

### **After Wilms Tumor Treatment**

Get information about life as a Wilms tumor survivor, next steps, and what you can do to help your child 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 Tumors?

# What Happens After Treatment for Wilms Tumors?

During treatment for Wilms tumors, the main concerns for most families are the daily aspects of getting through treatment and beating the cancer. Afterward, these concerns

If your child's tumor <u>comes back</u><sup>5</sup>, or if it doesn't respond to treatment, the cancer care team will discuss treatment options with you.

Children with bilateral Wilms tumors (tumors in both kidneys) or <u>Denys-Drash</u> <u>syndrome<sup>6</sup></u> will also need regular tests to look for possible early signs of kidney failure. This includes urine tests, blood pressure checks, and blood tests of kidney function.

#### Asking the cancer care team for a survivorship care plan

Talk with your child's treatment team about developing a <u>survivorship care plan</u><sup>7</sup>. This plan might include:

- A summary of your child's diagnosis, the tests that were done, and the treatment that was 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

It's 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<sup>8</sup>.

It's also very important to keep <u>health insurance</u><sup>9</sup> 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 for Wilms tumor

Young people treated for Wilms tumor are at risk, to some degree, for several possible late effects of their cancer treatment<sup>10</sup>.

Because of major advances in treatment, most children with Wilms tumors are now surviving into adulthood. Doctors have learned that treatment can affect a child's health later in life, so watching for health effects as they get older has become more of a concern in recent years.

It's important to discuss these possible effects with your child's cancer care team. Make sure you understand what to watch for and what to report to the care team. The earlier problems are found, the more likely they can be treated effectively.

Your child's risk of late effects will depend on a number of factors. This includes which treatments they had, the doses they received, and their age during treatment.

Possible late effects could include:

#### Reduced kidney function or kidney failure

Because children treated for Wilms tumor usually only have 1 kidney, they have a slightly higher risk of kidney failure and will need to be monitored for the rest of their lives. They also need to keep well hydrated to promote good kidney health. Some medicines, such as codeine and ibuprofen, should only be taken in small amounts to avoid kidney damage.

#### Heart problems

Children who get the chemo drug doxorubicin have a higher risk of developing heart problems, even years after treatment has ended. This is especially true if they did not receive dexrazoxane to protect their heart.

Children who get doxorubicin and radiation therapy to the lungs have an even higher risk of heart problems. Echocardiograms may be done to check oxorubR4ylogii.33 Tm 0 0 cirt prfhand

happen in children who get radiation therapy to the spine. The risk depends on the location and dose of the radiation therapy.

#### Second cancer

Wilms tumor survivors have a slightly higher risk of getting another type of cancer, called a second cancer, after treatment. The most important risk factors for a second cancer are whether treatment included radiation therapy and whether the chemo drug doxorubicin was used.

For example, young girls who get radiation therapy to treat a Wilms tumor that has spread to the lungs have an increased risk of breast cancer.

#### Pregnancy and fertility concerns

People who had radiation to the abdomen for a Wilms tumor should be considered "high risk" during pregnancy and closely watched by their doctors.

Young girls who got radiation to their abdomen for a Wilms tumor may have fertility problems when they get older. They may also have premature menopause. They need to be followed closely during puberty and may need to be referred to a fertility expert during this time.

#### **Dental problems**

A child treated for a Wilms tumor may have dental issues, depending on their age at treatment. This could include problems with teeth formation, enamel issues, or missing teeth. Regular dental care is very important.

#### Other complications

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

#### Long-term follow-up care

The <u>Children's Oncology Group (COG)</u><sup>11</sup> has developed long-term follow-up guidelines for survivors of childhood cancers, such as Wilms tumors. These guidelines were created to help increase awareness of late effects and improve follow-up care of childhood cancer survivors throughout their lives.

The 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. 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 cancer care team about the COG survivor guidelines. You can also read them online at <u>www.survivorshipguidelines.org</u><sup>12</sup>. 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.

For more about some of the possible long-term effects of treatment, see <u>Late Effects of</u> <u>Childhood Cancer Treatment<sup>13</sup></u>.

## Helping your child with the emotional and social effects of Wilms tumor treatment

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