



Congenital Limb Deficiencies and Acquired Amputations in Childhood, Part 3

Prosthetic Issues for Children

by Douglas G. Smith, MD

In Parts 1 and 2 of our series on children and their prosthetic needs, we examined congenital limb deficiencies, amputations acquired during childhood, response to limb loss, and early management. In this segment, we focus on issues such as whether or when a child should use a prosthesis, how often a new prosthesis is needed, simplicity versus complexity in technology, and the important role that attitude plays for both the child and family.

The Prosthesis and Your Child: Whether or When?

Children, parents and healthcare professionals may have widely differing viewpoints on prosthetic use and resolving these issues can be quite challenging. Sometimes, a child doesn't want to use a prosthesis, even though the adults think the child would benefit from it. Who should decide? Is it different for people with upper-limb versus lower-limb loss? Should a prosthesis be used full-time, only sometimes, or not at all? There's a wide spectrum of answers.

Some parents insist that their child use a

prosthesis full-time. Others leave the final decision up to the child. Generally, there's a balance in the middle that works best. But the balance changes as the child grows up. As with other issues, the younger the child, the more vocal and active the parents are in making decisions. As children grow older and show more maturity in decision-making, parents may back off and give the child more leeway.

All children generally adjust to change and new situations more readily than adults. Children with limb differences often adapt to prostheses better than adults as well. This helps illustrate why children should not be regarded as "little adults." But, even though they may adapt more readily, some children may still refuse to use a prosthesis. When this occurs, we need to try and understand why.

How Often Will My Child Need a New Prosthesis?

Children grow. As bodies change, they outgrow their prostheses just like their shirts, pants and shoes. Although young children can exhibit many physical changes in very short periods of time, I believe it's a mistake to try to keep up by replacing the prosthesis every few months. It simply can't be done.

There's a balance between allowing a child enough time to adapt to a new prosthesis and changing so often that the child never completely adjusts to a new one. It usually takes several months to fit, adjust, and get used to a new prosthetic limb. With that much time invested, you

want the prosthesis to function for as long as possible. That's why some modular, adjustable features can be built into the device for minor adjustments or replacements until a whole new prosthesis is needed. This option is more valuable than any bells and whistles.

Traditionally, when a child gets a new prosthesis, it's also a bit oversized and padded with foam to adjust the fit. This gives the child more time to adjust and grow into it, and the foam can be removed as needed to accommodate growth. The length of the prosthesis may also need to be adjusted sometimes to match the length of the other limb.

Certain conditions require a new prosthesis: significant change in body weight, trauma to the residual limb, skin ulceration, or a unique condition called "pediatric terminal bone overgrowth." Terminal bone overgrowth is a spike of bone at the end of the amputation that becomes larger and, in its most severe form, can actually push through the skin. Some researchers originally thought the growth plate at the far end of the bone pushed the entire bone down through the amputation site. We now know that this phenomenon is a local growth that begins at the end of the transected bone. Fortunately, it becomes a problem for only 8 to 15 percent of children, but when this happens, surgery is often needed. Bone-capping procedures have been designed to avoid overgrowth recurrence and reduce the number of surgeries. After a surgical revision for terminal bone overgrowth or other reasons, a new

prosthetic socket is often needed.

Although there's not a lot of detailed literature on the exact frequency of replacing limbs, a study by Dr. Claude Lambert at the University of Illinois found that, on average, children require a new lower-limb prosthesis annually up to the age of 5, every two years from ages 5 to 12, then every three to four years to the age of 21.

It is worth mentioning again that fitting, fabricating and aligning a new device takes time. It's more of a process, not a one- or two-day event. It frequently takes several months of adjustments to work out all the kinks of a new prosthesis. Therefore, you

want the prosthesis to function for as long as possible. That's why some modular, adjustable features can be built into the device for minor adjustments during growth until a whole new prosthesis is called for.

Technology: The Goal Is to Have the Right Tech

It's human nature to see a new development in technology and think, "That's cool....I want that!"

