatment for Childhood Cancer](#) [10]

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## Links

- [1] <http://www.cancer.net/node/27136>
- [2] <http://www.cancer.net/node/25394>
- [3] <http://www.survivorshipguidelines.org/>
- [4] <http://www.acor.org/ped-onc/treatment/surclinics.html>
- [5] <https://www.thenccs.org/home>
- [6] <http://www.cancer.net/node/24868>
- [7] <http://www.cancer.net/node/24571>
- [8] <http://www.cancer.net/node/25400>
- [9] <http://www.cancer.net/node/31318>
- [10] <http://www.cancer.gov/types/childhood-cancers/late-effects-pdq>