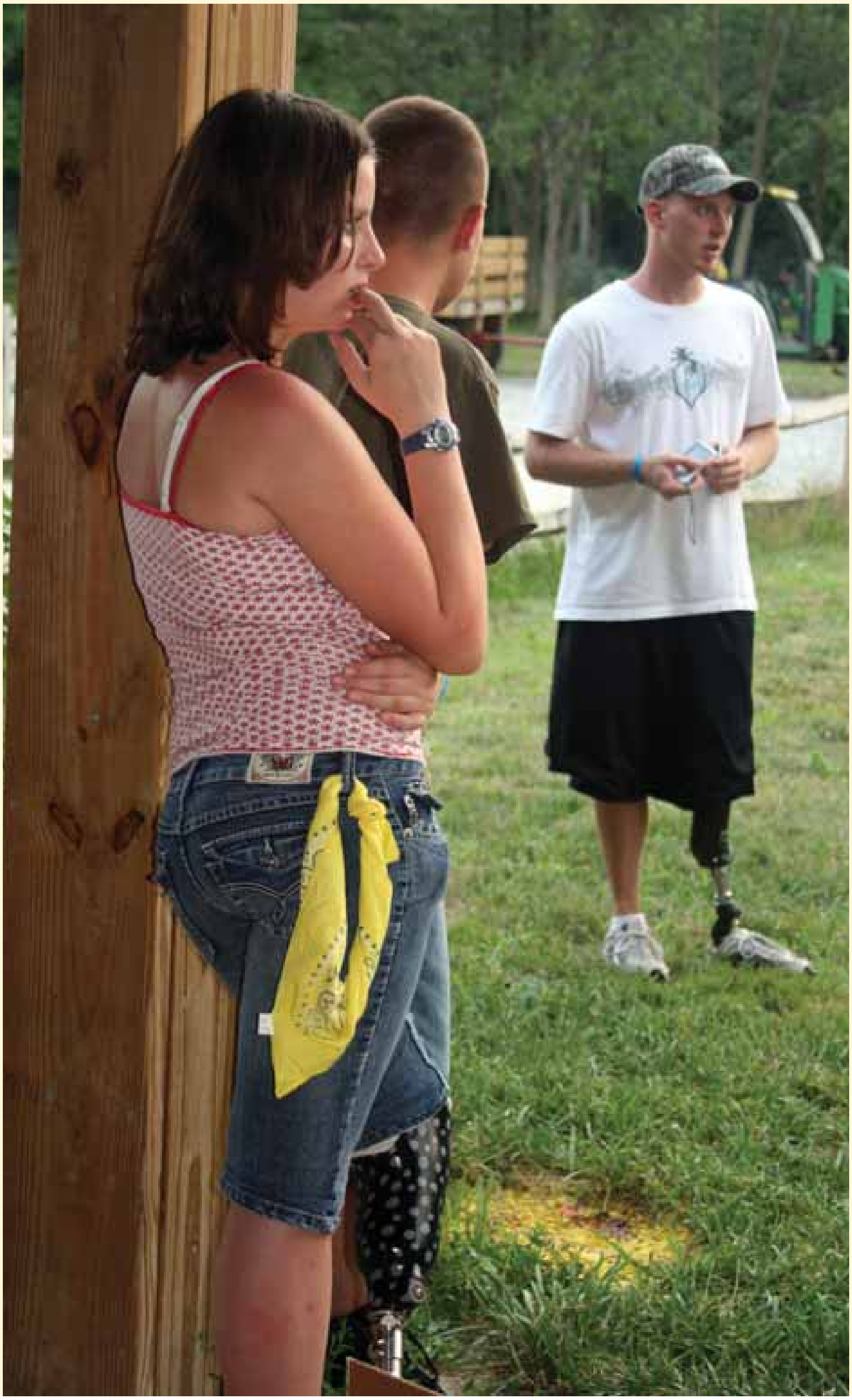
Prostheses for Children With Limb Differences

Issues and Expectations

by Douglas G. Smith, MD,
and Kellye M. Campbell, MN, ARNP

Children with limb differences tend to adapt remarkably well to a prosthesis, far better than adults in most cases. But there can be bumps in the road, just like there are with almost every childhood and developmental issue.



Prosthesis use will certainly not be perfect every day in every way. There may be times when a parent thinks the child should be using a prosthesis, but the child doesn't want to. When it comes to prosthesis use, children, parents and healthcare teams may sometimes see things quite differently. Although it can be challenging to resolve these issues, it may help to know that conflicts about use and nonuse of the prosthesis can mirror those other disagreements associated with the normal physical, emotional and social development of childhood. It comes with the territory.

