

in motion

The Living Well With Limb Loss Magazine

Adapting as an Amputee



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Adapting *Instructions not Included*

Bill Dupes, Editor-in-Chief



Life is a never-ending series of transitions. Some changes are welcomed, while others range from annoying to catastrophic. In the case of limb loss, whether it is of an upper or lower limb, or the result of illness, trauma or birth, the experience is life-changing.

The amputee community is as diverse as the larger family of man. It is fascinating to see how people choose a path to recovery, each with its own unique set of twists, turns and triumphs. How you adapt to these challenges can make the difference between sliding into a downward spiral or rebuilding your life.

We all have different situations, needs and desires. As a result, there is no one-size-fits-all instruction book. People who were born with limb difference may not know any other way of doing things, while individuals who lost a limb later in life may be forced to relearn how to do certain functions. Specific solutions that allow a young woman who was born without her left arm to live to her fullest potential may not apply to a middle-aged man who lost his right foot on the job. Choosing whether or not to wear a prosthesis and deciding which type is appropriate can be difficult.

Often it is only by trial and error that we find what works best for us. Trying to figure everything out on your own can be frustrating and can take time. While it may feel like you are alone in your efforts, it is important to understand that there are resources available to help you find your way.

Because adaptation to amputation is so multifaceted and because it is an evolving process requiring different kinds of attention at each stage, the team approach is considered the ideal method of rehabilitation. The team may include physicians, therapists, family members, friends and successfully treated amputees.

Although there may be no single place to find the answers to all of your questions, tapping into the knowledge of your team and other resources, such as the Amputee Coalition's National Limb Loss Resource Center, can go a long way to help you achieve your goals.



*"As human beings,
we have the blessing and the curse
that we're able to adapt to almost anything.
No matter how extreme the circumstances
you're in, they become normal."*

~ Kevin Powers
Writer, poet and Iraq War veteran

BE AN INFORMED READER

Editorial content (articles, news items, columns, editorials, etc.) in *inMotion* often contain healthcare information. As an informed reader, you should never make a decision about managing or treating your condition without consulting your own clinicians: They know you best.

Sometimes, in our interviews with people who are amputees, the person being interviewed will say something about his or her personal experience that may not be entirely consistent with standard practice. In these cases, we print what the person said because we think it gives readers insight into that individual's experience that we believe will resonate with others. But: We urge you to always check with your medical team before changing your own healthcare regimen.

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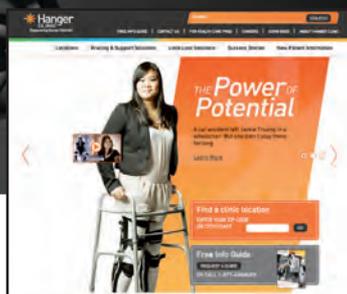
Since she was a little girl, Carrie Davis knew she was unique. Born without her left arm, she often wondered "Why me?" She longed to be known for her contributions, not what she was missing.

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Helping your child thrive in school after an amputation

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InMotion magazine publishes unbiased journalism that seeks to "empower and motivate" living well and thriving with limb loss. The magazine targets amputees and their families and is provided free electronically to all friends of the Amputee Coalition and in hard copy to all subscribers. Each issue covers health, well-being, exercise, life issues and advocacy for amputees and their families. Stories showcase amputees living and thriving with limb loss and profile Amputee Coalition programs and services.

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endolite



by Dan Ignaszewski

Adapting to Change

Doesn't Have to Mean **Accepting** It

The one true constant is change. In recent years, that has never been truer than with prosthetic devices in healthcare, insurance and the Medicare program. Since the early 2000's, we've seen private insurance capping prosthetic device coverage under Durable Medical Equipment (DME). When the Affordable Care Act was passed, it was generally believed that prosthetic devices would be covered under the Essential Health Benefits (EHB) category of "Rehabilitative and Habilitative Services and Devices," but in many states this was not the case. In addition to those changes, the Office of Inspector General (OIG) came out with a report in 2011 titled "Questionable Billing by Suppliers of Lower Limb Prostheses," which has had a significant impact on how Medicare is handling lower-limb prosthetic claims up until now and into the future.

When things are changing, everyone affected must adapt to keep up with the new realities. Adapting doesn't mean you have to simply accept the situation, but it *does* mean that we need to figure out what's happening, the direction in which things are going, and what can be done to change the new realities to address our concerns.

Fighting for Fairness on the State and National Levels

With respect to private insurance, the Amputee Coalition has worked since 2000 to combat caps on DME, and specifically prosthetic and custom orthotic devices, through Insurance Fairness laws. The Amputee Coalition has worked with advocates to pass 20 of these state laws that work to ensure appropriate access to prosthetic devices without arbitrary caps and restrictions on care. The Amputee Coalition has also worked on a federal bill since 2008 to try to eliminate these arbitrary caps and restrictions. We still have a long way to go, but we realized what was happening and the direction the insurance industry was going; as a result, we adapted and began working on a way to address it.

Likewise with the Affordable Care Act and the EHB, the Amputee Coalition has worked to map out every state's benchmark plan and coverage for prosthetic devices. Some states have very good coverage for prosthetic devices in the benchmark plan for their insurance marketplace, while others need to be addressed. The Amputee Coalition continues to fight to raise awareness and make

corrections to the EHB because when the law was passed, Congress clearly articulated in supporting documents that prosthetic and custom orthotic devices fell under the “Rehabilitative and Habilitative Services and Devices” provision. Subsequent rules and comments by the Department of Health and Human Services have reiterated the importance of these devices for patients. While some states still do not provide coverage for prosthetic devices in their benchmark plans, others have limitations. After several unsuccessful challenges to the Affordable Care Act, we can see that it is here to stay, and that changes need to be made to ensure all states recognize that prosthetic devices are essential to patients.

Addressing Medicare Audits and Proposed Changes

Finally, we come to Medicare. Since the OIG report in 2011, Medicare has employed auditors to look into past and current claims to see if Medicare was billed appropriately for the most medically necessary device for an individual patient (these are commonly referred to as RAC audits). These audits primarily focus on patients who fall between the K2 and K3 functional levels outlined in Medicare’s K0-K4 functional status definitions. When auditors make a determination that there is not enough information in the patient’s medical record, they take back the money that was paid to the prosthetist for that device, leaving the prosthetist to swallow that cost until an appeal can be heard. Most of the audits are being overturned, but it can take a long time to do so, which is having a significant impact on many prosthetic offices.

The Amputee Coalition believes that patients should be able to get the most appropriate prosthetic device for their needs when they need it. This means that patients, prosthetists and doctors must work together to ensure the appropriate documentation is provided to support higher functioning devices. The Amputee Coalition’s guide, *Insurance Coverage and Reimbursement: How to Be Your Own Advocate*, seeks to help patients navigate their healthcare and ensure they receive the most appropriate care for their needs.



These same auditors recently submitted a draft proposal that, among other things, could significantly change K-level definitions, alter current guidelines for coverage, and limit patients to certain types of devices or components based on arbitrary determinations. The Amputee Coalition continues to work with Medicare, patients and professionals to ensure patients are not impacted inappropriately by any proposed changes. We have voiced our concerns about this latest draft proposal, and will continue to keep the community apprised of this situation and how you can help.

It is vital that we all remain vigilant and aware of changes in these areas. The Amputee Coalition encourages patients to stay up to date on these issues by joining our email list and Facebook page so that we can continue to share with you the ways that you can help make a difference for yourself and your community. 

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The LLED Series: A Chance to Get Together, Learn and Have Fun

by Kate Anderson

There is something powerful about the experience of coming together with others who are living with limb loss. It's a time to find inspiration in your fellow peers, to understand the latest trends in rehabilitation and technology and to find out you can engage in any adaptive recreation activity you set your mind to. Luckily, there is an event created to accomplish these tasks: Limb Loss Education Day (LLED).

The Amputee Coalition's LLEDs are regional events designed to provide the opportunity for people to gather together, learn and have fun trying adaptive recreation activities. "We are very pleased to be able to bring our highly successful LLEDs to local communities again in 2015 and to provide this program at a very low cost to amputees and their families," says Susan Stout, president & CEO of the Amputee Coalition. "Our regional LLEDs have been hugely successful because they make our programs accessible, from both a cost and a travel perspective, to amputees and their families. Regional LLEDs allow us to reach new amputees with relevant information who have not participated in Amputee Coalition events in the past, while also keeping us connected to our longtime friends who are regularly present at our programs."

