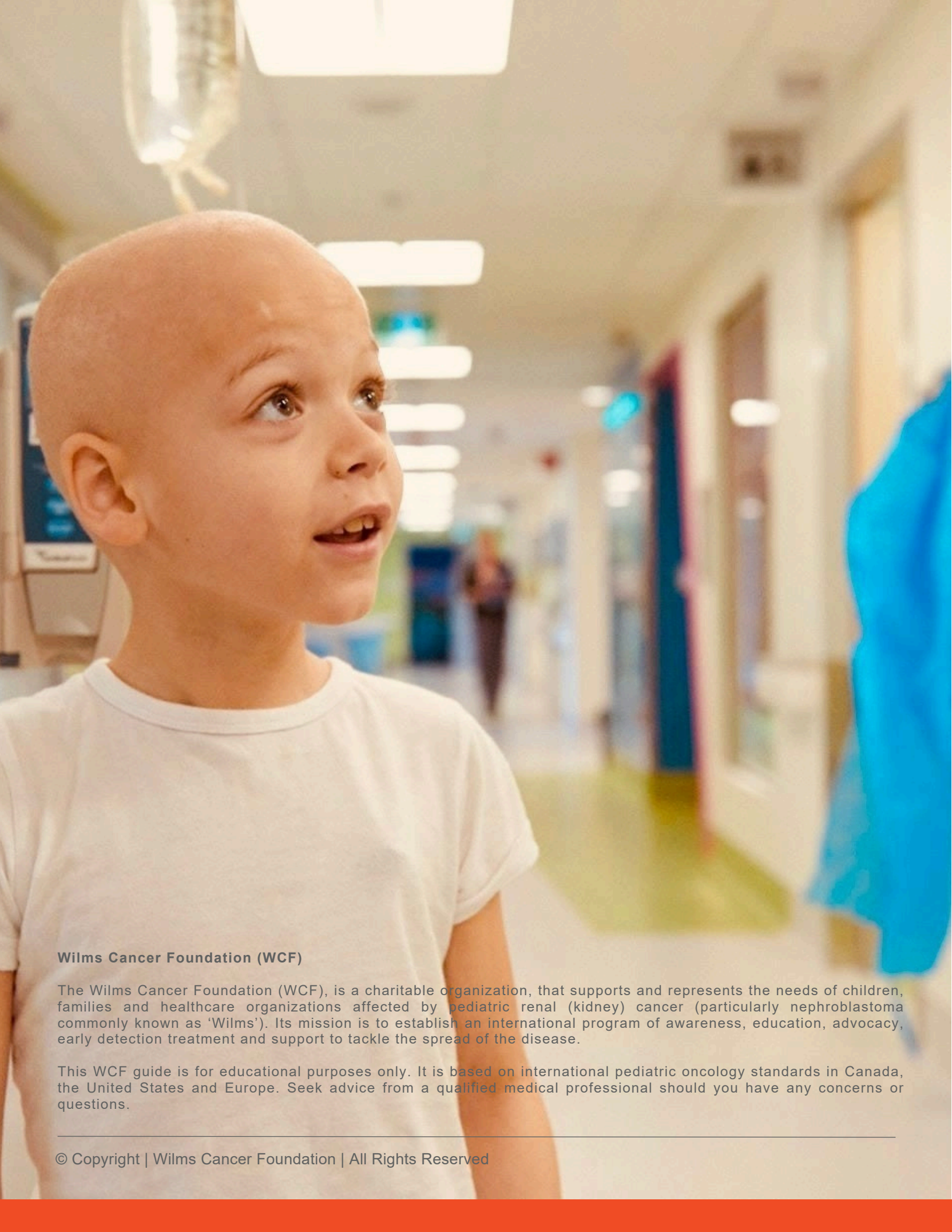


Wilms Tumor

# Early Diagnosis & Long-term Outlook

A Plain Language Guide for Parents and Caregivers





### **Wilms Cancer Foundation (WCF)**

The Wilms Cancer Foundation (WCF), is a charitable organization, that supports and represents the needs of children, families and healthcare organizations affected by pediatric renal (kidney) cancer (particularly nephroblastoma commonly known as 'Wilms'). Its mission is to establish an international program of awareness, education, advocacy, early detection treatment and support to tackle the spread of the disease.