I'm a big fan of high tech and I believe technology does much to improve our lives. But sometimes there's a downside that isn't immediately apparent. When it comes to prosthetics, careful attention must be paid to the child's needs and the features and demands of the technology. High tech is wonderful, but it doesn't fit everybody's lifestyle. Part of the physician's job is to match the appropriate technology to the person to maximize function.

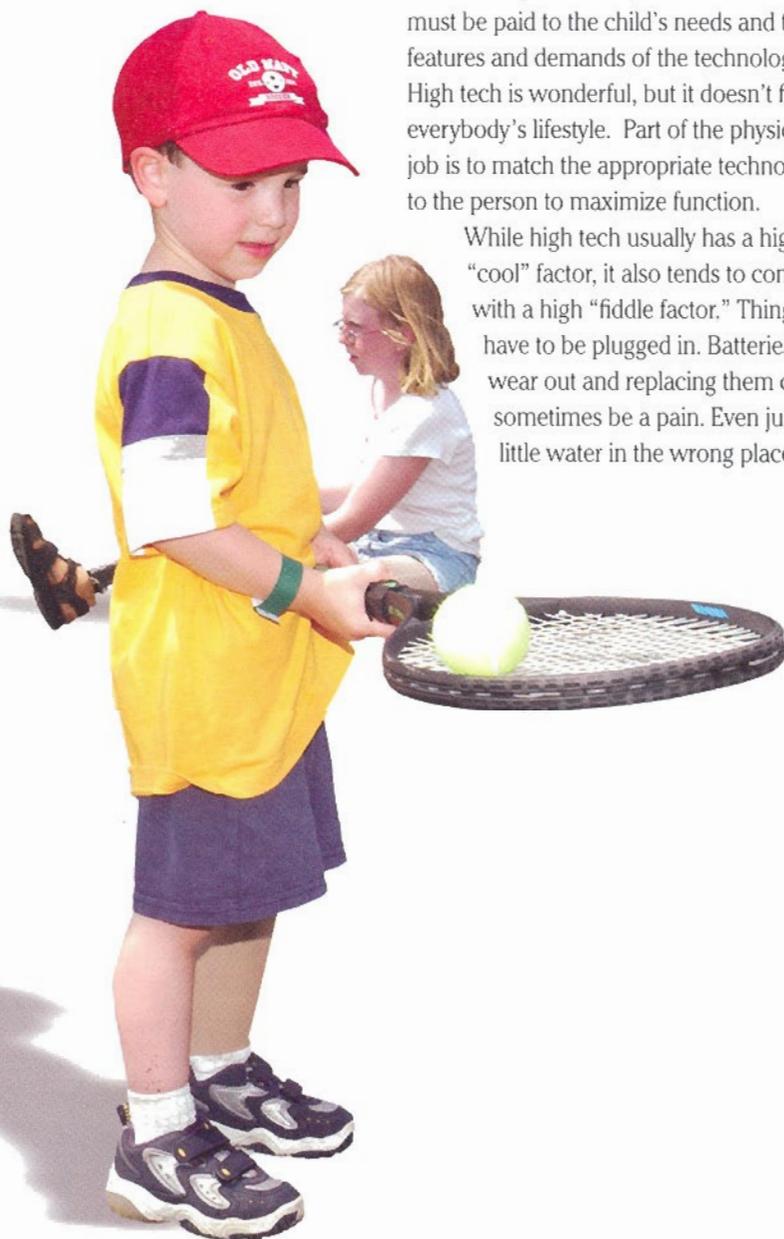
While high tech usually has a high "cool" factor, it also tends to come with a high "fiddle factor." Things have to be plugged in. Batteries wear out and replacing them can sometimes be a pain. Even just a little water in the wrong place can