With a hugely successful Washington, D.C. event already in the books, the Amputee Coalition is looking forward to visiting Columbus, Ohio on Saturday, September 19, 2015 and Portland, Oregon on Saturday, October 24, 2015. Each LLED will feature presentations that are developed with the assistance of area hosts who help to select topics of interest to amputees and the limb loss community in their specific regions. The Amputee Coalition is partnering with Amps4Ohio, the Amputee Recreational Support Group of Ohio, Columbus Paralympic Sports Club and Columbus Parks and Recreation to bring an LLED to Columbus, Ohio. In Portland, Oregon, the Coalition is partnering with Oregon Disability Sports and Shriners Hospitals for Children.

During the event, the first half of the day will feature three to four educational sessions, followed by lunch, then an afternoon filled with adaptive recreation. There also will be daylong exhibitor tables from our national and regional sponsors featuring technology, programs and services that are available to amputees. There will be both national and regional sponsors exhibiting at the LLEDs. In Columbus, Ohio we are proud to have Ace Prosthetics and WillowWood as our regional LLED sponsors.

Registration for the event is only \$15, and free for children 10 years and under. 

 For more information, contact Kate Anderson, Amputee Coalition's communications & events manager, at kanderson@amputee-coalition.org.

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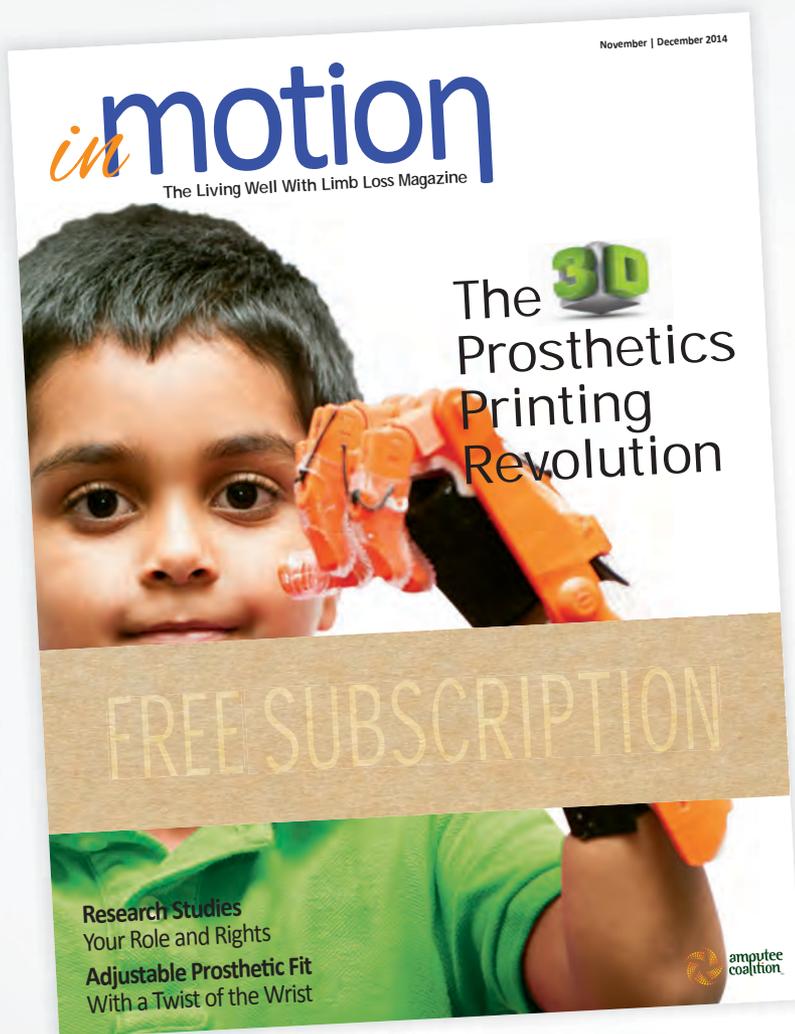
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From its humble beginnings as a four-page newsletter in 1991, *inMotion* magazine has expanded in size and readership over the years and has been through many transitions – both in content and design.

Through it all, our goal has remained constant: to fulfill the Amputee Coalition's mission to "reach out to and empower people with limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention."

To support our mission, we want to reach more people with limb loss, to engage them in our programs and to provide valuable information about living well with limb loss. We believe that eliminating *inMotion's* subscription fee will help us to achieve that goal. Therefore, *inMotion* is now available free of charge in both print and electronic format.

As always, we welcome and look forward to your feedback and suggestions. Please feel free to contact us at editor@amputee-coalition.org.

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September

PAD AWARENESS MONTH

vasculardisease.org

PAIN AWARENESS MONTH

painawarenessmonth.org

11

OPAF First Swing

Boise, Idaho
opafonline.org

18 – 20

Abilities Expo

Boston, Massachusetts
abilitiesexpo.com/boston

19

Limb Loss Education Day

Columbus, Ohio
amputee-coalition.org

Board Short Mile

Hermosa Beach, California
challengedathletes.org

23

Fall Prevention Day

ncoa.org/healthy-aging/falls-prevention

September 26 – October 3

Travel Adventures | Accessible Seas II

Ft. Lauderdale, Florida, Labadee, Falmouth (Jamaica), Cozumel
amputee-coalition.org

27

Jordan Thomas Foundation

Low Country Boil
Chattanooga, Tennessee
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28

Jordan Thomas Foundation Golf Tournament

Chattanooga, Tennessee
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Note: Dates listed for events are subject to change. Check Amputee Coalition online calendar and listed Web sites for current information.

October

NATIONAL BULLYING PREVENTION MONTH

pacer.org/bullying/nbpm

NATIONAL DISABILITY EMPLOYMENT AWARENESS MONTH

dol.gov/odep/topics/ndeam

NATIONAL MRSA AWARENESS MONTH

worldmrsaday.org

NATIONAL PHYSICAL THERAPY MONTH

apta.org/nptm

2

World MRSA Day

worldmrsaday.org

3 – 4

Back to Back Cycling Challenge

Manhattan, New York
challengedathletes.org

6 – 9

Southwest Conference on Disability

Albuquerque, New Mexico
cdd.unm.edu/swconf

10 – 22

Travel Adventures | Israel Tour 2015

Tiberias, Dead Sea, Jerusalem, Tel Aviv
amputee-coalition.org

18

San Diego Triathlon Challenge

La Jolla, California
challengedathletes.org

22 – 25

Skills for Life 4 Workshop

Houston, Texas
usispo.org/skills_for_life.asp

23

Classy Golf Classic

Coronado Island, California
cancerforcollege.org

24

Limb Loss Education Day

Portland, Oregon
amputee-coalition.org

AWESOME...



WHO IS YOUR AMPUTEE HERO?

UNSTOPPABLE

by Brandy Grajeda

My son's name is Adrian Grajeda. He is 12 years old and is currently in the seventh grade in Palm Desert, California.

Adrian was hit by a drunk driver on October 23, 2013. As the car came crashing through his school playground, sending debris everywhere, it struck Adrian in the right leg as he pushed a girl out of the car's path.

He was airlifted to a local hospital and then ambulated to a children's hospital an hour away. Adrian never cried – he remained calm and conscious throughout the entire ordeal. Two days later, after emergency surgery, they amputated his leg below the knee. They tried to save it, but there was too much nerve and artery damage.



In spite of undergoing five surgeries and seven blood transfusions, Adrian was still very optimistic about his life.

The day Adrian got his first prosthesis, he walked out of the place like there was no tomorrow. Now, he is playing on a soccer team, as well as a tackle football team, he's back in regular PE, running an eight-minute mile, he plays outside with his friends, hikes local trails and more.



He is also the mascot for the children's hospital, and you can see his face on billboards, print ads, commercials and more. But more than all of that, he is *my* amputee hero. 🌀

Who is your amputee hero, and why?

Whether they're an amputee or not, the special person who inspires you to live well with limb loss can be a relative, a friend or someone you've never met. We invite you to send us an article (350 words or less) for consideration to be included in *inMotion* (editor@amputee-coalition.org).

