



PHOENIX  
CHILDREN'S

# QUESTIONS TO ASK AFTER A CANCER DIAGNOSIS



No parent wants to see his or her child suffer. A diagnosis of cancer in a child is one of the most devastating events in a parent's life. Becoming informed is one of the best coping mechanisms. Cancer is extremely complex and difficult to understand. It is important for you to ask questions to be completely clear about the diagnosis and what to expect. It is also important to understand why certain tests are being done and what the treatment options are. You are entitled to a clear explanation about anything related to your child's condition.

To help ensure safe, quality care, the Agency for Healthcare Research and Quality recommends that you become an active member of your child's health care team.

## **The following recommendations will help you start this active role:**

- Keep asking questions until you understand the answers. Be prepared with questions before your visits with health care providers, and start by asking the ones that are the most important to you. A cancer diagnosis is so overwhelming that it is very hard to understand all the information being shared with you. Take notes, or bring a relative or friend to take notes for you.
- Keep a list of all medications your child is taking, including the doses, length of time used, results, and side effects. Ask the pharmacist about the medication if it looks different from what you expect.
- Keep a file with the results of any tests or procedures. Don't assume that test results are fine if you don't hear back from the health care provider. Call and ask for results. Also ask what the results mean for your child's care.
- If surgery is recommended, make certain you know what will happen. Find out how often the surgery is performed, what will be done, how long it will take, what will happen after surgery, and how your child will be expected to feel during recovery.



**In addition, here are some important questions you may consider asking your child's health care provider:**

*What type of cancer does my child have?*

*What is it called and what does the name mean?*

*What caused the cancer?*

*How do I explain the disease to my child? How much does he or she need to know?*

*What do we do about the disease? What is next?*

*How do we know if a treatment is working? What about other treatments I have read about in magazines and on the Internet?*

*Are there any problems that will occur from the treatment?*

*What if the disease comes back again?*

*What do I do if my child has a problem coping with the disease or the treatment for the disease? Where do I turn for help?*

*What support groups are available?*

Always tell your child's health care provider about vitamins or alternative treatments you may be interested in trying. Some may be harmful, rather than helpful.

The American Academy of Pediatrics and the National Cancer Institute (NCI) both recommend that the diagnosis, staging, and treatment of childhood cancers occur in a center that specializes in childhood cancers. In these centers, children are treated by a health care provider (pediatric oncologist) who specializes in the care of children with cancer. Equally important, your child's care is developed within a multidisciplinary team. This means that a variety of specialists work together to develop the best treatment, or "protocol" for your child.

A cancer diagnosis is a crisis not only for your immediate family, but also for your relatives and friends. It is important to identify your support resources. Reaching out for help may be hard, such as asking doctors numerous questions, and using outside community resources. However, in the long run, these strategies will help ensure safe care for your child, and emotional and physical support for you and your family.