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 Tumors Be Found Early?
- Signs and Symptoms of Wilms Tumors
- Tests for Wilms Tumors

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.

- Wilms Tumor Stages
- Survival Rates for Wilms Tumors

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.

- Questions to Ask Your Child’s Doctor About Wilms Tumor

Can Wilms Tumors 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 Tests for Wilms Tumors.) But because Wilms tumors are rare, it’s not practical to use
ultrasound exams to screen all children for them. (Screening is testing for a disease like cancer in people with no signs or symptoms.) There are no blood tests or other tests that are useful in screening otherwise healthy children for Wilms tumors.

**For children at increased risk**

On the other hand, screening is very important for children who have syndromes or birth defects known to be linked to Wilms tumors. For these children, most doctors recommend physical exams by a specialist and ultrasound exams of the kidneys on a regular basis (for example, about every 3 or 4 months at least until the age of 7) 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, genetic testing can be done to see if they have passed the mutation on to their children. (This can be done even before birth.)

**References**


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**Signs and Symptoms of Wilms Tumors**

Wilms tumors occur most often in young children. These tumors often grow quite large before causing any symptoms. Children may look healthy and act and play normally.
Swelling or a large lump in the abdomen (belly)

This is often the first sign of a Wilms tumor. Parents may notice swelling or hardness in the belly while bathing or dressing the child. The lump is sometimes large enough to be felt on both sides of the belly. It’s usually not painful, but it might be 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 doesn't 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 of Wilms tumors are more likely to be caused by something else. 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


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Tests for Wilms Tumors

Certain signs and symptoms could suggest that a child might have a Wilms tumor (or another type of kidney tumor), but exams and tests are needed to find out for sure.

Medical history and physical exam

If your child has signs or symptoms that suggest he or she might 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, as this might point to an increased risk or Wilms tumors.

The doctor will also do a physical exam to look for possible signs of a kidney tumor or other health problems. The focus will probably be on your child’s 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 imaging tests. These tests use sound waves, x-rays, magnetic fields, or radioactive substances to create pictures of the inside of the body. Imaging tests might be 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(s) 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 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.

This test can also show if the tumor is 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 creates detailed images using radio waves and strong magnets instead of x-rays, so there is no radiation involved. This test 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 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.

**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 anaplastic), as described in What Are Wilms Tumors?

Most often, a sample is removed during surgery to treat the tumor. 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


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Wilms Tumor Stages

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 Tests for Wilms Tumors, 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 divides Wilms tumors into 5 stages using Roman numerals I through V.

Stage I

The tumor is 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.

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.

Stage III

This stage refers to Wilms tumors that most likely have 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.

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.

Stage V

Tumors are found in both kidneys at the time of diagnosis.

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 anaplastic. These are described in more detail in What Are Wilms Tumors?

To learn more about how the stage and histology of a Wilms tumor might affect prognosis, see Survival Rates for Wilms Tumors.

References

Survival Rates for Wilms Tumors

Survival rates are often used by doctors as a standard way of discussing a person’s prognosis (outlook). These numbers tell you what portion of people in a similar situation (such as with the same type and stage of cancer) are still alive a certain amount of time after they were diagnosed. They can’t tell you exactly what will happen with any person, but they may help give you a better understanding about how likely it is that treatment will be successful. Some people find survival rates helpful, but some people might not.

For Wilms tumors, survival is often measured using a 4-year survival rate. This refers to the percentage of children who live at least 4 years after their cancer is diagnosed. For example, a 4-year survival rate of 80% means that an estimated 80 out of 100 children who have that cancer are still alive 4 years after being 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.

But remember, survival rates are estimates, and they can’t predict what will happen in a particular child’s case. Each child’s outlook can vary based on a number of factors specific to them. 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 Are Wilms Tumors?) But other factors can also affect a child’s outlook, such as the child’s age and how well the tumor responds to treatment.
Even when taking other factors into account, survival rates are only rough estimates. Your child’s cancer care team can tell you how the numbers below might apply, as they know your child’s situation best.

**Survival rates for 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. Some of these rates are based on only small numbers of children, so it’s hard to know how accurate they are.

<table>
<thead>
<tr>
<th>Tumor Stage</th>
<th>Favorable Histology</th>
<th>Focal Anaplastic</th>
<th>Diffuse Anaplastic</th>
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<tbody>
<tr>
<td>I</td>
<td>95% - 100%</td>
<td>85% - 90%</td>
<td>75% - 80%</td>
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<tr>
<td>II</td>
<td>95% - 100%</td>
<td>80% - 85%</td>
<td>80% - 85%</td>
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<td>95% - 100%</td>
<td>75% - 90%</td>
<td>50% - 70%</td>
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<tr>
<td>V</td>
<td>95% - 100%</td>
<td>95% - 100%</td>
<td>65% - 70%</td>
</tr>
</tbody>
</table>

**References**


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**Questions to Ask Your Child’s Doctor About Wilms Tumor**

It’s important to have honest, open discussions with your child’s cancer care team. Ask
any question on your mind, no matter how small it might seem. Below are some questions to consider:

**If the tumor has been biopsied**

- What kind of kidney cancer does my child have? Is it a [Wilms tumor](#)?
- Is the [histology](#) of the tumor favorable or anaplastic?
- What is the [stage](#) of my child’s cancer, and what does that mean?
- Do we need any other [tests](#) before we can decide on treatment?
- How much experience do you have treating this type of cancer?
- Will we need to see other doctors?
- Who else will be on the treatment team, and what do they do?

**When deciding on a treatment plan**

- What are our [treatment options](#)?
- Are there any [clinical trials](#) we might want to consider?
- What do you recommend and why?
- Should we get a [second opinion](#)? How do we do that? Can you recommend a doctor or cancer center?
- 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.)?

**During and after treatment**

Once treatment begins, you’ll need to know what to expect and what to look for. Not all of these questions may apply, but getting answers to the ones that do may be helpful.

- How will we know if the treatment is working?
- Is there anything we can do to help manage side effects?
- What symptoms or side effects should we tell you about right away?
- How can we reach you or someone on your team on nights, weekends, or holidays?
- Who can we talk to if we have questions about costs, insurance coverage, or social support?
- What are the chances of the cancer coming back after treatment? What might our options be if this happens?
- 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 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 aren't 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.

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