How does a parent ever know what's absolutely best for the child, whether it's managing a residual limb, wearing a prosthetic device, participating in activities and sports, etc.? How does a grownup best guide the youngster's decisions? A child's view of himself or herself changes over time, especially with the arrival of adolescence. The issues faced by the boy or girl and mother and father are not constant and static. A variety of physical, social and emotional "blips" show up on the radar from time to time. Sometimes, parents and children value the tradeoffs between the cosmetic appearance of the prosthesis, the function of the device, and the durability of the device differently. Sometimes, for whatever reason, a child wants to be without the prosthesis more than the parent wants him or her to use it. Who should decide – the parent, the child or healthcare workers – whether a prosthesis should be used full time, part time or not at all?

This article looks at the issues surrounding prosthetics and children and offers insights into which approaches to using an artificial limb can be best – for all concerned.

Not All Limb Differences Are the Same

Limb differences may be congenital (something a person is born with) or they may be acquired as the result of an injury or disease that requires amputation. Some limb difference have aspects of both, such as when children have a congenital limb difference and then require surgery to modify their residual limb and make it more suitable for wearing a prosthesis.

Emotional reactions to these types of limb differences may vary. Some of the older medical literature stated that children who are born with a limb difference do not feel a sense of loss because the body with a limb difference is the only body they have ever known. According to this point of view, it's rare in the early years for a child who has a congenital difference to grieve over it because there hasn't been a sense of loss. In other words, you don't lose something you never had. Still, as the child grows and becomes more socially aware, there can be a sense of loss or of being physically "different" from those who have fully functional limbs. This can then lead to frustration ("Why me?") and some of the same feelings that occur while grieving.

A child who has an acquired limb difference through surgical amputation, on the other hand, is more likely to feel a profound and deeply personal sense of loss. The boy or girl must adjust to a different way of living with a different kind of body. This takes emotional and physical adjustments. Just as different amputation levels place different demands on a person, the demands resulting from amputation or a congenital difference are different.

Attitude Counts

Parental attitude counts a lot. Children readily pick up on their parents' attitudes, actions and reactions. Like it or not, Mom and Dad, you set the tone. Your acceptance of your child's limb difference and your attitude toward prosthetics can greatly influence how your child accepts himself or herself and his or her prosthetic limb. In addition, the way that you talk to your child, talk about your child, and treat your child all shape how others will behave toward him or her.

Does that mean, then, that a parent should absolutely insist that the child use a prosthesis full time? This can be a complex question, and there is a range of approaches. At one end of the spectrum are parents who encourage using a prosthesis to the point of forcing it on the child. At the other end are parents who allow the child total autonomy in deciding whether to use one. There are many issues that go with these decisions; while toddlers provide adults with clues, feedback and insights into their prosthesis use, many are just too young to decide for themselves. As in most aspects of child-raising, giving your child total decision-making control regarding his or her prosthesis use has its pitfalls. In most cases, we believe there's a balance in between that's probably best for all concerned, and this balance changes as the child matures.

Infants and very young children with a lower-limb difference can better explore their world by wearing a prosthesis because it helps them get to a standing position more easily. Crawling is a mixed bag. There's a point in their young lives when crawling is good and you want them to crawl. If a prosthesis interferes with their crawling, it probably should be taken off. But there's definitely a time when they need the prosthesis to go from crawling to standing, usually between the age of 8 and 14 months.

For children with an upper-limb difference, the ability to manipulate objects is an important part of their development as they explore their environment. Traditionally, an upper-limb prosthetic fitting is started earlier for infants than a lower-limb prosthetic fitting would be so that they can get their hand and prosthesis to the same level and start touching and moving things. Two-handed activity typically starts near the time infants develop sitting balance, usually around 4 to 6 months of age. A passive terminal device with blunt rounded edges is used initially to minimize injury to child and parent.

A downside to using a prosthesis is that you cover up a part of the body that has sensation. The child may perceive wearing his or her prosthesis as a bad thing because part of the limb that's providing feedback on the world is now encased in the device. Many children would, in fact, prefer not to wear a prosthesis because the skin gives us much-wanted feedback about our surroundings. Though arms and legs both provide tactile interaction with the environment, this feeling is more important in the arms.

Sometimes, it is simply more comfortable not to wear a prosthesis, which can be perceived as an "anchor" that hinders freedom. In fact, even children born with severe differences in both upper limbs often choose not to use prostheses and choose instead to adapt and manipulate objects with their feet.