This WCF guide is for educational purposes only. It is based on international pediatric oncology standards in Canada, the United States and Europe. Seek advice from a qualified medical professional should you have any concerns or questions.

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Briefing Series 2.2a

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# 1 - One Page Summary for Caregivers

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## 1.1 - What is Wilms tumor:

- Wilms tumor is a kidney cancer affecting young children, mostly under 5yrs;
- It is the 4th most common childhood cancer overall and the most common childhood kidney cancer.

## 1.2 - Why early diagnosis matters:

- Many children feel completely well at first, which is why knowing the early signs and acting quickly is so important;
- The good news: when Wilms tumor is found early, treatment is very effective, and most children live full, healthy lives with survival at over 90%.

## 1.3 - Most important warning sign:

- A firm, painless lump or swelling in the belly

## 1.4 - Other signs to watch for:

- Blood in the urine;
- High blood pressure, headaches, or fatigue;
- Belly pain, fever, or unexplained tiredness.

## 1.5 - What to do if you notice a sign:

- Seek medical attention immediately;
- Ask for urgent imaging (ultrasound);
- Do not wait to see if it improves;

## 1.6 - How Wilms tumor is diagnosed:

- Ultrasound of the abdomen;
- CT or MRI scan to define the tumor;
- Chest imaging to check the lungs;
- Referral to a pediatric cancer team.

## 1.7 - Important safety point:

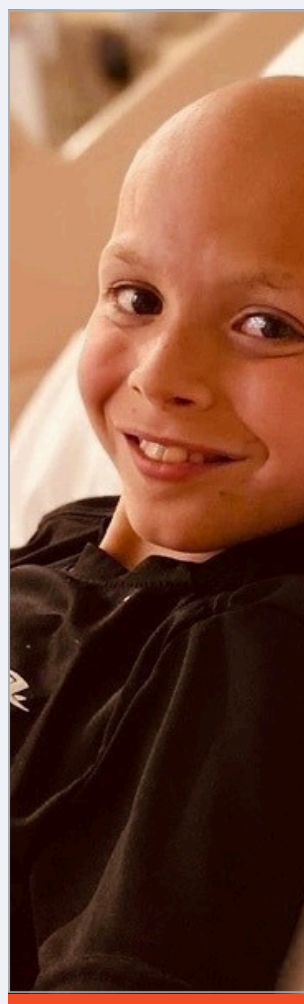
- Doctors usually do not biopsy Wilms tumors at diagnosis because biopsy can increase risk.

## 1.8 - Long-term outlook:

- Most children become long-term survivors;
- Relapse risk is highest in the first 2–3 years;
- After 5 years, relapse risk is very low;
- Follow-up care focus: kidney health, growth, wellness.

## 1.9 - Caregiver takeaway:

- A painless belly lump is never normal; Acting quickly leads to better outcomes.



## 2 - Screening

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### 2.1 - Universal Guidelines:

Doctors around the world follow shared expert guidelines (from COG and SIOP) that focus on fast recognition and imaging, not waiting to “see if it improves”.

When Wilms tumor is found early treatment is usually less intense, and long-term health outcomes are better

### 2.2 - Children Who Need Extra Screening:

Some children have a higher risk of Wilms tumor and need regular check-ups even if they feel fine.

These include children with:

- Beckwith–Wiedemann syndrome;
- WAGR syndrome;
- Denys–Drash syndrome Hemihyperplasia;
- known WT1 gene changes;
- Strong family history of Wilms tumor.

Screening often finds tumors early and smaller, which means easier treatment.

### 2.3 - Recommended Screening (Expert Standard):

Kidney ultrasound every 3 months; From infancy until age 7–8



## 3 - Diagnosis (Step by Step)

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### Step 1

#### Medical Exam:

- Doctor feels the abdomen
  - Gentle exam only (no repeated pressing)
- 

### Step 2

#### Ultrasound (First Test):

- Safe, painless, no radiation;
  - Confirms whether the lump is coming from the kidney;
  - Checks both kidneys.
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### Step 3

#### CT or MRI Scan:

- Shows tumor size and spread;
  - Helps doctors plan treatment;
  - MRI may be used to reduce radiation exposure.
- 