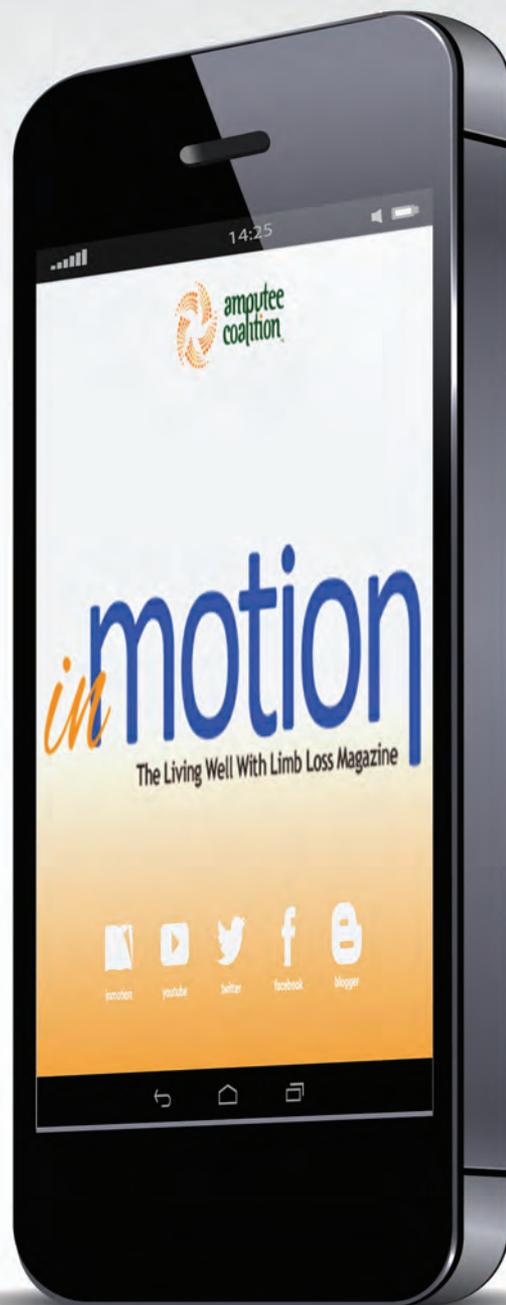


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Abuse/Misuse of Pain Medications:

Is the treatment of pain after amputation at risk?

by Danielle H. Melton, MD

For many amputees, pain is a daily part of life. Research shows that pain (phantom pain, residual pain or back/spine pain) affects 95 percent of all amputees. Pain can affect amputees, whether from acquired limb loss such as trauma, vascular causes and cancer or congenital (limb deficiency at birth) limb loss.

In 1995, the American Pain Society set forth guidelines to improve the quality of pain management. This followed with such institutions as the World Health Organization (WHO), Joint Commission Accreditation of Healthcare Organizations (JCAHO) and the Veterans Hospital Administration (VHA) recognizing Pain as the 5th Vital Sign (P5VS), an initiative to raise awareness in healthcare providers to address and treat pain. P5VS is widely adopted but has had mixed results in improving overall pain management.

While it is clear that pain management needs to be a priority, has the pendulum swung the other way?

In 2011, the Centers for Disease Control and Prevention (CDC) reported that 1 in 20 people over the age of 12 report using prescription painkillers for non-medical use. There are 15,000 prescription drug overdoses annually, and deaths from prescription painkillers have reached epidemic levels over the last decade.

The answer has been to change the way pain medications are prescribed. In 2014, hydrocodone combination drugs such as Norco, Vicodin and Lortab were reclassified as Schedule 2 narcotics requiring a triplicate handwritten prescription monitored by the Drug Enforcement Agency (DEA), making it more difficult for patients to obtain painkillers.

While these statistics are concerning and seem to warrant efforts to address this healthcare crisis, amputees in pain may be at risk for not having their pain addressed. There is a fine line between ensuring an amputee has adequate pain control and preventing abuse or misuse of medications.





While it is clear that pain management needs to be a priority, has the pendulum swung the other way?

Amputee-Specific Pain

There are many reasons an amputee experiences pain. Post amputation pain can be from post-operative pain, neuropathic pain such as phantom limb syndrome or neuromas and musculoskeletal pain from compensatory strategies that cause overuse syndrome or degenerative changes from osteoarthritis.

Factors Affecting Pain Control

The ability to cope with limb loss depends on many factors, and psychological setbacks can be frequent and often negatively impact one's ability to cope with pain. Losing independence and function often lead to depression and anxiety. These emotional responses to stress and a lack of sleep all heighten the perception of pain.

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Level of Amputation



Cramping



Shooting



Stabbing



Burning

Assessment of Pain

Assessing the type and severity of pain is important in monitoring treatment effectiveness. *Qualifying* (describing the pain, e.g., “burning”) and *quantifying* (using a scale to determine the level) through a pain journal is often helpful in identifying the right pain medication. Pain is subjective, and a treatment plan needs to be tailored for each patient.

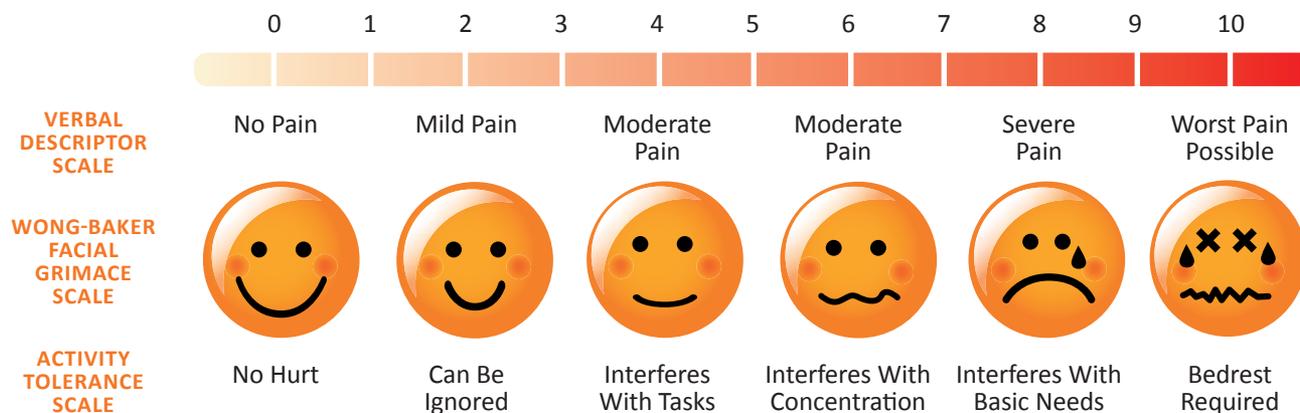
Types of Treatment

Treating pain with oral medications can be an important part of pain management for many amputees. Medications such as anti-seizure medications, antidepressants, anti-anxiety medications, sleep aids and opioid painkillers are some of the oral prescriptions that may be used to treat amputee-specific issues. If narcotics and other addictive medications are prescribed, these should be used with caution and monitored by a physician who is aware of the risks and looks at an amputee’s pain from a holistic approach. Other options include non-pharmacologic treatments such as:

- Desensitization with massage, tapping or rubbing the limb
- Pressure with a shrinker, wrapping or the use of a prosthesis
- Healing of the residual limb
- Transcutaneous electrical nerve stimulation (TENS) or mirror therapy
- Interventional procedures such as acupuncture, nerve blocks, trigger points, Botox injections and ablation or excision of neuromas
- Psychology of limb loss with psychotherapy and counseling.

Universal Pain Assessment Tool

This pain assessment tool is intended to help patient care providers assess pain according to individual patient needs. Explain and use 0-10 scale for patient self-assessment. Use the faces or behavioral observations to interpret expressed pain when patient cannot communicate his/her pain intensity.



Narcotics and other addictive medications have the potential risk for overuse, either by the patient taking more than the prescribed amount or by diversion, with the patient knowingly selling the medications or by others stealing the medication from the patient.

Providers treating chronic pain must screen for abuse by asking patients about personal or family history of addictions and monitor closely for red flags that point to problems of overuse or diversion of prescription medications. Monitoring with a urine drug screen is the preferred initial test. Appropriate collection techniques minimize the risk of tampering with the specimen.

