QUESTIONS TO ASK YOUR CHILD'S DOCTOR ABOUT NEUROBLASTOMA

Your child's healthcare team is your best resource when learning about and understanding each step in your neuroblastoma treatment journey. You can make the most of your time with the oncologist by preparing questions to ask.

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Questions to ask your doctor... ABOUT DIAGNOSIS

- How long will it take to determine if my child has neuroblastoma?
- What tests will be done to diagnose my child with neuroblastoma?
- Will all the tests be performed at the hospital?
- Is this hospital fully equipped to test whether my child has neuroblastoma?
- What are the results of my child's tests and scans?
- Where is my child's neuroblastoma located?
- Has my child's neuroblastoma metastasized (spread)? If so, where has it spread?
- What stage of disease does my child have?
- Notes

- What other risk factors does my child have?
- Is my child's neuroblastoma non-high-risk or high-risk?
- How do I get copies of my child's test results?
- What should we do to be ready for treatment?
- How will treatment affect our daily activities?
- Can my child continue with school and extracurricular activities?
- What resources does your hospital have available to support my family during this time?
- How do I get a second opinion from another hospital or research group?



Questions to ask your doctor...

WHEN MAKING A TREATMENT DECISION

- Does this hospital specialize in the treatment of neuroblastoma?
- How many children with my child's risk level has this hospital treated in the past year?
- Which pediatric oncologist will be primarily responsible for my child's care?
- Will the same oncologists who take care of my child in the hospital also be in the clinic?
- Who will perform my child's surgeries?
- How many neuroblastoma surgeries does this surgeon perform each year?
- Are there neuroblastoma experts who you'd recommend in the United States?

- Which children's hospitals specialize in neuroblastoma treatment in the United States?
- Are there any leading neuroblastoma surgeons you know of in the United States?
- Where does treatment take place and how long does it last?
- Who will be part of my child's healthcare team, and what does each member do?
- Can I speak to other families that have been through neuroblastoma treatment here?



Questions to ask your doctor... ABOUT CLINICAL TRIALS

- What is being studied?
- Why do researchers believe the intervention being tested might be effective? Why might it not be effective? Has it been tested before?
- What are the possible interventions that my child might receive during the trial?
- How is it determined which interventions my child will receive (for example, by chance)?
- Who knows which intervention my child will receive during the trial? Will I know? Will members of the research team know?
- How do the possible risks, side effects, and benefits of this trial compare with those of standard treatment?
- What will we have to do?
- What tests and procedures will be involved?
- Notes

- How often will we have to visit the hospital or clinic?
- Will hospitalization be required?
- How long will the study last?
- Who pays for my participation?
- Will I be reimbursed for other expenses?
- What type of long-term follow-up care will be part of this trial?
- If my child benefits from the intervention, will they be allowed to continue receiving it after the trial ends?
- Will results of the study be provided to me?
- Who will oversee my child's medical care while we are participating in the trial?
- What are my options if my child is injured during the study?



Questions to ask your doctor about...

THE SAFETY OF YOUR CHILD'S NEUROBLASTOMA TREATMENT

- Can we talk about the results of the clinical trial that my child's therapy is based on?
- How will this treatment affect my child's daily life?
- How long will it take my child to recover from treatment?
- What are the possible side effects from treatment, both in the short term and the long term?
- How will your team help manage the side effects?
- How might treatment affect my child's ability to develop?
- Will my child's treatment affect their ability to have children of their own someday?



Questions to ask your doctor about...

YOUR CHILD'S NEUROBLASTOMA TREATMENT

- What will the treatment plan be for my child's neuroblastoma?
- What are the goals for my child's treatment?
- How will I be involved in treatment decisions for my child?
- How many children like mine have you treated with this treatment plan?
- How long has this treatment plan been in use?
- What is the survival rate for children given this treatment plan?
- Do survival rates vary depending on the treatment plan?
- Do we have any choices about the treatment?
- Are there other neuroblastoma treatments available elsewhere?
- Are there clinical trials that might provide my child with a better chance of survival?



