What Happens After Treatment for Ewing Tumors?

Following treatment for a Ewing tumor, most families are mainly concerned about the short- and long-term effects of the tumor and its treatment, and about the tumor still being there or 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 your child 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. Doctor visits and tests are done more often at first. If nothing abnormal is found, the time between tests can then be extended.

Physical exams, x-rays, and other imaging tests (CT, MRI, PET, and/or bone scans) are often done every few 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 is 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.

Measurements of growth and blood tests may be done. 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.

**Possible late and long-term effects of cancer treatment**

More young people treated for cancer are now surviving into adulthood. Doctors have learned that the treatment might affect children's health later in life, so watching for health effects as they get older has become more of a concern in recent years.

Treating cancer in young people requires a very specialized approach, and so does care and follow-up after treatment. The earlier problems are recognized, the more likely it is they can be treated effectively.

Young people with cancer are at risk, to some degree, for several possible late effects of their cancer treatment. This risk depends on a number of factors, such as the size and location of the cancer, the treatments received, doses of cancer treatment, and the patient’s age when they are treated. For example, the after-effects of surgery 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 drugs or radiation therapy to the chest)
- Slowed or decreased growth and development (in the bones or overall)
- Changes in sexual development and ability to have children (see below)
- Learning problems
- Development of second cancers (see below)

There may be other possible complications from treatment as well. Your child’s doctor should carefully review any possible problems with you before your child starts treatment.

Along with physical side effects, some childhood cancer survivors might have emotional or psychological issues. They also may have problems with normal functioning and school work. These 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 after cancer treatment.

**Fertility issues:** Fertility problems are not common after treatment for Ewing tumors, but they can occur. Young women may have changes in menstrual periods during chemotherapy, but normal monthly cycles usually return after treatment ends. Boys and men may lose the ability to make sperm. This usually returns, but the sperm count might remain low. Radiation to the pelvis can also affect fertility.

Talk to your cancer care team before treatment about the risks of infertility, and ask if there are options for preserving fertility, such as sperm banking. For more information, see *Fertility and Women With Cancer* and *Fertility and Men With Cancer*.

**Second cancers:** Children who have been treated for Ewing tumors are at higher risk for other cancers later in life. Some chemotherapy drugs used to treat Ewing tumors can cause leukemia in a small fraction of children later on. If this occurs, it is usually within 5 years after treatment. A concern in those treated with radiation therapy is the development of a new cancer (usually another type of bone cancer) at the site of treatment. These typically begin to develop about 5 years after radiation, and the risk remains higher for many years.

The importance of treating the Ewing tumor generally far outweighs the small increased risk of getting another cancer. Still, doctors are studying ways to reduce these risks while maintaining the effectiveness of current treatments. For more information on second cancers, see *Second Cancers Caused by Cancer Treatment*.

**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. 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.
For more about some of the possible long-term effects of treatment, see *Children Diagnosed With Cancer: Late Effects of Cancer Treatment*.

**Keeping good medical records**

As much as you may want to put the experience behind you once treatment is completed, it is very important to keep good records of your (child’s) medical care during this time. This can be very helpful later on if you (or your child) change doctors. Gathering these details during and soon after treatment may be easier than trying to get them at some point in the future. Be sure the doctors have the following information (and always keep copies for yourself):

- A copy of the pathology report(s) from any biopsies or surgeries
- Copies of imaging tests (CT or MRI scans, etc.), which can usually be stored digitally (on a DVD, etc.)
- If there was surgery, a copy of the operative report(s)
- If you (your child) stayed in the hospital, copies of the discharge summaries that doctors prepare when patients are sent home
- If chemotherapy was given, a list of the drugs, drug doses, and when they were given
- If radiation therapy was given, a summary of the type and dose of radiation and when and where it was given

It’s also very important to keep health insurance coverage. Tests and doctor visits cost a lot, and even though no one wants to think of the tumor coming back, this could happen.

- **References**
  
  See all references for Ewing Family of Tumors

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