While signs of abuse, dependency and addiction are often unreliable just as detecting diversion or trafficking proves difficult, certain behaviors should raise a red flag. These include resisting other treatment options, reluctance to be drug tested, requesting specific drugs (particularly those with known "street value"), noncompliance with prescribed regimen (taking more than prescribed and running out early) losing prescriptions, giving excessive flattery or displaying anger with threats.

It is also important for healthcare providers to understand and educate patients on the serious and life-threatening interactions of opioid medications with other addictive drugs, including benzodiazepines like alprazolam (Xanax) or diazepam (Valium) and alcohol. Also part of the recent debate is the legalization of marijuana for medical purposes. As of July 2015, the District of Columbia and 23 states have legalized marijuana for treatment of chronic pain. While many report cannabis as an effective tool for pain management, the FDA prohibits a physician to prescribe opioids and marijuana at the same time, which may further limit other treatment options for patients who choose to use cannabis for pain management. Adding to the controversy is the lack of long-term research on side effects of pain medications.

Pain management for amputees is of vital importance for everyone involved in the process but potential abuse of treatment options highlights the barriers that many face. Focusing on safe and effective treatment options is crucial for addressing an amputee's pain. 🌀

Related Resources

Drugs.com

Online drug information in an A to Z format.

MedicineNet.com

medicinenet.com/medications/article.htm

PDRhealth

pdrhealth.com/drug_info/index.html

U.S. Food and Drug Administration

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www.accessdata.fda.gov/scripts/cder/drugsatfda/index.cfm

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The purpose of this research study is to determine if putting local anesthetic (numbing medication) through one or two tiny tube(s) placed next to the nerve(s) that go to an amputated limb will decrease and/or resolve phantom limb and stump pain. The procedure, device and infusion are all FDA approved and have been used for over 20 years to decrease pain immediately after surgery.

Participants will receive \$100 following each catheter insertion plus \$50/day during the 6-day infusion(s), up to a maximum of \$800/subject.

This study is being conducted at the University of California (San Diego, California); Cleveland Clinic (Cleveland, Ohio); Walter Reed National Military Medical Center (Bethesda, Maryland); Veterans Affairs Palo Alto Medical Center (Palo Alto, California); and Naval Medical Center (San Diego, California).

- No surgery involved
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Fishing in 3D:

by Leif Nelson, DPT, ATP, CSCS

October 22, 2012 is United States Army Captain Edward “Flip” Klein’s “Alive Day.” On that date he was on dismounted patrol with his infantry platoon in Afghanistan when he stepped on an improvised explosive device.

For nearly three years, Klein has been in rehab at Walter Reed National Military Medical Center (WRNMMC), and is planning for military retirement in the near future. In addition to multiple neurological injuries, Klein is living with bilateral above-knee amputations, a right above-elbow amputation, and the loss of three fingers on the left hand. “I try not to define my life by what I’ve lost, but what I can do with what I have left,” he says distinctly.

Klein is a detail-oriented guy with an engineering degree. He quips that this probably doesn’t make him the easiest patient, but it has led him to be part of many new inventions that have met his needs, as well as those of fellow injured service members. Klein proudly associates with a community of injured services members who “have challenged what a disabled person can do.” He adds, “It’s been difficult for industry to keep up with our needs; 3D printing allows the users to drive development.” Klein’s insight has made him an essential member of his rehabilitation care team.

Lead prosthetist David Beachler has been working with service members at WRNMMC since 2006. More specifically, he has undertaken the challenge to outfit task-specific solutions for Klein’s upper-limb prosthesis, which he wears 8-12 hours a day. Klein approaches the challenges of daily life by using his infantry officer training. “It’s all about task analysis, understanding your limitations, and then putting your limitations up against the task at hand,” he explains. “I try to see potential problems, and then prioritize possible solutions.” Beachler describes his own approach as being similar. He says that in creating prosthetic solutions, he uses all the resources available at WRNMMC. He understands that most patients, like Klein, need multiple solutions to succeed in the wide range of daily living activities.

“There is a gap in what is commercially available and what our service members need to achieve their goals,” says



Hook, Line and Tinker

David Laufer, director of orthotics and prosthetics at WRNMMC. To fill this gap, the orthotists and prosthetists at WRNMMC have partnered with the 3D Medical Applications Center (MAC). Peter Liacouras, PhD, director of services for the 3D MAC at WRNMMC, now finds himself as a member of the amputation care team. Using a fleet of nine printers that manufacture plastics, plasters and metal medical devices, Dr. Liacouras works under the Radiology Service and supports all of Surgical Service lines in addition to Rehabilitation and Orthotics and Prosthetics Services.

As department head, Laufer strives “to enable creative people to find creative solutions.” His process includes regular team meetings with his staff of 20, along with experts in other fields like Dr. Liacouras, to “tap into their inner MacGyver” and “throw around screwball ideas” with the end product being an out-of-the box solution to ultimately help patients successfully achieve personal goals.

Klein loves the outdoors and dreamed of fishing, but commercially available options limited his independence, as he would have to remove his hook. The prosthetics team presented Dr. Liacouras with a laundry list of needs that became the blueprint for a new device capable of interfacing with Klein’s prosthetic set-up. Ideal design meant this device could also be used by other patients with various



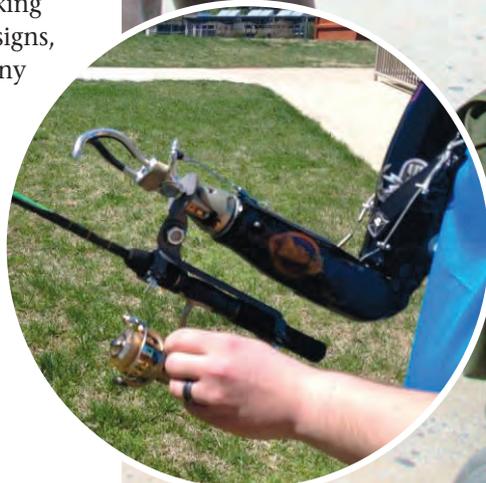
Prosthetist David Beachler (left) and Dr. Peter Liacouras make adjustments to Army Cpt. Edward “Flip” Klein’s adaptive fishing rod.



Photo Credit: Sarah Marshall WRNMMC Public Affairs

levels of limb loss. The first step was Dr. Liacouras modeling the fishing attachment using advanced computer design software. The 3D MAC then rapidly prototyped the device using a 3D printer that creates in plastic. Once the proof of concept was established, a definitive device was printed in titanium alloy. This is the device that Klein uses today.

The benefits of this innovation are that Klein is able to wear his hook and hold his fishing pole at the same time. In addition, the device allows the fishing rod to be held at any angle, making it compatible with all socket designs, and the adjustable brackets fit any size fishing pole. The device fits any level of amputation, as long as the device has a quick disconnect wrist unit. Dr. Liacouras has printed a dozen of these titanium fishing adaptations for service members at WRNMMC.



Looking back, mobilized by what a patient had to say, the WRNMMC team used creative ingenuity and 3D printing technology to find a titanium solution to a fishing problem that didn’t require duct tape or a Swiss Army knife. Sorry, MacGyver. 🌀



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Lessons Learned

by Sean Brame

My car is pulling up to the dorm after an hour of congested traffic. I am greeted with a warm smile and inviting arms. About half a dozen students are helping me move my luggage into my dorm to start off my first semester at The Pennsylvania State University (PSU).

I'm standing in line waiting to get my ID when the first words out of someone's mouth was, "Hello! Where ya from? What's your major?" I was kind of surprised at first. My life for the past 10 years was filled with endless stories of telling how I lost my limbs and where my scars came from, but when my feet touched the campus, everything changed. Everyone around me stopped looking away and started looking *at me*. For the first time in my life, I felt free – free from judgment, free from fear.

I felt naked the first few weeks on campus because everyone went about doing their own thing while I was left in the dust. I finally had a chance to redefine "me," but at the same time I didn't know how.

One night I left my dorm around 9pm to fill up my water bottle when I overheard a group of guys talking about movies. I sat down with them for a bit and one thing led to another and the clock hit 1am. It was weird to stay up that late with people I'd never met and yet walk away with new friends. We told stories from back home, discussed politics, and talked about life. If we had stayed up an hour longer, we probably would have discovered the key to world peace.

