



# Congenital Limb Deficiencies and Acquired Amputations in Childhood, Part 2

## *Emotional Response and Early Management*

by Douglas G. Smith, MD

In Part 1 of our series on children and prosthetics, we discussed the causes and complexities of both congenital and acquired limb deficiencies. In Part 2, our focus turns to emotional factors, parent-child conflicts, when prosthetic use begins, and body image.

### **Emotional Factors**

Parents of children born with limb deficiencies are, naturally, very distraught and invest a great deal of time in trying to understand and determine exactly why this happened. Some mothers replay practically every minute of their pregnancy in their minds, including very commonplace events: “Was it the day I inhaled that spilled oven cleaner?” “Was it because I had a headache and took aspirin?” They often try and reconstruct the entire pregnancy to search for an answer.

Fortunately, we have a much better understanding of congenital limb deficiency now than in the past, and for peace of mind, I think it’s very important to say that common day-to-day events do not cause limb deficiencies. Many possible causes have been studied and have been ruled out. That being said, unfortunately, for the vast majority of children with congenital limb deficiency, we simply do not know why it occurred.

Parents can also be extremely hard on

themselves in cases of amputations that result from trauma, second-guessing and criticizing their decisions in hindsight: “Why did I let Bobby sit on the lawn mower with me? Why didn’t I realize he could fall off?” “If I’d kept an eye on Tommy, maybe he wouldn’t have run into traffic.” “Should I have let Susie ride her bike through the neighborhood?” The scenes play over and over and over again in parents’ minds.

Guilt feelings sometimes can lead to interesting thoughts and requests concerning prosthetic replacement. Parents sometimes need to step back and ask themselves about their own motivations for their child’s prosthesis use. As a physician, I’ve frequently had parents tell me, “I want a prosthesis my child will wear all day, every day. And I want it to look and feel exactly like the real thing.” Sometimes, they even ask for a prosthesis their child will wear while sleeping. These types of comments lead me to believe that they’re trying to make the limb deficiency disappear. While this can be a natural desire, it’s just not realistic. Wearing a prosthetic limb might help the child functionally, but it doesn’t make the limb deficiency disappear. Also, refusing to give the child time without the prosthesis can reinforce the concept that it’s wrong to be without it. The child may even feel ashamed of the limb deficiency. That’s both undesirable and unhealthy.

According to some older medical literature, a child born with a limb deficiency does not feel a sense of loss because this is the only body he or she has ever known. In other words, they suggest a child will not feel a loss

over something he or she never had. I am not so certain how to interpret this opinion. Infants and toddlers with congenital deficiencies naturally try to do whatever all children do: roll, crawl, reach, grasp, explore, etc. Limb loss may well impose some physical limits, but the child will push the boundaries and figure out ways to get things done.

As the child grows, however, he or she will certainly experience a sense of being “different” from others. In this sense, I believe the boy or girl certainly can feel a loss over something he or she never had. This leads to emotional frustration – “Why did this have to happen to me?” “Why is it so hard for me to do this?” – and feelings of grief over not having four “normal” limbs.

A child with limb loss through acquired amputation will almost certainly feel a deeply personal sense of loss. People with acquired limb loss often wish to turn back the clock and be the way they were before the amputation. It takes emotional and physical adjustments to live and function with such a profound bodily change. As we’ve noted in previous columns, different amputation levels certainly do place different physical demands on people. I must also point out, however, that the emotional response is not always proportional to the amputation level or the amount lost. I have occasionally witnessed an individual adjust more quickly after losing an entire leg up to the hip than another person who lost the front part of a foot. There can be a tremendous variation in the emotional impact of both congenital and acquired limb loss.

## Mom and Dad, You Will Be Blamed

As your child grows, you will be involved in a great many decisions about surgery, rehabilitation, prosthetic use, hobbies, athletic activities, physical education, summer camps, etc. With all of these decisions, you can count on one thing: You are going to get blamed for *something*.