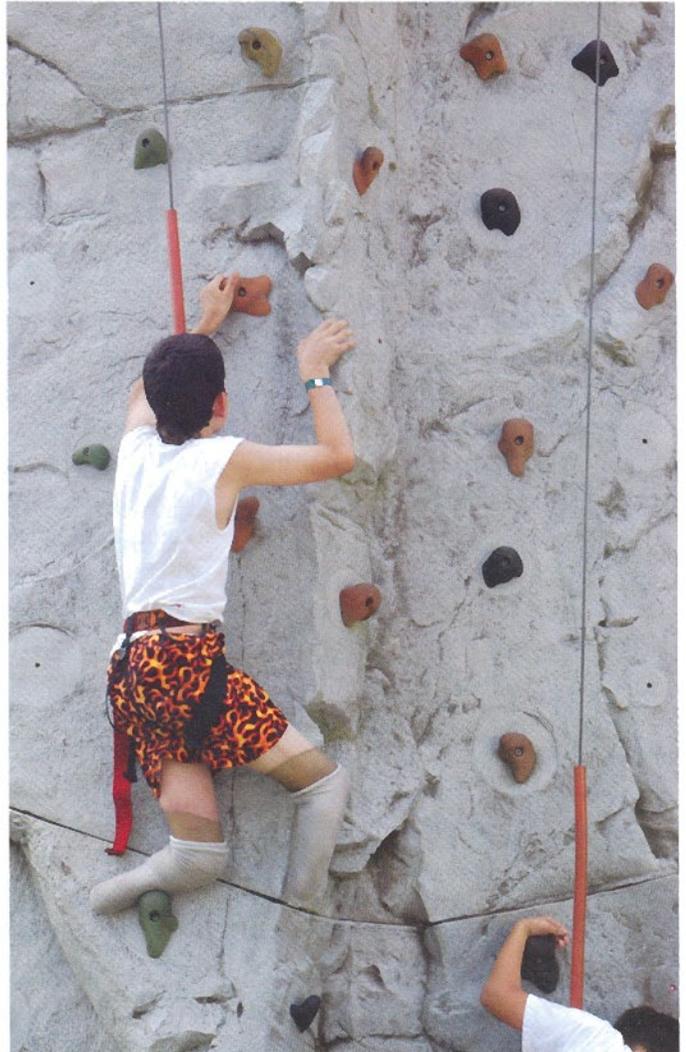
damage electronics. Lower tech prostheses may be less "sexy," but they can sometimes be more durable and reliable. While we may cast jealous glances at someone with the latest high tech, if it stops working and that person can't get around, then we may be envied for our ability to get from here to there with simpler technology.

Let's give the engineers credit: Technology certainly is becoming more durable and reliable. Batteries are improving. Electronics are better, computers are faster. There's less of a fiddle factor than before, and that's good. But as any parent knows, children can be tough on things, and prosthetic devices are no exception. Simpler systems have less parts to break, and therefore less maintenance and downtime. I have a wide range of patients, both adults and children, and I've seen many of them benefit from high tech. But other prosthetic users of all ages have told me, "Although that high tech looks great, I'm happier with something that's simpler and has lower maintenance."

Children with congenital limb loss and their families tend to grow into this understanding. But the families of children with acquired limb loss often struggle with this concept, especially in the first one or two years after amputation. Some people think if they don't have the latest and greatest tech, they're being cheated. It takes time to learn that sometimes simplicity and durability can be a blessing. There's no single "right" answer when it comes to prosthetics and technology. You have to look at each family's lifestyle and goals individually to decide which is the right technology.

Historically, high tech was generally thought best for the youngest and the strongest. But we have also learned that high tech has distinct advantages, such as improved safety, for people who aren't so young or strong. We've also found that many young people can make both high and low tech work pretty well. It's a good idea to keep tech practical and aimed at meeting specific goals. Experience has taught me and others in the prosthetic field that functional goals are key. We must





understand each child's goals, needs and limitations and match the child with the appropriate technology: high, low or both.