I joined a Paralympic group on campus called Ability Athletics. Our group was filled with disabled athletes ranging from paraplegic to amputees. A couple were vets and I was the rookie. Our program is run by former Olympic track athlete Teri Jordan. Although Teri doesn't coach swimming, she took me in while I swam with State College High School's coach Ryan Sprang. Together they helped me to find my place at PSU.

With a new school comes new problems, though. Life as an amputee is never simple. My first problem was getting around campus with 40,000 students heading to class. My schedule was filled with 16 credits and I was trying to get from point A to point B. The Office of Disability Services gave me testing accommodation and priority scheduling. This allowed me some wiggle room. However, due to the size of PSU I opted to use my wheelchair; plus, it made things easier when I swam. I pretty much hit every door twice and got lost more times than Columbus discovering the New World. The handicapped entrances are either hidden behind buildings or in delivery entrances. I could easily see that accessibility was an afterthought, but the campus is changing.

I've also noticed features of buildings and roads that fail to take people with disabilities into consideration. For example, they placed a new pathway by the library, but instead of a nice steady incline, they put in stairs – the ramp was placed out of the way. It seems picky, but when you're in a rush it can hold you up. PSU has several rooms on campus with handicapped facilities, some with private bathrooms, but you have to hunt them down. Overall, I felt the campus was a C- rating for people with disabilities.

When my first classes started, I found my professors were very understanding and helpful. However, I overloaded my schedule. My personal advice is to never take more than 12 credits for your first major semester. Amputees need more of an adjustment period because it's a whole new animal. I was forced to drop a course because I had no hands, and keeping up with my work was too difficult. I found that easing my way in and establishing roots first would have helped me transition better.

My last words of wisdom comes down to one word: Perseverance. You will feel like you are drowning if you don't pace yourself. Surround yourself with good friends and become your own advocate. The true beauty of college is how you tame the beast. And like I always say, "Never turn down a late night conversation." 



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Back to Sc

Helping your child thrive in school after an amputation

by Karen Henry



When Laura Hittle starts third grade this fall, she says she doesn't need her mom to talk to her class about her amputation.

"The whole school knows me," the eight-year-old says. "Plus, our puppy ate the doll we used to demonstrate."

Laura was born with proximal focal femoral deficiency (PFFD) and fibular hemimelia – basically, a shorter than normal leg and a lot of missing bones. Her femur was too short to lengthen, so just after she turned four, her parents decided to have her leg amputated below the knee. She had a knee fusion to form a thigh two years later.

Every year since her amputation, Laura's mother Amy Hittle has visited her daughter's class on the first day of school to talk about it. "We talk about how we're all just a little bit different," Amy says. "Some people might have freckles, some might wear glasses, and some people might be in a wheelchair or need a hearing aid. And then we talk about how Laura was born with a little leg and that's why she has a prosthesis – so she can run and walk and do all the things a regular kid likes to do." Amy would also bring in the doll, which also had an amputation, and one of Laura's prosthetic legs to help answer questions.

For children with limb loss or limb difference, the excitement associated with starting a new school year may be replaced with heightened levels of fear and anxiety. Other kids will be curious. They might stare, point or ask questions. As a parent, not only is it important to prepare yourself and your child for questions that might come up, it's also important to prepare your child's school and classmates about what it means to have an amputation.

hool

Laura says she liked it when her mom talked to her classmates about her amputation because then she didn't have to answer any questions. She doesn't like talking about it, partly because she gets tired of being asked the same questions over and over again and partly because it's difficult for other kids to understand why she needed an amputation in the first place. One time, Laura got so frustrated with a little boy who kept asking her why she had a "robot leg," she ended up telling him a shark did it.

"I guess the story of 'I was born that way' isn't very exciting," Amy explains. "But when Laura told him the shark story, he said that was cool and didn't ask any more questions."

Laura has been at the same school for several years, so she's not as worried about the questions. She has a group of close friends, which also helps to alleviate her anxiety. "Now everyone knows Laura and her story, so it's not a big deal," her mother says.





Educating Classmates

When Andrew Seelhoff was seven years old, he was diagnosed with vascular malformation in his right leg. The pain in his calf was so severe, he couldn't walk. Within a year of his diagnosis, he was in a wheelchair. Despite numerous surgeries, the disease continued to progress. In June 2014, Andrew decided to have his right leg amputated above the knee. He was 13 years old.

Before his amputation, "we had a small assembly at my school to educate the kids and let them know that I'm still going to be me, just without a leg," Andrew says.

The assembly included a presentation from Travis Ricks, senior programs manager at the Challenged Athletes Foundation (CAF). When Ricks was 17, he was diagnosed with cancer. His right leg was amputated above the knee when he was 23. In addition to his work with CAF, he is a competitive athlete and has his sights set on competing in the 2016 Paralympics.

"He showed videos and brought his running leg and all the medals he has won since his amputation," Andrew's mother Mary Seelhoff recalls. "It was wonderful."

Andrew is starting 10th grade at a new school this year and has not decided if he wants to have another assembly. He has a group of close friends, and many of them are also going to the new school or are already students there. Besides, his mother explains, "I don't think he considers himself different anymore."

"The kids who have the most trouble are the ones who haven't had that education component at their schools," she continues. "Kids are afraid of what they don't understand. When kids don't know what's wrong, they get nervous. If you educate them, it takes all the mystery away. They find out it's no big deal."

If parents don't feel comfortable talking with the class, she suggests sending a letter to students in the same grade.

Andrew agrees. "Just educate the classroom," he says. "That's probably what helps the most."



Setting Priorities

It has been 10 years since Sean Brame lost both feet, his right hand, and all but two fingers on his left hand to sepsis. Like Laura and Andrew, Sean surrounded himself with a group of close friends, and his parents have always been strong advocates for him.

Sean is entering his sophomore year at Penn State and says he wants to pursue a mechanical engineering degree so he can design prosthetics.

Looking back at his primary and secondary school days, he says he put so much focus on learning to walk again and re-establishing his everyday habits that he didn't really think about taking the time to establish new study skills. While some of that is understandable, he advises other amputees to keep their priorities in line when it comes to school. "Because I didn't establish the best studying skills in high school, now that I'm in college, I'm scrambling," he says.

He encourages parents to educate themselves about school policies so they are prepared for things that might be necessary for their child, such as getting a medical order to request an aide. "I even had to get a medical order to wear shorts during the winter because the school said it was unfair to the other students," Sean recalls.

Although college is a challenge, he loves being on a big campus and says his study skills are improving every semester.

"I am where I am now because I work hard," he says. "Because of that, I've had more people and more professors look at me for me and not just as the 'the amputee,' or 'the kid with a back-story,'" something he says he struggled with in high school.

Over the years, he's also learned to stand up for himself. "You have to know when to speak up," he says. "If something isn't working right for you, say something. Never take 'no' for an answer." 🌀



Back to School

Parents With Amputation

If you have limb loss and you're the parent of a school-aged child, is it still necessary to educate your child's classmates about amputation?

ABSOLUTELY, says Peggy Chenoweth, who elected to have her left leg amputated below the knee in 2003, four years after a computer cart fell on her foot, crushing multiple bones and causing nerve damage.

At the beginning of every school year, Chenoweth wears long pants the first few times she drops off her son Robby. "I want him to make friends on his own merit and not be identified as the kid with the amputee mom," she says.

Once Robby's classmates see his mother's prosthetic leg, Chenoweth says he gets "bombarded" with questions. "Then I go to the school and talk to the kids about it. I try to answer all

of their questions up front so it's not an issue all year long."

Robby is going into 4th grade this year. When he was younger, Chenoweth says she struggled with how to tell the story about her foot. "I wanted the kids to know, but I didn't want them to be fearful, so I tried to put a positive spin on it."

Brian Conley knows firsthand that even when you think you're ready for every question or concern that might come up, there are some things you just can't anticipate.

Conley, who works as a school monitor at his daughter Jaeden's school, developed a severe bone infection in his

left foot in 2006. He spent five years trying to save his leg before electing to have it amputated below the knee in 2011. While Jaeden and her classmates had grown up seeing Conley in a leg brace or in a wheelchair and understood the relief the amputation would bring, the younger kids would need to be prepared.

