Early Detection, Diagnosis, and Staging

Detection and Diagnosis

Catching cancer early often allows for more treatment options. Some early cancers may have signs and symptoms that can be noticed, but that is not always the case.

- Can Wilms Tumor Be Found Early?
- Signs and Symptoms of Wilms Tumor
- How Are Wilms Tumors Diagnosed?

Stages and Outlook (Prognosis)

After a cancer diagnosis, staging provides important information about the extent of cancer in the body and anticipated response to treatment.

- How Is Wilms Tumor Staged?
- Survival Rates for Wilms Tumor, by Stage and Histology

Questions to Ask About Wilms Tumor

Here are some questions you can ask your cancer care team to help you better understand your cancer diagnosis and treatment options.

- What Should You Ask Your Child’s Doctor About Wilms Tumor?

Can Wilms Tumor Be Found Early?

Wilms tumors are usually found when they start to cause symptoms such as swelling in the abdomen (belly), but by this point they have often grown quite large. They can be found earlier in some children with tests such as an ultrasound of the abdomen. (See the section How are Wilms tumors diagnosed?) But because Wilms tumors are rare,
it’s not practical to use ultrasound exams as a screening test (a test to look for disease in people with no signs or symptoms) in all children who are not at increased risk. There are no blood tests or other tests that are useful in screening otherwise healthy children for Wilms tumors.

On the other hand, screening for Wilms tumor is very important for children who have syndromes or birth defects known to be linked to this disease. For these children, most doctors recommend physical exams by a specialist and ultrasound exams on a regular basis (for example, about every 3 or 4 months at least until the age of 8) to find any kidney tumors when they are still small and have not yet spread to other organs.

Wilms tumor can also run in families, although this is rare. Talk to your doctor if you have any relatives who have had a Wilms tumor. If you do, the children in your family may need to have regular ultrasound exams of the abdomen. If a man or woman is known to have a WT1 gene mutation, testing can be done to see if they have passed the mutation on to their children. (This can be done even before birth.)

- References

See all references for Wilms Tumor

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Signs and Symptoms of Wilms Tumor

Wilms tumors can be hard to find early because they can often grow quite large without causing any symptoms. Children may look healthy and play normally.

Swelling or a hard mass in the abdomen (belly): This is often the first sign of a Wilms tumor. Parents may notice this while bathing or dressing the child. It feels firm and is often large enough to be felt on both sides of the belly. It’s usually not painful, but it might cause belly pain in some children.

Other possible symptoms: Some children with Wilms tumor may also have:

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

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

Many of the signs and symptoms above are more likely to be caused by something other than a kidney tumor. Still, if your child has any of these symptoms, check with your child’s doctor so that the cause can be found and treated, if needed.

• References
See all references for Wilms Tumor

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How Are Wilms Tumors Diagnosed?

Wilms tumors are usually found when a child is brought to a doctor because of symptoms he or she is having. The doctor might suspect a child has a Wilms tumor because of the physical exam or other test results, but the diagnosis can only be made for certain by taking out a small piece of the tumor and looking at it under a microscope.

Medical history and physical exam

If your child has signs or symptoms that suggest he or she may have a kidney tumor, the doctor will want to get a complete medical history to learn more about the symptoms and how long they have been there. The doctor may also ask if there’s a family history of cancer or birth defects, especially in the genitals or urinary system.
The doctor will examine your child for possible signs of a kidney tumor or other health problems. The focus will probably be on the abdomen (belly) and on any increase in blood pressure, which is another possible sign of a kidney tumor. Blood and urine samples might also be collected and tested (see “Lab tests” below).

**Imaging tests**

If the doctor thinks your child might have a kidney tumor, he or she will probably get one or more of the imaging tests below. These tests use sound waves, x-rays, magnetic fields, or radioactive substances to create pictures of the inside of the body. Imaging tests are done for a number of reasons, including:

- To help find out if there is a tumor in the kidney(s), and if so, if it's likely to be a Wilms tumor
- To learn if and how far the tumor has spread, both in the kidney and to other parts of the body
- To help guide surgery or radiation therapy
- To look at the area after treatment to help determine if it has worked

**Ultrasound (sonogram)**

Ultrasound is often the first imaging test done if the doctor suspects your child has a Wilms tumor (or another type of tumor in the abdomen). 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 abdomen. It's also very useful when looking for tumor growing into the main veins coming out of the kidney. This can help in planning for surgery, if it's needed.

