

# Upper-Limb Prosthetics: Part 3

## Insights about the loss of both arms

by Douglas G. Smith, MD



*So far, our discussions about people with upper-limb loss and prosthetics have focused on those who have lost all or part of one hand or arm. Now, our focus turns to bilateral limb loss – the absence of both hands or arms as the result of a birth defect (congenital) or a catastrophic accident or disease (acquired).*

The demands and challenges faced by people who lose both upper limbs can be exceptional, even overwhelming. Yet, driven by the human spirit and persistence – and sometimes with the help of others – many people with bilateral upper-limb loss find solutions and coping skills that are truly inspirational.

The loss of one arm or hand is physically and emotionally devastating. Tasks that once were done easily and automatically with both hands are more challenging now. The person must make major adjustments and learn to perform two-handed daily activities with one hand or with the aid of a prosthesis. It's obviously distressing and demoralizing to lose the non-dominant hand, but it's still possible to do an amazing number of things with the remaining, dominant hand. Frustrations are even higher with the loss of the dominant hand, but, with time and practice, the non-dominant hand can improve at handling tasks until it becomes the dominant hand out of

necessity. In our clinic, many young people describe the ways playing Ping-Pong has helped to improve their non-dominant hand skills. The game is a wonderful tool for teaching hand-eye coordination and reflexive skills and developing a better sense of touch.

In contrast, a person who loses both hands or arms lives in an entirely different state of reality. The loss is even more profound. The person does not have even a single, God-given upper limb with all of its fluid, cohesive and intricate movements that work so well with little or no conscious thought. Function is extremely complicated. Frustrations can increase exponentially. Individuals with bilateral limb loss can feel trapped and helpless, fearful that they will be extremely dependent on others for the rest of their lives. It's not uncommon for anybody with limb loss to feel this way, but people who lose both upper limbs may experience these feelings more often and more intensely because we rely on our hands and arms for so much in our daily lives.

In addition to affecting themselves, the frustrations they feel can have a major impact on their relationships with friends and loved ones. The ways they express their sense of dependency and frustration may seem confusing to those who care about them and want to help. The person may get angry and lash out when things aren't going right, or become withdrawn and emotionally remote. A loved one trying to help may not understand why the person is having these feelings, and also can become frustrated, feeling confused, rejected and unwanted. There's a sense of ambivalence for all involved: help is necessary but everybody wishes that it wasn't. The person who needs help hates needing it; the person giving the help knows it's

necessary but is heartbroken that the loved one needs it.

When it comes to prosthetics, people with limb loss below the elbow typically need prosthetic hands that open and close. When the amputation sites are above the elbows, the complication rate increases because multiple joints are involved. A person with bilateral above-elbow limb loss needs prostheses that can extend and withdraw, as well as grasp and release. Individuals with dual limb loss, especially above the elbows, rely on prosthetics to a great extent. But even with prosthetic devices, sometimes assistance from others is needed for certain tasks. And some individuals require total assistance with daily living activities.

### **Congenital Bilateral Upper-Limb Loss**

Dr. Hugh Watts has written that multiple limb loss affects 30 percent of children born with limb deficiencies, compared to 10 percent of children with acquired amputations. He says that six of every 10 children seen in pediatric amputee clinics have congenital conditions, and children with multiple limb deficiencies make up a significant proportion of those patients. It's widely believed that limb deficiencies in children most often involve the upper limbs, but Dr. Watts notes that this may be, in part, because some children who undergo amputation as the result of traumatic injuries may be treated in community medical facilities and not pediatric amputee centers. He says that while less than half (40 percent) of acquired amputations among children involve upper limbs, an upper limb is twice as likely to be involved in children with congenital conditions seen at amputee clinics.\*

It's emotionally devastating for families

when a baby is born with limb loss. But it's important to understand that children with congenital bilateral upper-limb loss often develop the range of motion and lower-limb dexterity to use their feet for a wide range of functions. I think it's extremely important that children with bilateral upper-limb loss learn to do this. There is a common assumption that technology provides the entire solution to limb loss problems. In reality, while assistive technology provides us with marvelous, useful tools, their functions are limited and they can have their own drawbacks, such as weight, breakdowns, putting them on and taking them off, and lack of sensory perception.

Using the feet or residual limbs provides sensory feedback that is impossible to duplicate with a prosthesis. Dr. Watts notes that most children who are born without arms will not wear prostheses throughout their lives. These children have a unique

ability at a very early age to develop a huge range of motion and dexterity with their feet and legs that will help provide them with functional abilities independent of technology. This remains the first line of treatment: They're learning to do something that is always with them. They don't necessarily have to put something on to pick up objects or perform other tasks. By the time they become adults, many are able to do almost everything for themselves with their feet, including eating, bathing, brushing their hair, writing and even driving a car. Objects also can be grasped between the chin and shoulder or between even a very short residual arm and the chest. These individuals never had upper limbs, so, for them, it has been necessary to use their legs and feet for many tasks that we typically do with our hands and arms. As we'll see later, this starkly contrasts with those who lose their upper limbs later in life and can become far more dependent on technology.

*"Acceptance is not submission; it is acknowledgement of the facts of a situation. Then deciding what you're going to do about it."*

*– Kathleen Casey*

*Theisen, author*

## **Acceptance Is Not Submission**

Having a newborn with a limb difference is one of the most emotionally painful things parents can face. They typically experience shock and mourning, and even guilt that they must have done something wrong during the pregnancy – perhaps taking the wrong drug or inhaling something toxic. However, in almost all cases, they did nothing wrong. Birth defects usually happen for reasons we don't understand.