### Step 4

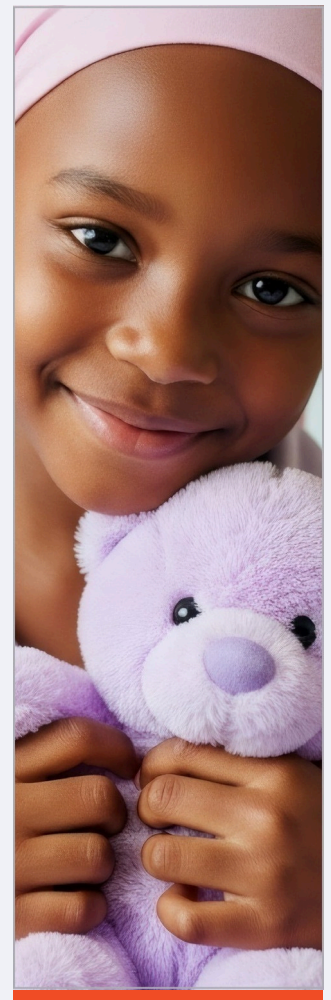
#### Chest Imaging:

- Chest CT or X-ray;
  - Lungs are the most common place Wilms tumor can spread.
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### Step 5

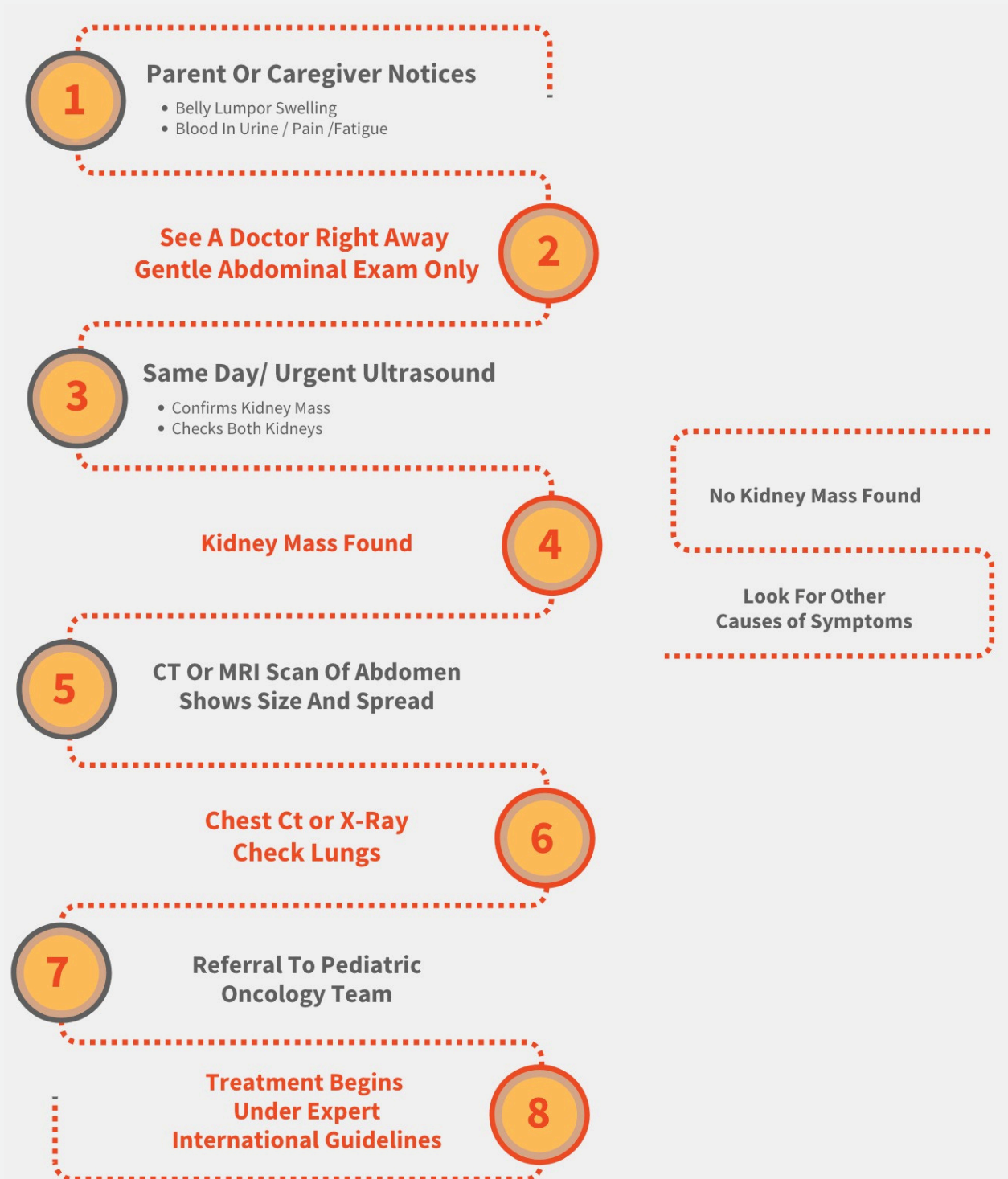
#### Blood and Urine Tests:

