

# Questions to Ask Your Child's Doctor

by Mary Williams Clark, MD

Your child might be facing amputation surgery for one of a variety of reasons. The reason – whether it is trauma, disease or a condition the child was born with – will likely have a dramatic impact on how much time you will have to gather information and make decisions about the amputation.

Your child might have been born with a significant difference in an arm or a leg, and amputation might be proposed as a way to help her or him gain more function. If a child is born, for example, with an undeveloped tibia (the larger bone between the knee and the ankle), leaving her with no real knee or ankle joint and an unstable foot that won't reach the floor, an amputation of part of her leg might better allow her to wear a prosthesis and walk and run.

If a 4-year-old who was born with all of his limbs intact runs out into the yard one day while his father is mowing the lawn and slips under the lawn mower and damages his foot, he may be rushed to the Emergency Room (E.R.). He will need an urgent surgical inspection, and he may need an amputation.

In the first situation, you have more time to discuss and plan the best way to help your child. There may, in fact, be weeks or months to ask questions. The second situation is, of course, more urgent, but you should still have some opportunity to talk with the doctors and meet the surgeon.

Following are some questions you might want to ask:

## **“May we talk with the most experienced doctor who has seen our child?”**

The senior doctor will usually have the most accurate answers to your questions. This doesn't mean that younger doctors can't also give you good information, but amputations are not as common as hernias or fractures, so the most experienced doctor can usually give you the best

answers. You will also want to find out which doctor will actually be performing the surgery and his or her level of experience with the type of amputation your child is having.

**“Can you tell us what you know so far about the injuries?”** Knowing something about the situation will probably help you relax a little. If it has only been a short time since your child arrived at the E.R., however, there will be fewer and less specific answers. And that should be expected. Your child may still need x-rays, CAT (Computerized Axial Tomography) scans, MRIs (Magnetic Resonance Imaging), laboratory work and other tests before the doctors can tell you very much.

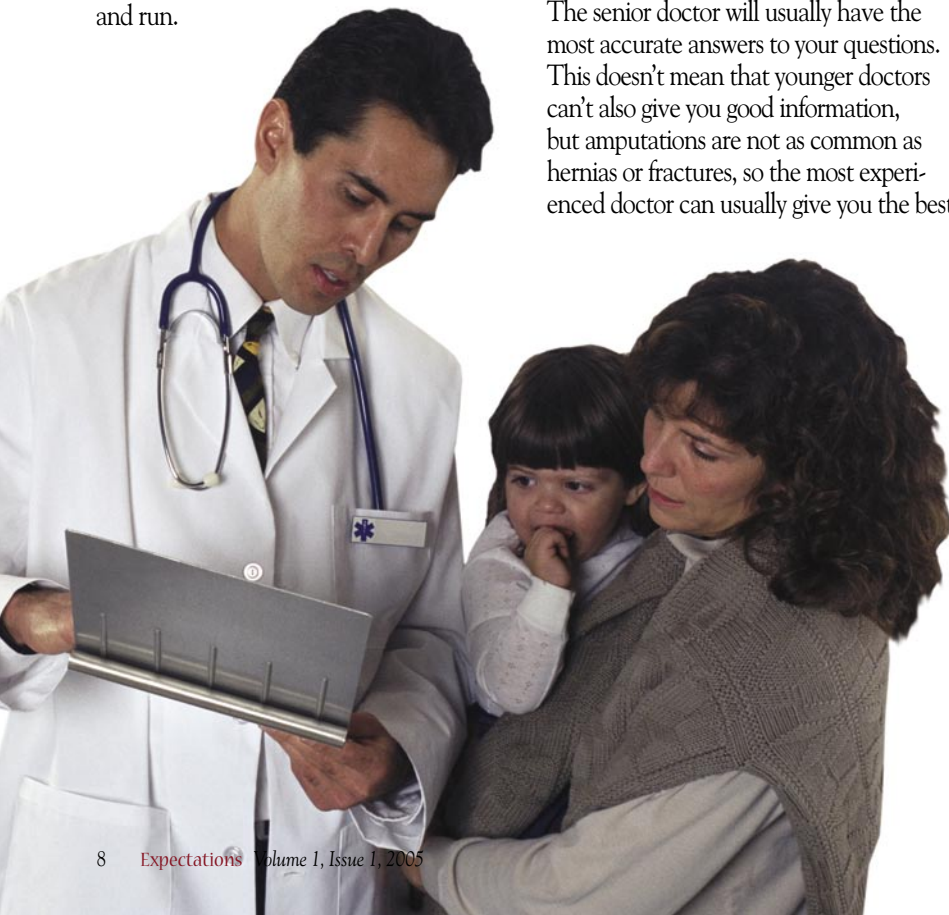
## **“Will you go over the tests with us?”**

Ask the doctor to explain the tests and his or her plan for addressing the results, in a way that you can understand.