**Computed tomography (CT, CAT) scan**

The CT scan uses x-rays to make detailed cross-sectional images of parts of your child's body, including the kidneys. This is one of the most useful tests to look for a tumor inside the kidney. It's also helpful for checking whether a cancer has grown into nearby veins or has spread to organs beyond the kidney, such as the lungs. Your child will need to lie very still on a table while the scans are being done. Younger children may be given medicine to help keep them calm or even asleep during the test to help make sure the pictures are clear.

**Magnetic resonance imaging (MRI) scan**
An MRI scan might be done if the doctor needs to see very detailed images of the kidney or nearby areas. For example, it might be done if there’s a chance that a kidney tumor might have reached a major vein (the inferior vena cava) in the abdomen. An MRI scan might also be used to look for possible spread of cancer to the brain or spinal cord if doctors are concerned the cancer may have spread there.

Your child may have to lie inside a narrow tube, which is confining and can be distressing. The test also requires a person to stay still for several minutes at a time. Younger children may be given medicine to help keep them calm or even asleep during the test.

**Chest x-ray**

Chest x-rays may be done to look for any spread of Wilms tumor to the lungs, as well as to have a baseline view of the lungs to compare with other x-rays that might be done in the future. This test might not be needed if a CT scan of the chest is done.

**Bone scan**

Bone scans can help show if cancer has spread to bones. Doctors don’t usually order this test unless they think your child has a type of Wilms tumor that's likely to spread.

**Lab tests**

Lab tests might be done to check urine and blood samples if your child’s doctor suspects a kidney problem. They may also be done after a Wilms tumor has been found.

A urine sample may be tested (urinalysis) to see if there are problems with the kidneys. Urine may also be tested for substances called catecholamines. This is done to make sure your child doesn’t have another kind of tumor called neuroblastoma. (Neuroblastomas often start in the adrenal glands, which are just on top of each kidney.)

**Kidney biopsy/surgery**

Most of the time, imaging tests can give doctors enough information to decide if a child probably has a Wilms tumor, and therefore if surgery should be done. But the actual diagnosis of Wilms tumor is made when a small piece of the tumor is removed and checked under a microscope. The cells in Wilms tumors have a distinct appearance
when looked at this way. Doctors also look at the sample to determine the histology of the Wilms tumor (favorable or unfavorable), as described in How is Wilms tumor staged?

In most cases, a sample is removed during surgery to treat the tumor (see the Surgery section). Sometimes if the doctors are less certain about the diagnosis or if they aren’t sure the tumor can be removed completely, a sample of the tumor may be taken during a biopsy as a separate procedure before surgery.

See Testing Biopsy and Cytology Specimens for Cancer to learn more about different types of biopsies, how the biopsy samples are tested in the lab, and what the results might tell you.

- References

See all references for Wilms Tumor

How Is Wilms Tumor Staged?

The stage of a cancer describes how far it has spread. Your child’s treatment and prognosis (outlook) depend, to a large extent, on the cancer’s stage. Staging is based on the results of the physical exam and imaging tests (ultrasound, CT scans, etc.), which are described in How are Wilms tumors diagnosed?, as well as on the results of surgery to remove the tumor, if it has been done.

Children’s Oncology Group (COG) staging system

A staging system is a standard way for the cancer care team to sum up the extent of the tumor. In the United States, the Children’s Oncology Group staging system is used most often to describe the extent of spread of Wilms tumors. This system describes Wilms tumor stages using Roman numerals I through V (1 through 5).

Stage I
The tumor was contained within one kidney and was removed completely by surgery. The tissue layer surrounding the kidney (the renal capsule) was not broken during surgery. The cancer had not grown into blood vessels in or next to the kidney. The tumor was not biopsied before surgery to remove it.

About 40% to 45% of all Wilms tumors are stage I.

**Stage II**

The tumor has grown beyond the kidney, either into nearby fatty tissue or into blood vessels in or near the kidney, but it was removed completely by surgery without any apparent cancer left behind. Nearby lymph nodes (bean-sized collections of immune cells) do not contain cancer. The tumor was not biopsied before surgery.

About 20% of all Wilms tumors are stage II.

**Stage III**

This stage refers to Wilms tumors that may not have been removed completely. The cancer remaining after surgery is limited to the abdomen (belly). One or more of the following features may be present:

- The cancer has spread to lymph nodes in the abdomen or pelvis but not to more distant lymph nodes, such as those inside the chest.
- The cancer has grown into nearby vital structures so the surgeon could not remove it completely.
- Deposits of tumor (tumor implants) are found along the inner lining of the abdominal space.
- Cancer cells are found at the edge of the sample removed by surgery, a sign that some of the cancer still remains after surgery.
- Cancer cells “spilled” into the abdominal space before or during surgery.
- The tumor was removed in more than one piece — for example, the tumor was in the kidney and in the nearby adrenal gland, which was removed separately.
- A biopsy of the tumor was done before it was removed with surgery.