Prosthetic "Wear" Time

Should parents always have the final say regarding prosthetics use? When making decisions concerning your child, you've probably had moments when you asked yourself, "Am I right? Or am I totally clueless?" For many with lower-limb loss, the improvement in walking and balance with a prosthesis makes the decision a simple one. However, most children with upper-limb loss become very skilled at one-handed activity and often achieve high function with or without a prosthesis. The issues related to upper-limb prosthetic wear time are more complex.

Some adults with congenital limb deficiencies believe that parents should get the child to wear a prosthesis as soon as possible. They say this is a realistic approach and the best way for the child to learn to be independent. Children may say, "You're being too hard on me!" but as adults, they'll thank their parents for insisting that they learned to use the prosthesis.

At the other end of the spectrum are those who say, "Let the children decide. Why insist they use it if they don't want to?" Their attitude is that when children are forced to do something they don't want to do, they will find a way to avoid it.

Most people believe that the prosthesis is a tool for increasing function, and exposing a child to it is a good thing. But most children simply don't want to wear one continuously from the moment they get up to the time they go to bed. There can be many reasons why. Sometimes it's just too hot or uncomfortable. They may just want a break, to feel the air against their skin. But if a child rejects it on a regular basis, it may be worthwhile to see if it still fits well or if it's time for a new one.

Skin, especially on our arms, provides an incredible tactile interaction with the environment. When a child wears a prosthesis, we are covering a part of the body that has normal skin sensation. The child may perceive this as a bad thing because part of a limb that's providing feedback on the world is inside the prosthesis. Many children would sometimes prefer not to wear a prosthesis because they want their skin free to give the much-wanted feedback about their surroundings.

There are also times when children just want to be contrary. When parents say, "Yes," the child says, "No!" Sometimes, disagreements over prosthetic use may be just a normal part of the Terrible Twos. How to deal with that? You can try to make a game



out of wearing the prosthesis. Or you can get your child to put a prosthesis on a teddy bear or doll. A sticker chart or other child-motivational tools and games may help. Older kids may use decisions about prosthetics to express their independence. They say, "Don't treat me like a baby. It's my body!" Wise parents realize that resolving complex issues takes a bit of balance and flexibility.

The Personal Side of Attitudes and Role Models

When it comes to role models for children, nobody counts more than parents. Siblings and other close relatives are also important. Children zero in on the attitudes of all these relatives. If limb differences are talked about in a negative way, either in or out of the child's presence, it will be picked up on by the child. Kids also are keen observers of the ways their parents interact with the rest of the world. They notice when their parents display one set of attitudes at home and another for the rest of the world. And how. You may think you're cleverly masking inconsistent attitudes, but you're probably not. And the acorn doesn't fall far from the tree.

Other role models are also beneficial for growing children. Most people believe that exposure to others with limb deficiencies who have mastered certain activities is a positive thing. The kids see their accomplishments both with and without prosthetic devices, such as world-class competitive swimmers, and begin getting mental images of themselves also becoming accomplished. They

may not necessarily all become great swimmers, but it instills the idea that there may be greatness inside of them that can be tapped and encouraged to grow.

Many parents agonize over whether their child should go to a regular camp or one for kids with limb loss. In a perfect world, children could attend both. Generally, it's good for children with limb deficiencies to interact with each other. It gives them opportunities to share experiences and feelings with others who are in similar situations and who understand.

I know of a girl who lived in a small town and had never met another person with limb loss. It wasn't until she attended a summer camp for kids with limb deficiencies that her true sense of self came out. She realized she wasn't "different" from everybody else. She was in an environment where all the children with differences were all the same. They were all just kids. She really came out of her shell.

As people, we share many of the same values and beliefs. As individuals, we find differences within our group attitudes and outlooks. What's typical for one family may be way outside the norm for another. How we deal with successes and issues defines who we are as individuals and as a family. There is no universal answer

that works for everybody, nor can we look into a crystal ball to see what the future holds. What we can do is work together to bring the abilities and talents of the individual to the surface, nurture them and watch them grow. ■

“Adversity is another way to measure the greatness of individuals. I never had a crisis that didn't make me stronger.”

— *Lou Holtz, football coach*

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