**May we have a second opinion?** Even in the E.R., there is usually an opportunity to get another opinion. In a nonemergency situation, you will probably have to get a referral from your child's primary care provider (PCP) before your insurance will cover this. You may, however, rest more easily knowing that medical professionals agree on the necessity for an amputation and the type of amputation that should be done. (*See Cancer Was the Easy Part on pages 27-28*).

**“May we speak with another child and family who have gone through a similar situation?”** This is often difficult or impossible in an emergency room. Some hospitals have a limb difference clinic, however, and the coordinator may be available by phone. Most likely, the E.R. staff will have to leave a message, but that connection will still be useful to you.

In a nonemergency situation, the coordinator of such a clinic, or a nurse or secretary for your doctor, can usually call families who have indicated that they will talk with families of new amputees. With your permission, someone in that family will call you. Because of confidentiality rules, you will only give and be given first names and a phone number. After you have spoken by phone, however, you can agree to exchange more information and/or meet each other. (*For more information on peer support for children and parents, see pages 9 and 22*).



### **“May we tour the operating suite?”**

Many hospitals schedule such tours for children and families on certain days. If not, you should be able to make arrangements to tour the area so that the place and its routines will be a little more familiar.

### **“May one of us be with our child when he or she goes to sleep before the surgery?”**

This usually depends on the anesthesiologist who will be taking care of your child and the age of the child, but it is a relatively common practice for a parent to be there. In addition, your child can usually bring a favorite toy or blanket along to hold while going to sleep and waking up.

**“Will the surgery and the period after the surgery be painful?”** If so, ask the doctor to explain what will be done to address the problem.

**“Will our child have a cast on after the surgery?”** If so, you'll want to know if he or she can choose its color, which is highly likely. You might also want to purchase some stickers for your child to put on the cast to try to cheer him or her up after the surgery. It might seem like such a little

thing, but it might mean a lot to your child. Many hospitals have stickers in the pediatric areas, and they usually don't charge for them.

**“How many follow-up visits will our child need?”** After an amputation, done for any reason, children need to be seen periodically to be sure that healing is progressing well, that the therapy is effective, and that the type and fit of the prosthesis are appropriate. Because of children's ongoing (and often very rapid) growth, follow-up visits may be scheduled as often as every three months. They may be more frequent in the early postoperative stage and then may change to every six months if all is going well. As long as these children are still growing, most physicians/surgeons would like to see them at least once a year.

Additional questions you will want to ask your doctor include the following:

**“How soon will our child be able to wear an artificial limb (prosthesis)?”**

**“What kind of therapy will be needed and how soon after the surgery?”**

**“About how long will the hospital stay be?”**

Fear of the unknown is common. If you and your child have the answers to most of these questions, however, it may help you feel better about the surgery. Don't be embarrassed to ask about anything that concerns you or your child. Most doctors will be happy to answer any of your questions to help put you at ease. ❖

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**Editor's Note:** Surgery, rehabilitation and prosthetic care are all important to your child's well-being. The child's or teen's healthcare team should, therefore, consist of several professionals, including surgeon, nurse, physical therapist, occupational therapist, social worker and prosthetist. You and all of these team members should communicate with each other to ensure that appropriate care is provided.

# **Need support or information to help parent a child with limb differences?**

*The ACA Parent Support Network is here for you.*



If you are a new parent whose baby was born with a congenital limb difference or the parent of a child who has had an amputation, ACA's Parent Support Network can provide you with one-on-one support from parents who share your experiences. Parents of children with limb differences from all across the United States have volunteered to offer peer support to other parents who may need someone to talk to.

This network is simple to use and will provide you with another parent to talk to when you need practical information and when you need to discuss issues with someone who has faced similar challenges with their child.

If you would like to use the Parent Support Network to connect to another parent, just call the ACA, and we will put you in touch with a family that most matches yours in terms of your child's age, cause and type of limb loss, and geographic region. If you are a parent who would like to provide peer support to parents of new amputee children, please call us, and we will explain the system that is used to connect parents and caregivers. ❖

*For more information or to request a support meeting with another parent, call toll-free 888/AMP-KNOW (267-5669), ext. 8130.*