About 20% to 25% of all Wilms tumors are stage III.

**Stage IV**

The cancer has spread through the blood to organs away from the kidneys such as the
lungs, liver, brain, or bones, or to lymph nodes far away from the kidneys.

About 10% of all Wilms tumors are stage IV.

**Stage V**

Tumors are found in both kidneys at diagnosis.

About 5% of all Wilms tumors are stage V.

**Tumor histology**

The other main factor in determining the prognosis and treatment for a Wilms tumor is the tumor’s histology, which is based on how the tumor cells look under a microscope. The histology can be either favorable or unfavorable (anaplastic). These are described in more detail in What is Wilms tumor?

- References
  See all references for Wilms Tumor

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Survival rates are often used by doctors as a standard way of discussing a person’s prognosis (outlook). Some parents may want to know the survival statistics for children in similar situations, while others may not find the numbers helpful, or may even not want to know them. If you would rather not read about survival rates, don’t read any further.

The 4-year survival rate refers to the percentage of children who live at least 4 years after their cancer is diagnosed. Of course, many children live much longer than 4 years.
(and many are cured).

To get 4-year survival rates, doctors have to look at children who were treated at least 4 years ago. Improvements in treatment since then may result in a better outlook for children now being diagnosed with Wilms tumors.

These survival rates are based on the results of the National Wilms Tumor Studies, which included most of the children treated in the United States in the last few decades. The most important factors in determining a child’s outlook are the stage and histology of the tumor. (Histology refers to how the cancer cells look under the microscope – see What is Wilms tumor?) Some of these rates are based on only small numbers of children, so it’s hard to know if they are accurate.

Survival rates are based on previous outcomes of children who had the disease, but they can’t predict what will happen in any particular child’s case. Knowing the stage and histology of a Wilms tumor are important in estimating the child’s outlook. But other factors can also affect a child’s outlook, such as how well the tumor responds to treatment. Even when taking other factors into account, survival rates are only rough estimates. Your child’s doctor can tell you if the numbers below apply, as he or she knows your child’s situation best.

### Wilms Tumor 4-year Survival Rates

<table>
<thead>
<tr>
<th>Tumor Stage</th>
<th>Favorable Histology</th>
<th>Unfavorable Histology (Anaplastic Wilms Tumor)</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>99%</td>
<td>83%</td>
</tr>
<tr>
<td>II</td>
<td>98%</td>
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<td>94%</td>
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<td>38%</td>
</tr>
<tr>
<td>V</td>
<td>87%</td>
<td>55%</td>
</tr>
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</table>

### References

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What Should You Ask Your Child’s Doctor About Wilms Tumor?

It’s important to have honest, open discussions with your child’s cancer care team. You should ask any questions that are on your mind, no matter how small they may seem. Below are some questions to consider:

- What kind of kidney cancer does my child have? Is it a Wilms tumor?
- Is the histology of the tumor favorable or unfavorable?
- What is the stage of my child’s cancer, and what does that mean?
- Will we need to have other tests done before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- What other doctors will we need to see?
- What are our treatment options?
- Are there any clinical trials we might want to consider?
- What do you recommend and why?
- What are the risks and side effects of the suggested treatments?
- Which side effects start shortly after treatment and which ones might develop later on?
- Will treatment affect my child’s ability to grow and develop?
- Could treatment affect my child’s ability to have children later on?
- Will my child have a higher long-term risk of kidney problems or other cancers?
- How soon do we need to start treatment?
- What should we do to be ready for treatment?
- How long will treatment last? What will it be like? Where will it be done?
- How will treatment affect our daily lives (school, work, etc.)?
- Based on what you’ve learned about my child’s cancer, what is the outlook for cure?
- What would we do if the treatment doesn’t work or if the cancer comes back?
- What type of follow-up will my child need after treatment?

Along with these sample questions, be sure to write down any others you might have. For instance, you might want to ask about getting a second opinion, or you may want more information about recovery times so you can plan your school or work schedules. You might also want to ask about nearby or online support groups, where you may be able to get in touch with other families who have been through this.

Also keep in mind that doctors are not the only ones who can provide you with
information. Other health care professionals, such as nurses and social workers, may have the answers to some of your questions. You can find out more about speaking with your health care team in The Doctor-Patient Relationship.

- References

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