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After Wilms Tumor 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?](#)

What Happens After Treatment for Wilms Tumor?

During [treatment](#)¹ for Wilms tumors, the main concerns for most 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 treatment that offers your child the best chance for long-term recovery.

Follow-up exams and tests

Your child's health care team will discuss a follow-up schedule with you, which will

include **physical exams** and [imaging tests](#)² (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.

If your child had parts or all of a kidney removed, **blood and urine tests** will be done to check how well the remaining kidney tissue is working. If your child received the drug doxorubicin (Adriamycin) during [chemotherapy](#)³, 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 several factors, including:

- The initial [stage](#)⁴ and [histology](#)⁵ (favorable or anaplastic) of the tumor
- If the child has a [genetic syndrome](#)⁶ related to the tumor
- The type of treatment the child received
- 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](#)⁷, or if it doesn't respond to treatment, your child's doctors will discuss the treatment options with you.

Children with bilateral Wilms tumors (tumors in both kidneys) or [Denys-Drash syndrome](#)⁸ 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).

Ask the cancer care team for a survivorship care plan

Talk with the treatment team about developing a [survivorship care plan](#)⁹. 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 your child changes doctors. Learn more about this in [Keeping Copies of Important Medical Records](#)¹⁰.

It's also very important to keep [health insurance](#)¹¹ 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 treatment

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.

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](#)¹². 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 had, 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](#)¹³ drugs or [radiation therapy](#)¹⁴ to the chest
- Slowed or delayed growth and development

- Changes in [sexual development and ability to have children](#)¹⁵, especially in girls
- Increased risk of [second cancers](#)¹⁶ later in life (although these are rare)

There may be other possible complications from treatment as well. Your child's doctors should discuss any possible problems with you.

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 \(COG\)](#)¹⁷ 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

It's very important to discuss possible long-term complications with your child's health care team, and to 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.org¹⁸. The guidelines themselves 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 [Late Effects of Childhood Cancer Treatment](#)¹⁹.

Emotional and social issues

Most children with Wilms tumors are very young when they are diagnosed. Still, some children may have [emotional or psychological issues](#)²⁰ 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 types of issues 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. For more information, see [When Your Child's Treatment Ends](#)²¹.

Parents and other family members can also be affected, both [emotionally and in other ways](#)²². Some common family concerns during treatment include financial stresses, traveling to and staying near the cancer center/hospital, 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.

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](#)²³ that may work for you.

Hyperlinks

1. www.cancer.org/cancer/wilms-tumor/treating.html
2. www.cancer.org/treatment/understanding-your-diagnosis/tests.html
3. www.cancer.org/cancer/wilms-tumor/treating/chemotherapy.html
4. www.cancer.org/cancer/wilms-tumor/detection-diagnosis-staging/staging.html
5. www.cancer.org/cancer/wilms-tumor/about/what-is-wilms-tumor.html
6. www.cancer.org/cancer/wilms-tumor/causes-risks-prevention/risk-factors.html
7. www.cancer.org/cancer/wilms-tumor/treating/by-stage.html
8. www.cancer.org/cancer/wilms-tumor/causes-risks-prevention/risk-factors.html
9. www.cancer.org/treatment/survivorship-during-and-after-treatment/survivorship-care-plans.html
10. www.cancer.org/treatment/survivorship-during-and-after-treatment/be-healthy-after-treatment/keeping-copies-of-important-medical-records.html
11. www.cancer.org/treatment/finding-and-paying-for-treatment/understanding-health-insurance.html
12. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html
13. www.cancer.org/cancer/wilms-tumor/treating/chemotherapy.html
14. www.cancer.org/cancer/wilms-tumor/treating/radiation-therapy.html
15. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects.html
16. www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/second-cancers-in-adults.html
17. <http://childrensoncologygroup.org/>
18. <http://www.survivorshipguidelines.org>
19. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/late-effects-of-cancer-treatment.html

- [effects-of-cancer-treatment.html](#)
20. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer.html
 21. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer/after-treatment.html
 22. www.cancer.org/treatment/children-and-cancer/when-your-child-has-cancer.html
 23. www.cancer.org/treatment/support-programs-and-services.html

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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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