THE GUIDE FOR FAMILIES WITH SPECIAL NEEDS CHILDREN

(201) family's special parent

PART OF THE USA TODAY NETWORK

2017 EDITION

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making children whole again

Pediatric prosthetics elicit questions and concern first, rewards for a lifetime

WRITTEN BY **MICHAEL LAMENDOLA**

Imagine the unimaginable. Your 8-year-old son is struck by a vehicle riding his bike around the neighborhood. He'll survive, but his leg is too battered to save – it will need to be amputated. How will his life ahead be made whole? He'll be bullied. He won't be able to play sports. Will he need a walker, crutches, a cane?

Thousands of parents every year ask the same questions, whether their children through birth, or some unfortunate accident or illness, has lost a limb, partially or wholly. The unknown of a new artificial limb can be daunting for both parent and child.

"Children are usually the ones that are fine with it; it's usually the parents that are already in a panic from the beginning," Brooke Artesi, founder of Sunshine Prosthetics and Orthotics in Wayne, says. "Children seem to adapt while the parents are the ones with the questions and concerns."

Artesi says that while pediatric prosthetics are rare and account for less than 10 percent of her patient base, it's one of the most important population sectors to serve due to the confluence of factors that trauma, congenital deformities, partial limb loss or full limb loss can have on youth and their families.

BREAKING THE STIGMA

Artesi has intimate knowledge of the rigors of limb loss. At 15 years old, living in Rockaway, she departed the Dover train station for a trip with friends to Morristown. On the way back, a mishap on the platform dragged her beneath the train. It severed her right leg below the knee. After two weeks in the hospital and additional recouping time at home, she took the major step of any amputees' recovery. She was fitted with a prosthetic.

"It was difficult being in high school, but I adapted," Artesi says. "Basically, at that point, I just went through the motions. I told myself it happened for a reason; I always believed that."

Artesi says in many of her cases, it's the parent – more than the patient – that is concerned, apprehensive and sometimes lost in a sea of confusion about what their child will go through mentally, as well as physically, when equipped with an artificial limb.

To quell this, Artesi says she does her best as a professional to put parents at ease, but she always recommends the support of others going through the same thing. As an example, Artesi says organizations such as Camp No Limits, which she regularly volunteers for, create a network of support for not only amputees, but families as well. The camp offers therapeutic programs with specialized professionals, including physical and occupational therapists, prosthetists and adult amputee role models while offering five programs each day. Specific group sessions for siblings and parents are held to address the needs of families living with individuals with limb loss.

"You're going to learn a lot more when you meet with parents going through the same thing," says Artesi.

WHAT TO EXPECT AND WHAT'S THE RIGHT CHOICE

According to Artesi, approximately 90 percent of child limb-loss is caused either by illness or at birth; the others are caused by trauma. In either case, children will first be measured and fitted for a limb, as soon as two weeks after trauma or surgical induced amputation. Then an occupational therapist for upper limbs and physical therapists for lower limbs will teach the patient how to use their new arm or leg. For those born with limb loss, it's appropriate to have the child fitted with a prosthetic lower extremity before the child begins his or her cruising stage.

"With an upper extremity, I say leave it until the child may become self conscious about not having it," she says.

Artesi explains there are four levels of assessing what components are suitable for an individual. On the "K" scale, children are a four, meaning they need something that can withstand the everyday wear and tear of child's life.

"It's recommended, until say 15, that they are in a heavy duty, strong component – nothing too technologically advanced or expensive because children will need to be re-fitted with new pieces as they grow," she says. "The older you get, the better stuff you get." >

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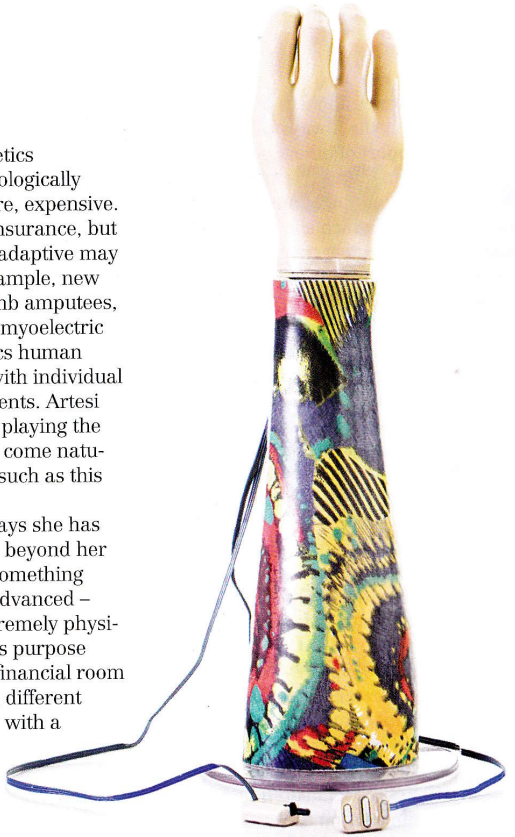

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And modern prosthetics have gotten very technologically advanced and, therefore, expensive. Many are covered by insurance, but the more advanced or adaptive may not be covered. For example, new technology in upper limb amputees, such the Michelangelo myoelectric prosthetic hand, mimics human anatomy and motion with individual digit and wrist movements. Artesi says that activities like playing the piano or using an iPad come naturally with a prosthetic such as this one.

