Surviving the First Year

Amputee Coalition Celebrates 25th Anniversary in 2011

Ashley Johnston from NBC's The Biggest Loser
As a prosthetic technician and amputee, I’ve tried a lot of different feet. Re-Flex Rotate is the lightest-feeling foot with shock absorption and rotation that I have ever worn. It’s smooth and comfortable, whatever the activity.”

— Kenny Buford, 41
Amputee Coalition Commemorates 25 Years of Service to the Limb Loss Community in 2011 (1986-2011)

This year, the Amputee Coalition proudly commemorates 25 years of service to the limb loss community. Even more importantly, we are dedicated to making our next 25 years even more beneficial to the people we serve.

To begin with, we spent 2010 learning about the needs and desires of our constituency, from our constituency. We know that if we want to better serve people at risk for or affected by limb loss, we need their input.

As a result, we recently developed a revitalized set of proactive brand principles to better reflect our enhanced plans for serving our constituency. Our new logo (see below), effectively symbolizes these new brand principles.

The logo’s main element, a swirling sun, reflects our goals to reach out to people at risk for or affected by limb loss and to significantly impact their lives throughout their lifespan to help them achieve their maximum potential. It also signifies that we will strive to “be there” for them every step of the way. We will first strive to prevent the loss of limbs and then follow up with those who do lose limbs to help them rebuild their lives. We will accomplish these goals through excellent service and high-quality professional programs.

Just as the sun is the main star in our universe, the Amputee Coalition strives to be the main organization in the lives of people at risk for or affected by limb loss. Like the sun, the Amputee Coalition:

- Provides a source of light to our constituents by supplying them with reliable information
- Is a source of energy and comfort during cold, difficult periods in their lives
- Helps them find their direction when they are lost
- Actively impacts their lives in many ways
- Is there for them every day throughout their lifespan — even when they don’t know it.

(For more details, see “The Amputee Coalition Logo: What Does It Symbolize?” at amputee-coalition.org/NewLogo)

“Our new, proactive brand principles will guide us in all of our interactions with our constituents in the future,” says Kendra Calhoun, Amputee Coalition president & CEO. “We will alter or develop our numerous programs and services with the goals of proactively reaching out to our constituents, following up with them, and making a significant impact in their lives. Our five core values of Service, Respect, Encouragement, Excellence and Integrity, driven by our Passion, will also inform everything that we do.”

In fact, the Amputee Coalition’s new, proactive brand principles are already impacting the direction of the organization. See page 9 to learn about one of our exciting new efforts to meet the needs of our constituents. Throughout the year, we will also be announcing several special events and other significant changes in our programs and services (see page 8).

As we evolve throughout 2011 to meet more of your needs, we definitely don’t want you to miss any of our exciting announcements and offers. It is, therefore, essential that we have your contact information, especially your e-mail address. If we don’t already have this information, please visit amputee-coalition.org/friends-update and give it to us today. Also, visit our Web site at amputee-coalition.org regularly throughout the year to stay informed.

Don’t forget: We’re here for you — even when you don’t know it!
What will our son’s life be like? Can he overcome this?

“When Connor was born without his leg, we had so many questions, so many worries about our little boy. But it didn’t take long for us to realize he was literally unstoppable. With the help of people we met at Hanger, our family found hope. They understood what we were facing and had the expertise to give Connor a future as bright as any child’s. Their confident, reassuring approach helped us stop seeing our son’s limitations, and start seeing him for what he was—a normal little boy. Thanks to their caring service and amazing technology, constant worry gave way to lasting joy.”

— Colleen & Michael Karow

Seven-year-old Connor Karow exemplifies the true spirit of independence. Each morning he puts on his own prosthesis and wears it all day. He loves to play with his brother Ryan, and when faced with a new challenge, he finds a way to adapt. His quick smile, curious mind and natural ability to put people at ease are all part of what make Connor special.

Our Patients Never Fail to Inspire Us. With our national network of offices, unsurpassed clinical expertise, advanced technologies and dynamic peer advocacy program, Hanger is the leader in prosthetic and orthotic care. But what satisfies us most are stories like Connor’s.

Moving Lives Forward
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Discover our inspiration. Visit Hanger.com to read stories of amazing people moving their lives forward every day.
Our Mission
To reach out to and empower people affected by limb loss to achieve their full potential through education, support and advocacy, and to promote limb loss prevention.
Contributors

Cindy Charlton is a triple amputee, a single mom of two boys, a substitute teacher, a certified child and family investigator and an author. She is active in her children’s sports and different nonprofit organizations. A member of the Colorado Coalition of Working Amputees, she helped pass Colorado’s Prosthetic Parity Bill in 2000. An Amputee Coalition-certified peer counselor, she helps people adjust to living with limb loss.