"In Canada, we have the Terry Fox walk for cancer every September, so the teacher had been saying that I would have a prosthetic leg like Terry Fox. Just before the end of the school year, a parent told us that we had really upset her daughter. She wasn't upset about the amputation, she was upset because Terry Fox had died. We had never thought of it that way. Once we realized what her concerns were, we told her that I didn't have cancer and that once the doctor took away my leg, I was going to be better." 🌀



Peggy & Robby Chenoweth



Jaeden & Brian Conley

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The Ertl Bone Bridge

Reconstruction Pre-Prosthetic Fitting Protocol

by Janos P. Ertl, MD, Jason T. Kahle, MSMS, CPO, FAAOP, and M. Jason Highsmith, PhD, DPT, CP, FAAOP



Amputation and use of a prosthesis can provide near-normal functional outcomes for the person living with limb loss (amputee). The Ertl bone bridge procedure was introduced by my grandfather in the 1940s to maximize the functional outcome of people who must have an amputation. This procedure reconstructs an end-bearing bone bridge between the tibia and fibula in a below-knee amputation. This type of amputation provides a mechanical advantage over a traditional technique by preventing painful movement between the tibia and fibula while allowing the user to end-bear on the bottom of the residual limb. The final result is a more comfortable socket that better accommodates volume changes in the residual limb. Traditional amputation does not allow end-bearing.

There are many other features of a true Ertl bone bridge procedure that could potentially lead to

more comfortable socket fittings and improved outcomes compared to the alternatives. However, there is a misconception about problems that could arise from having this procedure. There is no scientific evidence to prove an Ertl bone bridge creates complications or an increased rehabilitation. While a bone bridge will take several months to fully heal, it will not delay a first (preparatory) prosthetic fitting compared to the traditional amputation technique. However, it is important to understand that there are fitting protocol guidelines that need to be followed to ensure the optimum outcome. Because the Ertl includes bone reconstruction, it requires mechanical loading, which is conducive to bone healing. When loading is applied, there is a greater chance that a healthy, stable bone bridge will develop. It is true that there is some special consideration when rehabilitating with an Ertl bone bridge; the following article establishes some of those general guidelines.

Amputation Rehabilitation Timeline

A typical Ertl bone bridge procedure will allow the first prosthetic fitting within 8-12 weeks.

First two weeks post-surgery

You may experience swelling and mild to moderate pain. These are normal in the healing process. The most important part of these first few weeks is protecting the surgical site. Patients must do their part to protect themselves. Most surgeons use a special dressing to protect the surgical site, and it is recommended to use some type of limb protection device, or early post-op prosthesis. Make sure you are properly trained on crutches or a walker. Position a chair next to your bed to remind yourself of your recent amputation if you awaken in the night and try to stand out of habit. Precautions are necessary to prevent falls.

Mental health is an important part of the healing process. Use this time to take an active role in your own rehabilitation; schedule physical therapy, research prosthetic options online and interview many prosthetists to find one with whom you feel a connection. The Amputee Coalition has many recommended resources, including the peer visitor program, *inMotion* magazine, their expansive Web site and prosthetistfinder.org. There are nearly 2 million people in the U.S. just like you. Find a support group in your area and use social media like Facebook to meet people and gain knowledge about living with limb loss. You are not alone.

Two to four weeks post-surgery

Your pain and swelling will have subsided and the stitches will be removed soon. The suture line will be showing good signs of healing, and drainage will be minimal. Begin gentle compression self-massaging. This can be on bare skin or over suture line dressing. Schedule physical therapy consultation to discuss your individual rehabilitation. You will require weekly visits for several months to provide the proper preparation, strength-training, range of motion and gait training exercises. Therapy is an important part of preparing your body to use a prosthesis during the rehabilitation process.

Four to six weeks post-surgery

Begin outpatient physical therapy to emphasize and assist you with key exercises and stretching, which will optimize your outcomes. Begin end-bearing exercises in standing when your surgeon gives the recommendation. These are unique to the Ertl bone bridge procedure and important to the bone healing process. Schedule a consultation with the prosthetist you have selected to begin the fitting process.

8-12 weeks post-surgery

Continue physical therapy to include stretching, muscle-strengthening exercises, end-bearing activities and prosthetic training. The first prosthetic fitting should begin around this time. It should be fit in conjunction with an ongoing physical therapy regimen. This first prosthesis is sometimes called a temporary prosthesis because your body will change over the next few months and will likely require another prosthetic socket or whole new prosthesis shortly.

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The Ertl Bone Bridge | continued



(Figure 1) Fold the towel in thirds lengthwise. Grasp each of the ends and push the stump into the towel as tolerated, and not to the point of pain. Hold pressure for 5 seconds. Release slowly and do not lose contact with your skin. Gradually increase the number of repetitions per session. 25 repetitions per session is a high goal to aim for.

Selected Exercises

These exercises can improve your muscle strength, weight-bearing function and desensitization of your residual limb to prepare you for prosthetic use. These particular exercises were selected because they may be used prior to prosthetic fitting and progressed after fitting. They are done in standing so they will facilitate your return to household activity while also improving muscle conditioning and balance.

1. Desensitizing the residual limb is important to preparing yourself for a prosthetic socket fitting. Massaging the residual limb manually with clean hands is an excellent start. From here, progressing to towel end-bearing exercises as tolerated is a logical progression (see Figure 1). Activities such as these should be done throughout the rehab process, starting around the second post-operative week, depending on your tolerance and under the advice of your healthcare providers.

2. Another progression includes placing a bathroom weight scale

on a stool and pressing the end of your residual limb onto the scale to the point that the pressure is uncomfortable, but not painful (see Figure 2). Use the weight number from the scale as feedback to determine how much weight you can tolerate. Try and increase the weight-bearing as you heal and move toward your prosthetic fitting.

3. Sit-to-stand (STS) exercise is a great exercise to concentrate on bilateral weight-bearing, leg muscle strength, core strength, balance and coordination (see Figure 3). Sit in a sturdy chair that will not slip on the floor. Ideally, the chair should include hand rests in case of fatigue or loss of balance. Also, it is ideal if the chair positions the hip and knees at or close to 90 degrees. Early on, it may be helpful to support sitting and standing while using hands for support. As you heal and gain strength and confidence, try using the hands less and the amputated limb more as you sit and stand. STS can be done prior to prosthetic fitting and can be continued after prosthetic fitting.



(Figure 2) **DO NOT DO THIS EXERCISE IF YOU ARE UNSURE IF YOU HAVE AN ERTL PROCEDURE.** It is important to feel the pressure under the tibia (the larger main bone in front of the leg under the knee cap). Do bear weight under the fibula (the smaller bone on the outside of your leg). Too much end-bearing to the degree of pain could cause injury and delay your progress. The amount of weight exerted should not exceed 50 percent of your weight prior to fitting. Use a towel for padding. You may do this exercise with the dressing on or off.

4. Single-limb standing (SLS) is an important exercise for walking because walking involves alternating periods of single-limb balance (see Figure 4). Begin by holding onto something (e.g., chair back, hand rail). Try to hold a standing position for 30 seconds. Slowly work up to a minute if possible. This version can be done prior to prosthetic fitting. After fitting, it is



(Figure 3) Try beginning with 5 sit-to-stand repetitions and work toward completing as many as you can in 30 seconds with less hand support. As you depend less on your hands, try crossing your arms across your chest during the movement.

possible to switch sides and engage the amputated limb. As your balance and core stability improves, place less force through the hands and eventually remove the hand opposite the stance leg. Eventually, you may be able to balance without using the hands at all. It is, however, recommended to always keep your hands close to a support surface in the event that you lose your balance.



For more information, you can contact Dr. Ertl's office and staff at 317/688-5189 or mhowell3@iuhealth.org.

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The Ertl Bone Bridge | continued



(Figure 4) Try to hold a standing position for 30 seconds. Slowly work up to a minute if possible.



(Figure 5) Each stretch should be held approximately 30 seconds with a 30-second rest in between.



(Figure 6) Never allow your leg to hang down. Keep your amputated leg in full extension during periods of rest at all times.

5. Wall squatting is an excellent exercise to strengthen the lower-limb extensor muscles and to improve weight-bearing through the amputated limb. Stand with your back to the wall. Your feet should not be against the wall, but about one foot's length from the wall (as comfortable and stable). Keeping contact between your back and the wall, slowly squat down. Early on, it is not necessary to squat to a deep knee bend – a mini-squat is sufficient. This particular version is done after prosthetic fitting. However, single-limb squats can be done under supervision prior to fitting as well.