- Check kidney function;
  - Look for anemia or blood in urine;
  - Establish a safe treatment baseline.
- 



## 4 - How Wilms Tumor is Detected

### 4.1 - Visual Diagram



## 5 - Important Safety Points

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### 4.1 - No Biopsy at Diagnosis:

- Parents are often surprised to learn that doctors do not usually biopsy Wilms tumors right away

### 4.2 - Why:

- Biopsy can cause tumor cells to spill;
- This can change the cancer stage;
- Imaging is usually clear enough to diagnose;
- This approach is used worldwide to keep children safer.

### 4.3 - Life After Treatment (Survivorship & Long-Term Care):

- Children treated for Wilms tumor become long-term survivors.

### 4.4 - Long-Term Follow-Up Focus:

- Kidney health (especially if one kidney was removed)
- Blood pressure;
- Heart & lung health (if certain medicines or radiation used);
- Growth and development.

**Note:** Children usually face regular periodic follow-up visits spanning many years.

### 4.5 - Understanding Relapse (Plain Language):

- Relapse means the cancer comes back.

### 4.6 - Key Points for Caregivers:

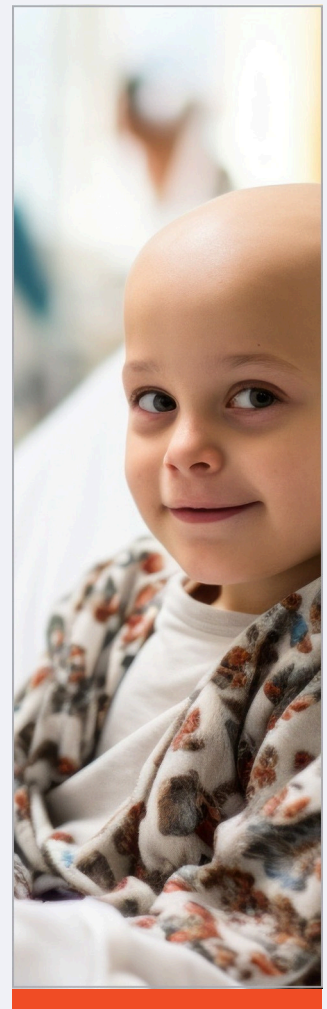
- Risk is highest in the first 2–3 years after treatment;
- After 5 years, relapse risk drops significantly;
- Children are still monitored closely during this period.

### 4.7 - What Lowers Relapse Risk

- Early-stage diagnosis Complete tumor removal;
- Following treatment and follow-up plans.

### 4.8 - Reassurance for Families:

- Most children with Wilms tumor survive and thrive;
- Early diagnosis reduces treatment intensity;
- Long-term follow-up is about protection, not expectation of relapse survivorship care is proactive and preventive.





## 6 - What to ask

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### 6.1- Bringing Questions Helps you Advocate for your Child:

- What stage is the tumor;
- What treatment plan are you recommending and why;
- Will my child need chemotherapy or radiation;
- How will treatment affect kidney function long term;
- What side effects should we watch for right now;
- How often will follow-up visits and scans happen;
- What signs of relapse should we watch for at home;
- Who do we contact if we are worried between appointments.

### 6.2 - Key Takeaways for Caregivers:

- Trust your instincts;
- A painless belly lump is never something to wait on;
- Early action leads to the best solutions.





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