How about teenagers? When they reach adolescence, children with limb differences undergo the same emotional and intellectual changes as their peers, plus a lot more. Having a limb difference definitely can make this period much more challenging. Because adolescents often don't want to seem "different" from their friends, they may try to conceal their differences. They may wear clothes that mask their limb difference or avoid certain activities, such as swimming. Some teens may even go to extremes to try to hide both the prosthesis and the amputation. Once they are accepted, however, they tend to resume using the prosthesis, particularly if it is for an upper limb.

On the other hand, if the parents have pushed the prosthetic device to the extreme, the child might refuse to wear it as a way to rebel and exert independence. We know of one mother whose guilt over her child’s congenital limb difference was so great that she demanded that he put on the prosthesis alone in his room before coming to breakfast and that he 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. It became his personal battle with his mother.

Interestingly, in recent generations we’ve seen more children who emphasize exposure of their limb differences rather than the more common behavior of concealing them. Some do this to express their independence. Others probably do this because society is finally maturing toward the understanding that physical differences should be accepted. Finally, while it is difficult to consider, some may do it in an attempt to gain favor, an advantage or sympathy. Reasons for this are as varied as children themselves.

Whose Opinion Counts Most?

While parental attitude, care and concern certainly count, does this mean the adult should have the ultimate say in these matters? Some adults who were born with limb differences advocate this. It’s their opinion that parents should get their children to wear a prosthesis as early as possible. They say this is a realistic approach and the best way for the children to begin learning their own way through life, even if the children believe that their parents are being “too hard” on them. When the children become adults, proponents of this view say, they’ll thank Mom and Dad for insisting that they become skilled and proficient with their prosthesis. At the other end of the spectrum is the “let the child decide” approach. If the child doesn’t want to wear the prosthesis, proponents of this view ask, why should we insist otherwise? Perhaps the desire to grant the child autonomy in this decision stems from guilt or a desire to “make things better.”

In some cases, parents of children born with limb differences can really beat themselves up trying to determine exactly what might have caused this to happen. We’ve seen mothers go over practically every minute of their pregnancy in search of clues: “Was it the day I dropped the bottle of oven cleaner and smelled it? Was it the aspirin I took?” They reconstruct the entire 9 months of pregnancy to try to find a cause. Though we have a better understanding of limb differences today than ever before, in most cases the precise cause of the limb difference remains unknown. The bottom line, folks, is this: Most of the time, we just don’t know why it happened. Unfortunately, wearing a prosthetic limb around the clock doesn’t make the problem go away. It’s the difference that’s the issue, not the prosthesis. Wearing a prosthesis might help the child functionally, but it doesn’t make the limb difference go away. This attitude is a big hurdle many families face.

The prosthesis is a tool for increasing function, and exposing a child to it is a good thing. Still, although the prosthesis is often very useful, there are times when the child simply does not want it. At these times, it is not useful. Many children simply do not want to wear their prosthesis from the moment they wake up until bedtime. Children may decide not to use their prosthesis for a variety of reasons. Sometimes, it’s just too hot or uncomfortable. They may just want a breather or to feel the regular environment against their skin. But if a child is rejecting it regularly, it may be wise to check whether it still fits well or if it’s time for a new one.

There also are times when little ones are just contrary. Take the "Terrible Twos," for example. When Mom or Dad says, "Yes," the child says, "No!" Sometimes, disagreements over prosthesis use may be just part of the normal battles of the Terrible Twos. How to deal with that? You can try to make wearing the prosthesis a game. Or you can get your boy or girl to put a prosthesis on a stuffed animal or doll. A sticker chart or other child-motivational tools and games may also be helpful. Older children may use decisions about prosthesis use as a way of expressing their desire for autonomy, to not be "treated as a baby."

Parents also should ask themselves about their own motivations for prosthesis use. As healthcare providers, we've had parents tell us, "I want a prosthesis my child will wear 24-7, and I want it to look just like the real thing." They're trying to make the limb difference disappear. That can be a natural urge for some family members, but it is just not realistic. If parents don't allow their child time without it, they may instill the concept that it's not OK to be without it. That approach may lead the child to feel ashamed of the limb difference – an outcome that is both undesirable and unhealthy.

A balanced approach may well be best. Parents are there to provide guidance, wisdom and understanding. They have experience. They know there are things that a child doesn't want to learn or do but that he or she will be grateful for as a teenager and adult. Still, the wise parent also realizes that there are times when a child's desire not to use the prosthesis should be indulged. Perhaps it's uncomfortably hot, and the child doesn't feel there's any need to use a prosthesis for immediate activities. Flexibility in attitude counts.