Range of Motion – Stretching

You do not want your joints to get stiff while you are healing, so stretching is important. Tight muscles will be uncomfortable and limit the quality and efficiency of your walking. Current recommendations are to warm up with gentle strengthening and conclude an exercise session by stretching warm muscles.

1. Lying prone – pressing. Lie face-down (prone) on the floor or another stiff surface (see Figure 5). Some people may not be able to achieve a fully prone position due to hip flexor tightness. For these people, turn the body slightly toward the tight side to accommodate the tightness and lean body weight into the tight

side to achieve a stretch. For those who can lie completely prone on the chest, slowly and gently move from lying face-down to raising up onto the elbows. This puts a slight stretch on the abdominals and the hip flexor muscles (the muscles in the front of the hips). As tolerated, progress from raising up on elbows to raising up on hands with elbows flexed. Eventually, you can extend the elbows.

2. Seated toe touch. Sit on the floor with the knees straight (see Figure 6). The back should be fully upright (not slouched). Slowly reach forward, bringing fingers toward toes. Many people will be unable to touch fingers to toes without bending the knees. The goal is to keep the knees straight

and reach as far toward the toes as possible. Once a stretch is felt in the hamstrings, it is not necessary to reach further; hold that position, relax and breathe for approximately 30 seconds. Sit back, relax the arms and rest for 30 seconds, repeat the stretch and attempt to reach slightly further each time.

Nutrition

Be conscious of your dietary choices throughout the rehabilitation process. Sound nutrition is essential to healing. Drink plenty of water – about half your body weight, in ounces (e.g., if you weigh 180 pounds, drink 90 ounces a day). Over 70 percent of your brain, muscles and blood is water; bones are 25 percent water. Water is a vital element to healthy living. Eat healthy – the more raw, non-processed fruits and vegetables, the better. Watch your calorie count – lower body fat will help improve balance, stamina and strength. Rehabilitation, physical and mental health will likely be improved with a healthy lifestyle. Speak with your physician about vitamin and mineral supplements in addition to healthy dietary decisions. This is especially important after any surgery.

Conclusion

These are general guidelines for the Ertl bone bridge procedure; if you do not understand them or experience pain, please contact your physician immediately. The Ertl bone bridge surgery is a highly specialized amputation surgery procedure, and the associated prosthetic rehabilitation process is also specialized. If you, a family member or a friend are considering an amputation or a revision amputation, talk to your local surgeon and prosthetist regarding their experience with this type of procedure and prosthetic fitting. It can be a successful rehabilitation with a qualified surgeon and prosthetist if you are healthy and in good physical and mental condition. The Ertl bone bridge technique does not scientifically report an increase in surgical complications and can provide a mechanical advantage to the prosthetic user by reconstructing a weight-bearing surface. This could lead to a more comfortable prosthetic fit and improved function. A fast, successful rehabilitation is an expected outcome from this life-changing procedure. 🌀

The views expressed in this article are not the opinion of the U.S. Department of Veterans Affairs.

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Osseointegration Moves Forward

FDA approves the procedure in the U.S.

by Carolyn Cosmos

By 2013, Fred Hernandez had seen his life turn around twice – and he’s at it again. As a teen, he was extracted from a car crumpled under an 18-wheel truck and pronounced dead at a California hospital.

Even with severe burns, multiple broken bones, a punctured lung and hip trauma, Hernandez survived – although, with his right leg amputated above the knee and his left badly damaged, he was told he wouldn’t walk again.

But he defied that prediction. With the help of a brace and a prosthesis, Hernandez resumed his walking as well as his life. He matter-of-factly describes his gait as “slow, painful, uneven,” and jokes, “I don’t jump.”

In spite of chronic pain and prosthesis problems, Hernandez worked in law enforcement, ran his own business and dedicated himself to a number of nonprofits. “I’m very action-oriented,” he says.

In 2013, his life turned around a second time when an “amazing technology ... changed everything about walking on a prosthesis.”

He became the first American to benefit from a bone-anchored leg prosthesis, but he had to travel to Australia to get one – a surgically implanted titanium device that grows into bone, protrudes through the skin and can be attached to an artificial limb.

The process, called osseointegration (OI) and familiar through dental implants, was not approved for amputees in the United States – until now.

Effective July 16 this year, the U.S. Food and Drug Administration (FDA) authorized U.S. use of a Swedish prosthetic osseointegration implant system, called OPRA for short.



“I can feel gravel if I walk on it now. Carpet, tile: I feel the difference.”



The post at the end of the implant allows a prosthesis to be attached or removed in a matter of seconds.

“This is a great step forward and long overdue,” Hernandez says.

OPRA grew out of dental implant technology and features two surgery-based stages that can take 18 months to implement. Developed under Dr. Per-Ingvar Brånemark, it’s produced by Integrum, a Swedish company with research partners that include the Walter Reed National Military Medical Center in Maryland.

Another major system, the Australian OPL, is, in contrast, single-stage, was developed from hip replacement technology, and remains unavailable in the U.S.

“Today [we] authorized use of the first prosthesis marketed in the U.S. for adults who have amputations above the knee and who have rehabilitation problems with, or cannot use, a conventional socket prosthesis,” the FDA said in July.

“The Osseanchored Prostheses for the Rehabilitation of Amputees (OPRA) ... uses fixtures and screws implanted into the patient’s remaining thigh bone to connect an external prosthetic limb.” After a second surgery, the amputee works for months with a physical therapist to gradually bear weight on the limb before fitting a final prosthesis.

Only the patient and disciplined need apply.

Troy Turner, MBA, chair of the research subcommittee of the Amputee Coalition’s Scientific and Medical Advisory Committee, praised the FDA action.

“It opens the door for above-knee amputees to consider direct-skeletal attachment,” Turner says. This “will eventually lead to increasingly robust solutions for amputees, and even advanced direct neural control of prosthetic devices. It won’t be the solution for everyone, but it is one more tool we can use to try and improve an individual’s quality of life,” he adds.

Along with the potential advantages of OI, there are possible challenges as well, including the risk of infection, fractures with falls, and loosening of the implant.

Aware of its drawbacks, Hernandez is passionate about its benefits: No sitting discomfort. No socket issues ever again. As for infection risk, he compares it to body piercing, such as for an earring.

Fracture risks are mitigated by safety adapters and systems are improving, he adds: “Patients with OPL implants are jumping out of airplanes.”

Most striking, Hernandez explains that bone has nerve reception and an implant offers “osseoperception.” “I can feel gravel if I walk on it now. Carpet, tile: I feel the difference.”

About 20 American amputees have OI implants from medical teams in Sweden, Australia and Germany, he says, but osseointegration will be a viable option for more. He points to other OI systems in the pipeline, including the one-stage OPL tech of his own Australian implant, as well as device developments at the University of Utah that feature a novel titanium coating.

Fred now sees his future as that of an educator and contractor, an OI exemplar and an amputee advocate – the third revolution in his life. 🌀

Related Resources

Associated Brånemark Osseointegration Centers
branemark.com

Brånemark Osseointegration Center
wipp.se/komplett/possible

Direct Skeletal Prosthesis – Osseointegration
amputeeimplantdevices.com

Integrum
integrum.se



by Harleen Chhabra Gupt

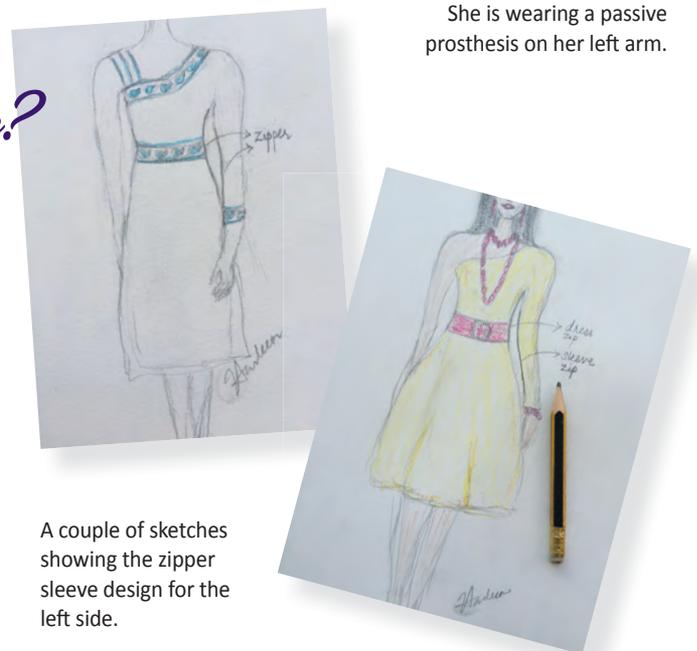
Playing Dress-Up

Harleen in one of her favorite ensembles in the zipper one-sleeve design. She is wearing a passive prosthesis on her left arm.

