Neuroblastoma:

What is neuroblastoma?
Neuroblastoma is a solid, cancerous tumor that begins in the nerve cells outside of the brain in infants and young children. The tumor forms when immature nerve cells (neuroblasts) do not mature properly. The cancer often starts in the tissue of the adrenal glands, which are the glands that control heart rate and blood pressure, located on the top of both kidneys. It can also start near the spine in the neck, chest, abdomen, or pelvis.

What does stage mean?
The stage is a way of describing where the cancer is located, if or where it has spread, and whether it is affecting other parts of the body. There are 2 staging systems for neuroblastoma; more information is available at www.cancer.net/neuroblastoma.

What does risk group mean?
Doctors use risk groups to predict how well treatment for neuroblastoma will work. The International Neuroblastoma Risk Group classification system uses a combination of factors, such as age and stage, to determine if a child’s disease is very low risk, low risk, intermediate risk, or high risk. The Children’s Oncology Group system describes a child’s disease as low risk, intermediate risk, or high risk. The lower the risk group, the more likely that treatment will work. Find more information about risk groups at www.cancer.net/neuroblastoma.

How is neuroblastoma treated?
The treatment of neuroblastoma depends on the size and location of the tumor, whether the cancer has spread, the risk classification, and the child’s overall health. The treatment is tailored according to the tumor’s risk group classification. Most children with low-risk disease have surgery, while children with intermediate-risk disease receive both surgery and chemotherapy. Usually, a combination of drugs is given. Several types of treatments, such as surgery, chemotherapy, radiation therapy, immunotherapy, and stem cell/bone marrow transplantation, are used for children with high-risk neuroblastoma.

When making treatment decisions, consider a clinical trial; most children with cancer are treated as part of one. Talk with your doctor about all treatment options. The side effects of neuroblastoma treatment can often be prevented or managed with the help of your child’s health care team. This is called palliative care and is an important part of the overall treatment plan.

How can I help my child cope with neuroblastoma?
Helping your child understand a cancer diagnosis is a key part of the coping process. Children who have cancer should be treated at a pediatric cancer center. These centers not only provide access to the latest treatments, but they also offer age-appropriate programs for social and emotional needs. Encouraging your child and other family members to share their emotions can be helpful in managing the diagnosis, treatment, and healing process.

ASCO ANSWERS is a collection of oncologist-approved patient education materials developed by the American Society of Clinical Oncology (ASCO) for people with cancer and their caregivers.
Questions to ask the doctor
Regular communication is important in making informed decisions about your child’s health care. Consider asking the following questions of your child’s doctors:

- Where is the cancer located?
- What stage is the neuroblastoma? What does this mean?
- What is the risk group? What does this mean?
- Can you explain my child’s pathology report (laboratory test results) to me?
- Would you explain my child’s treatment options?
- What clinical trials are available for my child? Where are they located, and how do I find out more about them?
- What treatment plan do you recommend for my child? Why?
- What is the goal of each treatment? Is it to eliminate the cancer, help my child feel better, or both?
- Who will be part of my child’s treatment team, and what does each member do?
- How will this treatment affect my child’s daily life? Will he or she be able to go to school and perform his or her usual activities?
- What short-term and long-term side effects may be associated with my child’s cancer treatment?
- What follow-up tests will my child need, and how often will he or she need them?
- If I’m worried about managing the costs of my child’s cancer care, who can help me?
- Where can I find emotional support for my child? For my family?
- Whom should I call with questions or problems?
- Is there anything else I should be asking?

Additional questions to ask the doctor can be found at www.cancer.net/neuroblastoma.

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