After Treatment

Living as a Wilms Tumor Survivor

For many people, cancer treatment often raises questions about next steps as a survivor.

- **What Happens After Treatment for Wilms Tumor?**
- **Emotional and Social Issues for Wilms Tumor Survivors and Their Families**

Concerns After Treatment

Treatment may remove or destroy the cancer, but it is very common to have questions about what effects to expect down the road.

- **Late and Long-Term Effects of Treatment for Wilms Tumor**

What Happens After Treatment for Wilms Tumor?

During and after treatment for Wilms tumors, the main concerns for most families are the short- and long-term effects of the tumor and its treatment, and concerns 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 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 treatment that offers your child the best chance for long-term recovery.

Follow-up exams and tests
Your child’s health care team will set up a follow-up schedule, which will include physical exams and imaging tests (such as chest x-rays, ultrasounds, and CT scans) to look for the growth or return of the tumor, or any problems related to treatment.

Since most children have had a kidney removed, blood and urine tests will be done to check how well the remaining kidney is working. If your child received the drug doxorubicin (Adriamycin) during chemotherapy, the doctor may also order tests to check the function of your child’s heart.

The recommended schedule for follow-up exams and tests depends on the initial stage and histology (favorable or unfavorable) of the cancer, the type of treatment, and any problems that the child may have had during treatment. Doctor visits and tests will be more frequent at first (about every 6 to 12 weeks for the first couple of years), but the time between visits may be extended as time goes on.

During this time, it’s important to report any new symptoms to your child’s doctor right away, so that the cause can be found and treated, if needed. Your child’s doctor can give you an idea of what to watch for.

If the tumor does come back, or if it doesn’t respond to treatment, your child’s doctors will discuss the treatment options with you.

Children with bilateral Wilms tumors or Denys-Drash syndrome will also need regular tests to look for possible early signs of kidney failure (including urine tests, blood pressure checks, and blood tests of kidney function).

- References

See all references for Wilms Tumor

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Late and Long-Term Effects of Treatment for Wilms Tumor

Because of major advances in treatment, most children treated for Wilms tumor...
are now surviving into adulthood. Doctors have learned that treatment can 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. We have information to help parents cope with the many issues that can come up during and after a child is treated for cancer.

Just as the treatment of childhood cancer requires a very specialized approach, so does the care and follow-up after treatment. The earlier any problems can be recognized, the more likely it is they can be treated effectively. Young people treated for Wilms tumor are at risk, to some degree, for several possible late effects of their cancer treatment. It’s important to discuss what these possible effects might be with your child’s medical team so you know what to watch for and report to the doctor.

The risk of late effects depends on a number of factors, such as the specific treatments the child has, the doses of treatment, and the age of the child when being treated. These late effects may include:

- Reduced kidney function
- Heart or lung problems after getting certain chemotherapy drugs or radiation therapy to these parts of the body
- Slowed or delayed growth and development
- Changes in sexual development and ability to have children, especially in girls
- Increased risk of second cancers later in life (rare)

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 might also have problems with normal functioning and school work. These can often be addressed with support and encouragement. If needed, doctors and other members of the health care team can recommend special support programs and services to help children after cancer treatment.

**Long-term follow-up care**

To help increase awareness of late effects and improve follow-up care of 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 type of screening tests should be done to look for problems, and how late effects can be treated.

Ask your child’s health care team about possible long-term complications and make sure there’s 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 online at www.survivorshipguidelines.org. You may want to discuss them with your child’s doctor.

Children Diagnosed With Cancer: Late Effects of Cancer Treatment tells you a lot more about some of the possible long-term effects of cancer treatment.

Things to keep

As much as you might want to put the experience behind you once treatment is completed, it’s very important to keep good records of your child’s medical care during this time. This can be very helpful later on as your child changes doctors. Gathering these details during and soon after treatment may be easier than trying to get them in the future.

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

- References

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Emotional and Social Issues for Wilms Tumor Survivors and Their Families

Most children with Wilms tumors are very young when they are diagnosed. Still,
some children may have emotional or psychological issues that need to be addressed during and after treatment. Depending on their age, they may also have some problems with normal functioning and school work. These can often be helped 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 treatment.

Parents and other family members can also be affected, both emotionally and in other ways. Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center, the possible loss of a job, and the need for home schooling. Social workers and other professionals at treatment centers can help families sort through these issues.

Centers that treat many patients with Wilms tumors may have programs to introduce new patients and their families to others who have finished their treatment. This can give parents an idea of what to expect during and after treatment, which is very important. Seeing another patient with Wilms tumor doing well is often helpful.

Support groups for families of children with cancer can also be helpful. If you need help finding such a group, call your American Cancer Society at 1-800-227-2345 and we can put you in touch with a group or resource that may work for you.

- References
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