Who doesn't like to play dress-up?

I loved dressing up as a little girl, and still do. However, most of us know that finding the right dress for the right occasion, and which accommodates our prosthesis or our residual limb (if we do not choose to show it), is no easy feat.

After years of practice and many tweaks, I have developed some styles that suit most of my needs as an upper-limb amputee. Allow me to begin by sharing my favorite design with you. I hope to share more in future columns and hear from you as you read through and perhaps try these out for yourself. 🌀



A couple of sketches showing the zipper sleeve design for the left side.

The Zipper Sleeve Design Key Features:

- Large armhole and bigger sleeve on one side to accommodate the socket of the prosthesis
- Hidden zipper sleeve on the inside seam
- Zipper can be attached to full length or 3/4th long sleeve
- Zipper can be attached on either or both sleeves

This design is versatile and is suitable for short tops, knee-length dresses and even long, mellifluous gowns. I used it for my two-piece traditional Indian wedding dress shown here.

The best part is that if the party is taking too long, you can easily unzip the sleeve on your own and slip out of the prosthesis without having to remove anything, leaving your makeup and hair intact!

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Amputation: *A Caregiver's Point of View*

by Christine Volker

I remember that I could see from his pale face that my husband was shocked to hear the doctor tell us that the next logical step on this lifelong journey of saving my failing left foot was to actually *stop* trying to save it and amputate below the knee. Now, two years later, I wanted to know what it was that helped him cope as my caregiver, and if he had any words of wisdom to other spouses, family members or caregivers of new or pending amputees. These are my husband's thoughts, based on my interview with him:

"My first response was fear. Would you be OK? Would you be completely dependent on me? And then I was afraid of what the emotional toil would do to our relationship. I wasn't sure we were ready for such a huge challenge. I was in denial up to and even several days after the amputation. We both knew the physical aspects of the surgery – well, pretty much – but we weren't ready, I think, for the *reality* of it all. It's a change.

"I watched you walk into the hospital, saw your uncertainty and that scared me, knowing I had to be strong and encouraging. I was also angry at first. It was hard, dealing with insurance, hospital forms and even dealing with family members, all asking really tough questions. I just wanted it over. When it was completed about two hours later, they just told me to go up to your room and there you were. I wasn't ready for that; I didn't know what to expect to see.

"I wish we had known more about the whole hospital part, like what types of medications they were going to give and when the physical therapist would start (*Chrissy: The PT spoke to me about important exercises while I was heavily medicated, but my husband wasn't there to write it down or ask questions*). They sent you home the next day and man, that was tough. Three days in, I'd reached the lowest point with this process. I hadn't slept or eaten. I was constantly worried. I had to track several medications, help you to the bathroom, and help you through some really long nights of pain and being ill from medication side effects.

"It was emotionally draining, seeing you suffering. There was a point where the pain wasn't managed and I had no idea who to call. It was the middle of the weekend in the late evening. The discharge papers said nothing about it so I had to figure out what to do.

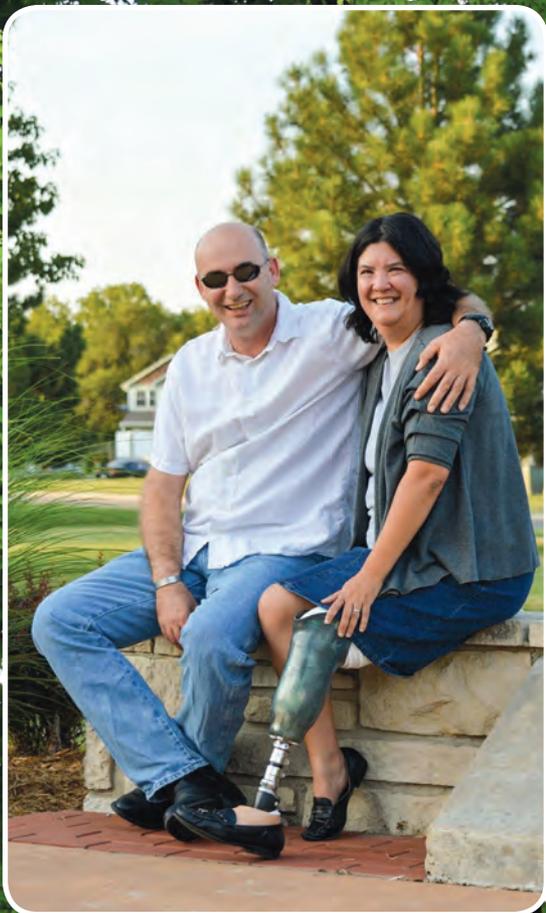
"If I could go back in time, I'd say I'd prepare better. But you don't know what you don't know until you're in the middle of it. What do you do if you can't tolerate the medicine? What if it's no longer helping to manage pain? Could I have help figuring out a medication schedule? What does an infection look like, and what do you do about it? It was hard. Exhausting. A few weeks of rehab or home nursing care would have been great. Finally, a friend came over and helped you out and I was able to sleep.

"After a couple of weeks, I realized one day we were OK. I took you out of the house even though you were scared to. I stayed with you, encouraged you to interact with people. We tried to get back into a normal routine. It was a relief seeing you trying to find different ways to do normal stuff. I realized the amputation was the best decision when I saw you get up on the leg for the first time and immediately walk better on it



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- Submit your question through the “Ask an Information Specialist” form on our Web site (amputee-coalition.org/forms/nllicask).

with a walker than you ever had on the foot. Two months after amputation, I deployed for nine months. When I got home, you were walking – even running. I knew we’d be just fine then, seeing you look so happy, confident. My best advice for caregivers: Take care of yourself. Stay strong. Be patient, and give it time.”

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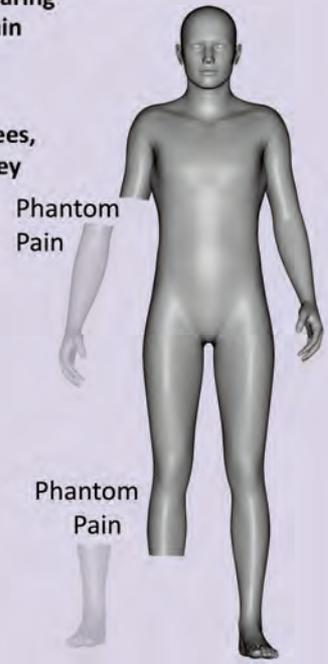
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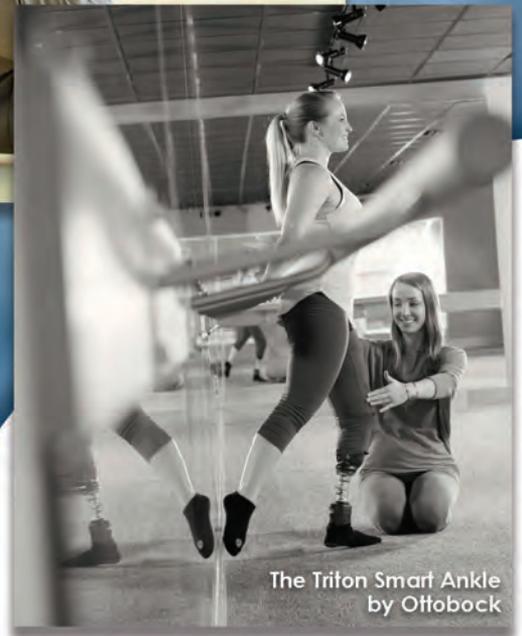
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