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Living as a Ewing Tumor Survivor

During [treatment](#)¹ for a Ewing tumor, the main concerns for most people and their families are the daily aspects of getting through treatment and beating the cancer. After treatment, the concerns tend to shift toward the short- and long-term effects of the cancer and its treatment, and concerns about the cancer coming back.

It's certainly normal to want to put the tumor and its treatment behind you and to get back to a life that doesn't revolve around cancer. But it's important to realize that follow-up care is a central part of this process that offers the best chance for recovery and long-term survival.

Follow-up visits and tests

Once treatment is finished, the health care team will discuss a follow-up schedule with you, including which tests should be done and how often. It's very important to go to all follow-up appointments. Follow-up visits are needed to check for cancer recurrence, as well as possible side effects of treatment.

Physical exams, along with [x-rays, and other imaging tests \(CT, MRI, PET, and/or bone scans\)](#)² are often done every 2 to 3 months for the first couple of years following treatment, and then less often over time if there are no issues. If Ewing tumors come back, it is usually within the first 2 years after treatment, but they can sometimes come back even many years later, so continued follow-up visits are important.

Physical therapy and rehabilitation are typically a very important part of recovery after treatment, and your doctors and other health providers will continue to monitor your (child's) progress as time goes on.

Blood tests and other tests might be done as well. For example, the chemotherapy drug doxorubicin (Adriamycin) can affect the heart, so tests to measure heart function (such

as echocardiograms) will probably be done as well.

During this time, it is very important to report any new symptoms to the doctor right away so that any problems can be found early, when they can be treated most effectively.

Ask the cancer care team for a survivorship care plan

Talk with the treatment team about developing a [survivorship care plan](#)³. This plan might include:

- A summary of the diagnosis, tests done, and treatment given
- A suggested schedule for follow-up exams and tests
- A schedule for other tests that might be needed in the future, such as early detection (screening) tests for other types of cancer, or tests to look for long-term health effects from the cancer or its treatment
- A list of possible late- or long-term side effects from treatment, including what to watch for and when to contact the doctor

Keeping health insurance and copies of medical records

As much as you might want to put the experience behind you once treatment is completed, it's also very important to keep good records of your (child's) medical care during this time. Gathering these details soon after treatment may be easier than trying to get them at some point in the future. This can be very helpful later on if you (or your child) change doctors. Learn more about this in [Keeping Copies of Important Medical Records](#)⁴.

It's also very important to keep [health insurance](#)⁵ coverage. Tests and doctor visits can cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

Possible late and long-term effects of cancer treatment

Treatment for a Ewing tumor might affect a person's health later in life. Young people in particular are at risk for possible late effects of their treatment. This risk depends on many factors, such as the size and location of the cancer, the treatments received, doses of cancer treatment, and the person's age when treated.

For example, the after-effects of [surgery](#)⁶ for Ewing tumors can range from small scars to the loss of a limb, which would require both physical rehabilitation and emotional adjustment.

Other late effects of cancer treatment can include:

- Heart or lung problems (caused by certain [chemo](#)⁷ drugs or [radiation therapy](#)⁸ to the chest)
- Slowed growth and development (in the bones or overall)
- Changes in sexual development and [ability to have children](#)⁹
- Learning problems in younger children
- Development of [second cancers](#)¹⁰

Other possible complications might come up as well. Your child's doctor should carefully review any possible problems with you before your child starts treatment. For more information, see [Late Effects of Childhood Cancer Treatment](#)¹¹.

Long-term follow-up care for children and teens

To help increase awareness of late effects and improve follow-up care for childhood cancer survivors throughout their lives, the Children's Oncology Group (COG) has developed long-term follow-up guidelines for survivors of childhood cancers. These guidelines can help you know what to watch for, what types of screening tests should be done to look for problems, and how late effects can be treated.

It's very important to discuss possible long-term complications with your child's health care team, and to make sure there is a plan in place to watch for these problems and treat them, if needed. To learn more, ask your child's doctors about the COG survivor guidelines. You can also read them on the COG website:

www.survivorshipguidelines.org.¹² The guidelines are written for health care professionals. Patient versions of some of the guidelines are available (as "Health Links") on the site as well, but we urge you to discuss them with your doctor.

Social and emotional issues

Most Ewing tumors develop during the teenage or young adult years, a very sensitive time in a person's life. Ewing tumors and their treatment can have a profound effect on how a person looks and how they view themselves and their body. It can also affect how they do some everyday tasks, including certain school, work, or recreational activities. These effects are often greatest during the first year of treatment, but they can

be long-lasting in some people. It's important that the treating center assess the family situation as soon as possible, so that any areas of concern can be addressed.

These types of issues can often be addressed with support and encouragement. Doctors and other members of the health care team can also often recommend special support programs and services to help children and teens after cancer treatment. For more information, see [When Your Child's Treatment Ends](#)¹³.

No one chooses to have a Ewing tumor, but for many people, the experience can eventually be positive, helping to establish strong self-values. Other people may have a harder time recovering, adjusting to life after cancer, and moving on. It is normal to have some anxiety or other emotional reactions after treatment, but feeling overly worried, depressed, or angry can affect many parts of a young person's growth. It can get in the way of relationships, school, work, and other aspects of life.

With support from family, friends, other survivors, mental health professionals, and others, many people who have survived cancer can thrive in spite of the challenges they've had to face. If needed, doctors and other members of the health care team can often recommend special support programs and services to help after cancer treatment.

Although Ewing tumors and their treatment can have social and emotional effects on children and teens (and their families), adults with this disease face many of the same challenges, and are also encouraged to take advantage of the cancer center's physical therapy, occupational therapy, and counseling services.

Hyperlinks

1. www.cancer.org/cancer/ewing-tumor/treating.html
2. www.cancer.org/cancer/ewing-tumor/detection-diagnosis-staging/how-diagnosed.html
3. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
4. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
5. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html
6. www.cancer.org/cancer/ewing-tumor/treating/surgery.html
7. www.cancer.org/cancer/ewing-tumor/treating/chemotherapy.html
8. www.cancer.org/cancer/ewing-tumor/treating/radiation-therapy.html
9. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/physical-side-effects.html

- [effects/fertility-and-sexual-side-effects.html](#)
10. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html
 11. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html
 12. <http://www.survivorshipguidelines.org/>
 13. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-treatment.html

References

Anderson ME, Randall RL, Springfield DS, Gebhart MC. Chapter 92: Sarcomas of bone. In: Niederhuber JE, Armitage JO, Doroshow JH, Kastan MB, Tepper JE, eds. *Abeloff's Clinical Oncology*. 5th ed. Philadelphia, Pa: Elsevier; 2014.

National Comprehensive Cancer Network (NCCN). Practice Guidelines in Oncology: Bone Cancer. Version 1.2018. Accessed at www.nccn.org/professionals/physician_gls/pdf/bone.pdf on March 8, 2018.

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Written by

The American Cancer Society medical and editorial content team
(www.cancer.org/cancer/acs-medical-content-and-news-staff.html)

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