Most parents of children born with limb differences initially have expectations for surgical reconstruction, prosthetic rehabilitation or both, which, unfortunately, are simply unrealistic. As noted earlier in this series of articles, there is nothing man-made that can completely replace what most people are born with naturally. But prostheses certainly can, and do, prove useful as the child matures. But when to start? Healthcare providers frequently go by the saying that a child should “be fit when they sit,” meaning prosthetic fittings usually should begin when the child can sit up without help. The parents and members of the healthcare team should then discuss the prosthetic options available for the child.

While prosthetics are definitely useful, there’s much wisdom in encouraging a child to be as independent as possible without artificial limbs. Children born with bilateral upper-limb loss can begin

developing flexibility and an increased range of motion in the hips, knees and ankles early on. As they develop, their legs and feet take on multiple responsibilities – they are used for walking *and* functions for which we typically use our hands and arms, such as grasping, pulling and lifting. The older you are when you start doing this, the more difficult it is. We typically are more capable of learning to do things as a child than when we’ve grown into adulthood. Another advantage for the child is comfort. Prosthetics can be heavy and cumbersome, and the socket gets hot. People typically prefer the feel of the air next to the skin as opposed to their limb or limbs being encased in a socket.

In all aspects of limb loss, the children and families I work with who are the least happy are those who are trying to undo a situation that simply can’t be undone. They’re always searching for that elusive, impossible “something” – a device, product

or surgery – that will make the limb loss go away. Some parents become fixated on the idea that a device will completely replicate and replace what their child was never born with. Unfortunately, that’s just not possible.

Those with the best outlook are those who are focused on working with the limb loss, defining the challenges and then creating task-based solutions. Unlike the families who remain frustrated by trying in vain to undo the loss, those who manage the problems with task-based solutions enjoy the happiness and pride that comes with each accomplishment. There’s something incredibly positive about problem-solving and task-based approaches. It’s about accepting the situation and moving forward with it as an aspect of your life, rather than constantly trying to undo it. As wonderfully stated by Elizabeth T. King, Bryn Mawr School co-founder, “I find that it is not the circumstances in which we are placed,



but the spirit in which we face them that constitutes our comfort.”

## Audrey

Audrey is a 7-year-old girl who was born with no arms. Her parents were grief-stricken when she was born, but adjusted when they realized early that the best thing for their little girl was for her to learn to use her legs for as many lower- and upper-limb functions as possible. They started her in physical therapy at a young age. The therapist made the exercises like a game for Audrey, who enjoyed them, while developing valuable skills and physical dexterity that, with continued practice, she will take with her as she grows up. Like all developing children she accomplished important physical milestones such as learning to roll over, sit up, rise to a standing position, stack blocks, and pick up and drink from a sipper cup. Audrey learned to do all these tasks - with her feet!

As she developed and her coordination improved, she learned to do more challenging tasks, such as brushing her teeth, combing her hair and feeding herself, using her feet. Although she still faces a lifetime of physical limitations, even with prostheses and improvements in prosthetic technology, she got a very early start in giving her legs and feet a dual focus that will benefit her throughout her lifetime.

In an ideal world, children with bilateral upper-limb loss would be completely capable of both using prosthetics and going without. However, to enhance their independence, it's important that they be encouraged to do things with their legs and feet. By starting early, Audrey developed the dexterity and flexibility that gave her legs and feet expanded multi-tasking roles. Some believe we can't feel a sense of loss for something we never had. I disagree; I think we can feel loss for something we never had because so many other people have it. But because Audrey is growing up without upper limbs, she's figuring out ways to do things with her lower limbs,

which increases her sense of accomplishment, capability and self-reliance. While she may feel less able than people with two arms, she does *not* feel helpless. Children born without upper limbs tend to figure out ways to get things done, such as opening doors with their feet, while this is far more difficult for adults with acquired bilateral limb loss.

Historically, many children born without arms preferred not to use prosthetic devices. However, we now see a broader mix of children who want to incorporate prostheses into their lives to varying degrees. I think this is a positive development. It gives children as many skills as possible and, as they grow, they have as many choices as possible. There is no longer just a single model of “the correct thing to do.”

After developing her primary independence skills, Audrey wanted to develop a second set of skills using prostheses. Audrey and others with amputation levels at the shoulder frequently find it very useful to have a different type of prosthesis for each arm, models that are different in mode and function but work in concert to give the user the advantages of more than one kind of prosthesis. The devices attach to the body at the shoulders, and the user hits toggle switches with the chin to change prosthetic functions, such as bending the elbow, opening the hand or extending the device. The prostheses complement each other in function and give the person multiple uses, but they cannot operate fluidly and symmetrically, and each function requires a conscious thought from the user to activate the device in a specific sequence. It's definitely not easy, but the positive features of each prosthesis give the person useful alternatives, which are extremely important for someone who is so very dependent on these prosthetic devices when they're needed.

Next in our series on upper-limb loss and prosthetics, we'll examine bilateral upper-limb amputations that result from disease

or trauma, called acquired limb loss. We'll look at the challenges, some of which can seem insurmountable, the struggles and, yes, the triumphs. The human spirit can accomplish incredible things. Stay tuned; we'll even be going to the movies! ■

## Reference

\*Multiple Limb Deficiencies. Hugh Watts, MD. *Atlas of Amputations and Limb Deficiencies, Surgical, Prosthetic, and Rehabilitation Principles*. Third edition. 2004. American Academy of Orthopaedic Surgeons. Pages 923 & 927.

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