To this day, Artesi says she has never decided to move beyond her basic artificial leg for something more technologically advanced – even though she is extremely physically active. It serves its purpose and affords her more financial room to express herself with different legs. She even has one with a high heal built on and another with a tattoo.

A COMMON ISSUE IN BABIES

Another common, but treatable, issue dealt with by parents all over the nation in babies is what is known as plagiocephaly. Also known as flat head syndrome, plagiocephaly is a condition that causes a baby to have a flat spot or be misshapen. The most common type is positional plagiocephaly, which typically develops after birth when babies spend time in a position that puts pressure on one part of the skull.

"Obviously, you want to try tummy time first, but, if the problem persists, a helmet is probably needed," Artesi says. "The helmets…that's the hardest part for the parents. But, it's compliant; the baby will need to have it on 23 hours a day or it will not work."

After being measured, a child's head will be fitted with the helmet and worn until the baby's head begins to grow into its intended natural shape again.

GET THE FACTS...

WHY DO PEOPLE HAVE AMPUTATIONS?
Amputations may be the result of diabetes, bacterial infections, circulatory diseases and trauma. Some people may be born with congenital birth defects which leave them with non-functioning limbs that may become more useful once removed and replaced with prostheses.

WHAT IS A PROSTHESIS?
A prosthesis is an external device designed to replace a missing part of the body, including arms, hands, fingers, legs, toes, breasts and even eyes.

HOW OFTEN WILL MY CHILD NEED A NEW PROSTHESIS?
Replacing the prosthesis every time the child grows (i.e. every few months) can be a mistake because it takes several months for the child to get adapted to a new prosthesis. The good news is that there are adjustable features which can be built into a prosthesis for a child to make minor adjustments until a new device is needed. In addition, a new prosthesis for a child may come with padding built in which can be adjusted to accommodate growth. Sometimes the length can also be adjusted to match the length of the other limb. A new prosthesis may be required in cases where there is a significant change in body weight, skin ulceration, bone overgrowth or trauma to the residual limb.

WILL I BE ABLE TO USE MY PROSTHESIS JUST LIKE I USED MY NATURAL LIMB?
Although a prosthesis will never completely replace your natural limb, it can help restore all or most of your original functioning. This is partially reliant on your level of amputation. Below the knee amputees usually do well in returning to former lifestyles. Above the knee amputees may proceed more slowly but usually can return to former lifestyles as well. Depending on personal goals and needs, patients with upper limb amputations have varied rates of success in restoring former lifestyles.

ARE PROSTHETICS COVERED BY INSURANCE?
While most medical insurance coverage will include prosthetic limbs with a prescription from your doctor, it is best to check your policy and call your insurance company to be sure.

DO I NEED ANY OTHER HELP IN LEARNING TO WEAR THE PROSTHESIS?
A prosthetist can help you find other health professionals, such a physical or occupational therapists, for additional instruction and training on using your prosthesis as well as necessary strengthening programs.

HOW DO YOU PUT ON A PROSTHESIS?
There are several ways for an amputee to don a prosthetic, depending on their individual anatomy, preference and the design of the prosthesis. Pull-in users work with a donning sock to be sure that all necessary tissue is contained within the suction socket. The donning sock is used where there is no liner interface and requires a lotion (wet fit) or powder (dry fit). Push-in donning is for amputees with longer above-knee residual limbs. Some prefer to push the residual limb into the prosthetic's socket using a wet or dry fit.

CAN MY PROSTHESIS GET WET?
Generally, your prosthesis should be kept as dry as possible to protect the components. However, there are covers which go over them to help prevent water from entering. There are also special prostheses designed for water activities, such as swimming and showering.

WILL MY PROSTHESIS LET ME DO EVERYTHING I COULD DO BEFORE MY AMPUTATION?
A well-fitting prosthesis will allow you to regain much of the function you have lost. There are limitations depending on the type of prosthesis and your personal health and abilities. Your prosthetist, physical therapist and doctor will work with you to ensure you get the most from your prosthesis.

SHOULD CHILDREN OR PARENTS DECIDE WHEN TO WEAR PROSTHESES?
There should be a balance between these two which will change as the child grows. Small children will need the guidance from their parents; as they become teenagers, they will want to make their own decisions. At this point they will also be more influenced by peers and amputee role models.

Source: Sunshine Prosthetics and Orthotics