

The kidneys do a number of things:

- They filter the blood to remove excess water, salt, and waste products, which leave the body as urine.
- They help control blood pressure.
- They help make sure the body has enough red blood cells.

Our kidneys are important, but we need less than one complete kidney to do all of its basic functions.

Most often, Wilms tumors occur in only one kidney. But a small number of children will have tumors in both kidneys.

Different types of Wilms tumor

Wilms tumors are grouped into <u>2 major types</u>¹ based on how they look under a microscope (called their **histology**):

• Favorable: The cancer cells in these tumors don't look quite normal, but they don't

look very abnormal, either. Most Wilms tumors have a favorable histology. The chance of curing children with these tumors is very good.

 Anaplastic: In these tumors, the look of the cancer cells varies widely, and parts of the cell tend to be very large and distorted. This is called *anaplasia*. Anaplasia can be either focal (limited to just certain parts of the tumor) or diffuse (spread widely through the tumor).

Questions to ask the doctor

- How sure are you that my child has a Wilms tumor?
- Is there a chance it's not a Wilms tumor?
- Would you please write down the kind of tumor you think my child has?
- What will happen next?

How does the doctor know my child has a Wilms tumor?

Wilms tumors often grow quite large before causing any <u>symptoms</u>². Often the first sign of a Wilms tumor is **swelling or hardness in the belly**, which might be on one side or both. It's usually not painful.

Other symptoms might include:

- Fever
- Nausea
- Loss of appetite
- Shortness of breath
- Constipation
- Blood in the urine

Wilms tumors can also sometimes cause **high blood pressure**. This might not cause symptoms on its own, but in rarely the blood pressure might get high enough to cause problems such as headaches, bleeding inside the eye, or even a change in consciousness.

If your child has symptoms that could be from a Wilms tumor, the doctor will want to get a complete medical history to find out more about the symptoms, and will do a physical exam. Tests might be needed as well.

Tests that may be done

Here are some of the <u>tests</u>³ your child may need:

Ultrasound: This is often the first test done if the doctor thinks your child has a tumor in the belly. This test is easy to have, does not use radiation, and it gives the doctor a good view of the kidneys and the other organs in the belly.

CT or CAT scan: This test uses x-rays to make detailed pictures of the inside of the body. This is one of the most useful tests to look for a tumor inside the kidney. It can also show if the cancer has grown into nearby veins or has spread to other organs, such as the lungs.

MRI: This test uses radio waves and strong magnets to make detailed pictures of the inside of the body. This test might be done if the doctor needs to see very detailed pictures of the kidney or nearby areas.

Chest x-ray: This test might be done to look for spread of Wilms tumor to the lungs. A chest x-ray likely won't be needed if a CT scan of the chest is done.

• What do we need to do next?

How serious is my child's tumor?

If your child has a Wilms tumor, the doctor will want to find out some <u>key pieces of information</u>⁴ to help decide how to treat it. The most important of these are:

The **stage**

Radiation treatment

Surgery

In the United States, <u>surgery</u>⁵ is the first treatment for most children with Wilms tumors. The main goal is to remove the entire Wilms tumor in one piece, if possible. If this can't be done safely, then other treatments like chemo might be done first to shrink the tumor and make surgery easier.

The main operations to treat Wilms tumors are:

Radical nephrectomy: This surgery removes the entire kidney and some nearby structures. This is the most common surgery for a Wilms tumor that's only in one kidney, as it gives the best chance of making sure all of the tumor is removed.

Partial nephrectomy (nephron-sparing surgery): This surgery removes only part of the kidney(s). It is used most often in children who have Wilms tumors in both kidneys, to try to save some normal kidney tissue.

Ask your doctor what type of surgery your child will need and what to expect.

If chemo is going to be part of treatment, surgery might be done to insert a small tube (called a <u>central venous catheter (CVC)</u>⁶ or port) into a large blood vessel – usually under the collar bone. This might be done during the surgery to remove the tumor, or as a separate operation if chemo is going to be given before the surgery.

Side effects of surgery

Any type of surgery can have risks and side effects, such as bleeding or infections. Ask your child's doctor or nurse what to expect. If your child has any problems, let them know. Doctors and nurses who treat children with Wilms tumors should be able to help you with any problems that come up.

Most children do well if only one kidney is removed. But children who have both kidneys removed, or even parts of both kidneys removed, might need regular dialysis treatments to filter their blood. They also might need a kidney transplant at some point.