Most adults who grew up with limb deficiencies, when looking back at their childhood, have very definite memories and opinions about conversations, discussions and battles concerning prosthetic use and activities. They strongly believe that when they were kids, their parents were harder on them than on their brothers and sisters who had fully functional limbs. They also believe their parents may have decided to challenge them a bit more because they had bigger obstacles to overcome, both physically and socially. Mom and Dad, there are simply going to be times when your kids say you're being too hard on them.

But when these same adults look back on their childhood, not only are they glad they were strongly challenged, they often have even bigger regrets over what their parents didn't make them do: "Why didn't they make me take PE in school?" "Why didn't they let me play soccer?" Most parents want to protect their children from failure, teasing, and from having to struggle harder than other kids. But this may inadvertently set up a child to be less capable as an adult. It's a wise parent who learns to say, "I love you and you need to try this." While many parents want to protect their child from difficult and awkward situations, overprotecting or sheltering the child can lead to disaster.

Keeping balance and perspective as a parent of a child with limb differences can be very difficult. I sometimes think St. Francis de Sales was speaking to parents when he said, "Do not lose your inward peace for anything whatsoever, even if your whole world seems upset."

## When Does Prosthetic Fitting Usually Begin?

At what age should prosthetic use begin? Although there is no single, universal answer for everybody, some criteria generally apply. For example, prosthetics usually aren't prescribed for infants in the nursery, even though some parents do request them. We try to match prosthetic use with functional goals: sitting up, reaching, grasping, crawling, standing and walking. Additionally, a significant disadvantage to covering up the residual limb too soon is the fact that prosthetic limbs don't provide sensation. We're very reluctant to cover the residual limb

with a socket early on because the prosthesis actually blocks normal sensory input and the child will lose an essential point of contact with the environment. Sensory input from arms and legs, including limbs with deficiencies, is vitally important.

A child is usually considered ready for a lower-limb prosthesis when he or she begins pulling to stand. This typically occurs between the ages of 9 and 16 months. A lower-limb prosthesis simply for crawling may or may not be a good idea. There are real differences of opinion on this. If a prosthesis interferes with crawling and exploration, it becomes more of an "anchor"





than an aid and probably should be taken off. But a prosthetic device can certainly help the child go from crawling to standing. A prosthesis that helps very young children with lower-limb deficiencies explore their surroundings is a good thing.

Children who require an upper-limb prosthesis are usually considered ready when they begin to sit. This is the age when children begin to manipulate objects, which is an important part of development. This typically occurs between the ages of 3 and 7 months, when children develop two-handed skills. Although the first prosthesis is usually passive, it can help with crawling, pushing, and pulling to sitting and standing positions.

A more functional prosthesis is usually appropriate between 1 and 2 years of age, when children begin to perform more complex and coordinated activities and gain coordination. The child needs to be able to develop a link, conscious or subconscious, so that a specific muscle action results in opening or closing the terminal device. Then, the child needs to be able to coordinate placement of the terminal device and use of the terminal device with success in the final activity. It is really a tribute to the human mind that children learn these skills at such a young age.

As mentioned earlier, when you wear a prosthesis, you're covering

a part of the body that has sensation. A child may perceive this as a bad thing because part of a limb that's providing feedback on the world is covered. The arms, in particular, provide an incredible tactile interaction with the environment. Many children would prefer not to wear a prosthesis because our skin gives us much-wanted feedback about our surroundings. And, it's simply more comfortable to not wear a prosthesis. The value of sensory feedback and comfort is highlighted in children born with severe deficiencies of both upper limbs. When both limbs are involved, we refer to this as "bilateral." Even with upper-limb prostheses, many of these children choose to adapt and manipulate objects with their feet because they respond well to the sensory feedback.