Questions to ask your doctor about...

HIGH-RISK NEUROBLASTOMA TREATMENT

- How does the treatment protocol offered here differ from those offered at other hospitals?
- Could I speak with the parent of a child who has completed this treatment?
- How long will each therapy last?
- What is the goal of each therapy?
- What side effects can my child expect during each therapy?
- What are the possible long-term side effects of each therapy?
- What can be done to relieve the side effects of each therapy?

Chemotherapy and stem cell harvest

- Will my child receive chemotherapy as a part of their treatment plan?
- What chemotherapy medicines will my child receive?
- Is this the chemotherapy regimen used at most hospitals?
- How many cycles of chemotherapy will my child receive?
- Will my child's stem cells be collected for a stem cell transplant later on?

Chemotherapy and stem cell harvest (cont'd)

- When will my child's stem cells be collected?
- What will the stem cell collection process be like?

Surgery

- Will my child receive surgery as part of their treatment plan?
- At what point in the treatment plan will my child have surgery? How does this compare to other hospitals?
- What type of surgery will my child receive?
- Will you remove any of my child's lymph nodes during surgery?
- How long will my child's surgery take?
- What are the short-term effects of this surgery?
- What are the possible long-term effects of this surgery?
- How long will my child be in the hospital after surgery?
- When will my child be able to move on to the next phase of therapy after their surgery?
- When will we find out the results of resection and the response of the tumor to chemotherapy?



Questions to ask your doctor about...

HIGH-RISK NEUROBLASTOMA TREATMENT (cont'd)

Radiation therapy

- Will my child receive radiation therapy as a part of their treatment plan?
- What type of radiation therapy will my child receive?
- At what point in the treatment plan will my child receive radiation therapy?
- Will I be able to see my child during or after radiation therapy?
- Will my child be awake during radiation therapy?
- What are the possible short-term side effects of radiation therapy? How will you manage side effects?
- What are the possible long-term side effects of radiation therapy?

Stem cell transplantation

- Will my child undergo a stem cell transplant?
- Does this hospital provide stem cell transplants, or will my child have to transfer to another hospital for this portion of their therapy?
- If we have to go to another hospital, will we stay there for follow-up, radiation, and antibody therapy, or come back to this hospital?
- What type of stem cell transplant will my child receive?

Stem cell transplantation (cont'd)

- Will my child receive more than one stem cell transplant?
- What type of chemotherapy will my child have during this portion of their therapy?
- What are the potential side effects of stem cell transplant and how will they be managed?
- How long will we be in the hospital for stem cell transplant?
- What are the guidelines and restrictions for patients receiving stem cell transplant at your hospital?

Antibody therapy

- Will my child be eligible for antibody therapy after transplant at this hospital?
- What type of antibody therapy does this hospital offer?
- How does the antibody therapy offered here differ from that offered at other hospitals?
- What is the admission process like for antibody therapy at this hospital?
- * What are the possible short-term side effects of antibody therapy?
- What are the possible long-term side effects of antibody therapy?

Questions to ask your doctor... AFTER TREATMENT

- What are the chances that my child's cancer could return after treatment?
- What is the plan if my child's neuroblastoma does return?
- Are there specific signs and symptoms of neuroblastoma I should watch for?
- What type of follow-up will my child need after treatment?
- What follow-up tests will be needed, and how often will they be needed?
- When will it be safe for my child to return to school or daycare?
- Will my child need to be reimmunized?
- What late effects of treatment are possible?
- Who on the healthcare team will follow my child 5 years after therapy?
- Does this hospital have a long-term follow-up specialty clinic?
- Which specialists should continue to monitor my child?
- How do I get my child's treatment summary?
- What is the protocol for transitioning to adult care for this hospital?