Chemo

Chemotherapy⁷ (chemo) is the use of drugs to fight cancer. These drugs are put into the

blood and spread through the body.

Most children with Wilms tumors will get chemo at some point during their treatment. (Some children with very low risk tumors might not need it.)

Most often chemo is given after surgery, but sometimes it's given before surgery to shrink the tumor and make the surgery easier.

Children with Wilms tumors will get 2 or more chemo drugs as part of their treatment. Chemo is given in cycles or rounds. Each round of treatment is followed by a break. Treatment often lasts for many months.

Side effects of chemo

Chemo can make your child feel very tired, sick to their stomach, or cause their hair to fall out. It might also cause other problems. But these tend to go away after treatment ends.

There are ways to treat most chemo side effects. If your child has side effects, talk to the cancer care team so they can help.

Radiation therapy

Radiation⁸

Most side effects get better after treatment ends. But some might last longer, or might

- Is there a clinical trial that might be right for my child?
- What about vitamins or diets that friends tell me about? How will we know if they are safe?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- Is there anything we can do to help the treatment work better?
- What's the next step?

What will happen after treatment?

You'll be glad <u>when treatment is over</u>¹¹. But it's hard not to worry about the tumor coming back. Even if it never comes back, you might still worry about it. For years after treatment ends, your child will still need to see the doctor. At first, these visits may be every few months. Then, the longer your child is cancer-free, the less often the visits are needed.

Be sure your child goes to all of these follow-up visits. Your doctors will ask about symptoms, do physical exams, and may do tests to see if the tumor has come back. They may also test to see if the cancer or its treatment has caused any long-term problems. If needed, they will help you and your child learn to deal with the changes.

For connecting and sharing during a cancer journey

Anyone with cancer, their caregivers, families, and friends, can benefit from help and support. The American Cancer Society offers the Cancer Survivors Network (CSN), a safe place to connect with others who share similar interests and experiences. We also partner with CaringBridge, a free online tool that helps people dealing with illnesses like cancer stay in touch with their friends, family members, and support network by creating their own personal page where they share their journey and health updates.

Hyperlinks

- 1. www.cancer.org/cancer/types/wilms-tumor/about/what-is-wilms-tumor.html
- 2. <u>www.cancer.org/cancer/types/wilms-tumor/detection-diagnosis-staging/signs-and-</u> symptoms.html
- 3. <u>www.cancer.org/cancer/types/wilms-tumor/detection-diagnosis-staging/how-diagnosed.html</u>
- 4. www.cancer.org/cancer/types/wilms-tumor/detection-diagnosis-

staging/staging.html

- 5. <u>www.cancer.org/cancer/types/wilms-tumor/treating/surgery.html</u>
- 6. <u>www.cancer.org/cancer/managing-cancer/making-treatment-decisions/tubes-lines-ports-catheters.html</u>
- 7. www.cancer.org/cancer/types/wilms-tumor/treating/chemotherapy.html
- 8. www.cancer.org/cancer/types/wilms-tumor/treating/radiation-therapy.html
- 9. <u>www.cancer.org/cancer/managing-cancer/making-treatment-decisions/clinical-trials.html</u>
- 10. <u>www.cancer.org/cancer/managing-cancer/treatment-types/complementary-and-integrative-medicine.html</u>
- 11. www.cancer.org/cancer/types/wilms-tumor/after-treatment/follow-up.html
- 12. www.cancer.org

Words to know

Biopsy (BY-op-see): Taking out a piece of an abnormal area to see if there are tumor cells in it.

Central venous catheter (CVC): A small tube that is put into a large blood vessel (usually under the collar bone), with one end staying outside of the body or just under the skin. It can be left in place for months and can be used to give chemo or take blood samples. Also called a venous access device (VAD) or a port.

Chemotherapy (KEY-mo-THAIR-uh-pee): The use of drugs to kill cancer cells. Also called chemo.

Metastasis (muh-TAS-tuh-sis): The spread of cancer cells from where they started to other places in the body.

Nephrectomy (nef-REK-tuh-mee): Surgery to remove a kidney (radical nephrectomy) or part of a kidney (partial nephrectomy).

Radiation (ray-dee-AY-shun) therapy: The use of high-energy rays (like x-rays) to kill cancer cells.

How can I learn more?

We have a lot more information for you. You can find it online at www.cancer.org¹². Or, you can call our toll-free number at 1-800-227-2345 to talk to one of our cancer information specialists.

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