## How About Older Children?

When they reach adolescence, children with limb deficiencies generally undergo the same emotional, intellectual and hormonal changes as their peers, "and then some." A limb deficiency can definitely make this period much more challenging. Adolescents often don't want to seem "different" from their friends, so they may go to extremes to conceal their deficiency. They may wear clothes that mask their limb loss or avoid certain activities, such as swimming. Concealing a limb deficiency is far more challenging for those with upper-limb deficiencies than lower. The hand is an extremely visible and important physical part of our body image. When a person loses a leg, the loss can be disguised somewhat by wearing pants and shoes. But for a person missing a hand, the loss is apparent whether he or she wears a prosthesis or not. Once the child feels he or she has established good peer acceptance, the desire to conceal or camouflage the limb loss is usually reduced or eliminated.

Conflict with parents is a normal part of adolescence, and battles do indeed develop over prosthetic use. If the parents have pushed the prosthetic device to the extreme, the child may refuse to wear it as a way to rebel and exert independence. One mom developed such strong feelings over her child's congenital limb deficiency that she demanded he put on his prosthesis alone in his room before coming to breakfast and not take it off again until he was back in his room at night, getting ready for bed. When the child reached adolescence, his way to rebel was by refusing to wear the device, even though it was functionally helpful.

Interestingly, in recent generations we now see some young people who actually emphasize exposure of their high-tech prostheses, in contrast to the traditional reaction of concealing them. Some do this to express their independence; others just like to show off something they think is "cool." Because more people with limb deficiencies are seen in advertising, TV shows and movies today, I believe the overall population generally feels less awkward about limb loss. Reasons for prosthetic use and hiding or highlighting a limb deficiency are as varied as children themselves.

## When Children Become Adults

Growing into adulthood is challenging and, sometimes, difficult. This can be especially true for the young person with limb deficiencies who enters the adult healthcare system. Children's specialty hospitals are designed to cater to kids and their parents. Young people "graduate" from the children's healthcare system between the ages of 18 and 21. As we know from our own high school experience, graduation is a major event. Young people are typically excited by it and the prospect of becoming adults. What we don't typically see at this stage of our lives is that life in the "real world" as adults is sometimes not easy. We now must begin to take responsibility for doing things for ourselves that were previously done for us. We aren't catered to nearly as much as before, if at all. Often, young people at this stage begin to realize, "Hey, I really am on my own now." Graduating from a children's hospital sounds cool, but it really can be tough.

When young people with diseases and deficiencies incurred in childhood transition to adult care, unfortunately they find very few physicians who are educated and trained to manage their special needs. This transition from specialty children's hospitals to the world of adult healthcare can be a culture shock. Fewer people understand their problems and there's certainly much less comfort and support. Young people can become frustrated and flounder. Some even give



up trying and their problems continue to get worse. Unfortunately, there's no easy answer right now. It takes persistence, patience and effort to find the right medical professionals to help navigate the adult healthcare system.

## Our Impressive Children

As children grow and mature, I continue to be impressed by the level of confidence and success achieved by many of the youngsters I've helped care for. These children are some of the most amazing, resilient people I've ever met. Overcoming their physical challenges has nurtured something good within themselves that often brings out the better part of their nature. To me, they are living examples of what Albert Camus was referring to when he wrote: "In the depth of winter, I finally learned that there was in me an invincible summer." ■

## Acknowledgments

Portions of this column were edited from an article titled "Prostheses for Children with Limb Deficiencies: Issues and Expectations," by Douglas G. Smith, MD, and Kellye Campbell, RN, ARNP, in the magazine *Expectations: Parenting Children and Teens With Limb Differences*, and from the book *Atlas of Amputations and Limb Deficiencies*, edited by Douglas G. Smith, MD, John W. Michael, MEd, CPO, and John H. Bowker, MD (Chapter 61 by John R. Fisk, MD, and Douglas G. Smith, MD, Chapter 63 by Joan E. Edelstein, MA, PT, and Chapter 64 by Donald R. Cummings, CP, LP).