How Often Does My Child Need a New Prosthesis?

Children grow. Their bodies change, and just as they outgrow shirts, pants and shoes, they will outgrow their prosthesis. How often is a new prosthesis required for a growing child? Although young children certainly can exhibit many physical changes in very short periods of time, we believe it's a mistake to replace the prosthesis every few months. That's just too often. Each new prosthetic limb takes some getting used to. Traditionally, when a child gets a new prosthesis, it's oversized to give the boy or girl a period of time to adjust and grow into it. Children typically get a prosthesis they'll grow into; otherwise, they'd be too big for it in no time.

Most people believe that a child who receives a new artificial limb too often never fully adapts to the one he or she has. The child is always adjusting to a new one, and that takes time. There's a balance between allowing the child enough time with one device to become totally accommodated so that he or she can take full advantage of it and changing so often that the child is always in that stage of getting used to a new one.

In addition, fitting, fabricating and aligning a new device takes time. It's often several months before the kinks in that process have been worked out. Therefore, you want the prosthesis to function 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 needed.

Though 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 children, on average, require a new lower-limb prosthesis annually up to the age of 5, every two years from ages 5 to 12, then every 3 to 4 years to the age of 21.

You're Going to Get Blamed!

Most adults who grew up with a limb difference believe that when they were young their parents were harder on them than they were on their able-bodied brothers and sisters. Their parents may have decided to challenge them a little more because they had bigger obstacles to overcome, both physically and socially. Count on it, Mom and Dad; there are going to be times when your child says you're being too hard on him or her. But when most adults look back on their childhood, they have bigger regrets over what their parents did not make them do than what they made them do. "Why didn't you make me learn to play the piano?" for example. "Why didn't you insist I learn a foreign language?" Not insisting that the child with a limb difference do something can backfire later. You may be setting your child up to be worse off as an adult. It's a wise parent who says, "I love you, but you're going to do this because I care more about the adult you're going to become than the child you are right now." On the other hand, some parents just want to be "nice" to their child with a limb difference. While this sounds pleasant, this recent definition of nice puts things into perspective. "Nice – a pleasant and nonconfrontational attitude that uniformly leads to disaster."

Role Models

When it comes to role models for children, nobody counts more than Mom or Dad. The parents' attitudes, insights, abilities, personalities, actions and reactions are readily picked up on by their offspring. Siblings and other close relatives are also important. Children zero in on the attitudes of all of these relatives. If limb differences are talked about in a negative way, either in or out of the child's presence, the child will notice. Children are very 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. 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 differences, especially those who have mastered certain activities, is a very positive thing. When children with limb differences see highly accomplished individuals doing great things both with and without prosthetic devices, such as a world-class swimmer, an artist or a public leader, they begin having mental images of themselves also becoming accomplished. Though they will not all become superstars, this instills in them the idea that, regardless of a limb difference, they have greatness inside of them that can be tapped, nurtured and encouraged to grow.

We generally believe that having children interact with others who have limb differences is a good thing. We know of one girl who lived in a small town and had never met another person with a limb difference. It wasn't until she attended a summer camp for children with limb differences that her true sense of self came out. She realized that she wasn't "different" from everybody else, that others in the world had limb differences too. The camp provided an environment where the limb differences did not matter because she saw them everywhere. She and the other kids were then just kids. This young girl really came out of her shell during this camp, and she carried this new attitude with her back to her small town.

But many parents agonize over whether their child should go to a regular summer camp or a camp for those with limb differences. In an ideal world, these children could attend both. But that isn't always financially possible. We've found that most youths who attend a camp with other amputees realize the value of spending time with others their age who also have limb differences. It gives them the opportunity to share experiences and feelings with others who are in similar situations and who understand them. These experiences can have a tremendous impact on a growing child.

Summing It Up

There are many issues and challenges surrounding limb difference and prosthesis use for children and parents. As actress Cicely Tyson has said, "Challenges make you discover things about yourself that you never really knew. They're what make the instrument stretch, what make you go beyond the norm."

Parents, maybe even more than children, will learn, discover and grow. How we deal with the successes and the challenges defines who we are as individuals and as families. One single set of rules or answers simply does not exist when raising a child with or without a limb difference. We cannot look into a crystal ball and see what the future will hold. But what we can do is work hard to bring their abilities, gifts and talents to the surface, nurture them, watch them grow and ultimately let them go. ■