Dan Conyers, CPO, national clinical director, supervises a nationwide team of prosthetists at Advanced Arm Dynamics’ Centers of Excellence. Conyers has more than 28 years of experience in prosthetics and orthotics and has been an upper-extremity specialist for 16 years. He is involved in international research and development projects, design consulting, and beta testing with scientific groups, component manufacturers and individual researchers.

Scott D. Cummings, PT, CPO, FAAOP, is employed by Next Step O&P in Manchester, New Hampshire. He received a BS in Physical Therapy from Northeastern University before completing his orthotic and prosthetic education at the University of California, Los Angeles (UCLA). Although a general practitioner in O&P, he specializes in pediatric and geriatric prosthetics and pediatric orthotics with an emphasis in scoliosis management. He is a member of the Amputee Coalition’s Medical Advisory Committee.

Dawn M. Ehde, PhD, is a clinical psychologist and professor in the Department of Rehabilitation Medicine at the University of Washington School of Medicine, Seattle. For the past 14 years, she has provided care to people with limb loss at Harborview Medical Center. She has conducted chronic pain treatment research in several populations, including amputees. She also collaborated with the Amputee Coalition and Johns Hopkins University on the Promoting Amputee Life Skills (PALS) program.

James Highsmith, MD, MS, practiced as a physician assistant in dermatology at James A. Haley VA Hospital (Tampa, Florida) prior to medical school. Currently, he is a resident physician at the University of South Florida.

M. Jason Highsmith, DPT, CP, FAAOP, is a physical therapist and certified prosthetist. He is an assistant professor in the School of Physical Therapy & Rehabilitation Sciences at the University of South Florida.

Jason T. Kahle CPO, LPO, is a certified and licensed prosthetist/orthotist. He is the director of lower-extremity prosthetics at Westcoast Brace & Limb and Faculty in the School of Physical Therapy & Rehabilitation Sciences at the University of South Florida in Tampa, Florida.

Shawn Swanson Johnson, OTR/L, joined Advanced Arm Dynamics (AAD) in 2009 as national director of occupational therapy. Her work is focused on enhancing training protocols for patients in the use of upper-limb prosthetics. Johnson has more than 10 years of experience in prosthetic therapy, including work with the rehabilitation teams at Walter Reed Army Medical Center and Brooke Army Medical Center.

Todd Norton, CP, LP, FAAOP, graduated from Florida State University with a BS Degree in Rehabilitation Services. Upon completion of his internship at Bremer Brace of Florida, Inc., he was hired as a prosthetic assistant. Norton then attended Northwestern University’s prosthetic program in 1995.

Patrick Prigge, CP, is the clinical manager of Advanced Arm Dynamics’ (AAD’s) Midwest Center of Excellence in Waterloo, Iowa, and the North Central Center of Excellence in Minneapolis, Minnesota. He has been an upper-limb specialist with AAD since 2008.

John Peter Seaman, CP, CTR, spent 30 years in the forestry and paperboard packaging industries. He chose to make a career change and attended Century College in White Bear Lake, Minnesota, to become a prosthetist. After completing his residency in 2009, he passed his certification exams and moved to Newark, Delaware, where he is now employed by Independence Prosthetics-Orthotics, Inc.

Sarah J. Sullivan, PhD, is a postdoctoral fellow in the Department of Rehabilitation Medicine at the University of Washington School of Medicine, Seattle. She received her PhD in Clinical Psychology from the University of California, Los Angeles (UCLA) and completed her clinical internship at UW. She has worked with individuals coping with a variety of health conditions, including chronic pain and cancer.

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About the Cover

Design by Michael Shannon
Photo by Bill Waldorf
We were with John. Every step of his way.

JOHN KENNEY, BOCO

John is one of the many BOC-certified practitioners making a difference to their patients and their profession every day.

Background: Bachelor’s degree from The University of California, Santa Cruz. Master’s degree from The University of Hawaii. More than 20 years as a healthcare executive.

Achievements: Holds seven U.S. patents for orthotic devices that have benefited ten of thousands of patients.

Impact: In 2010, more than 1,000 practitioners attended John’s educational courses on contracture management and rehabilitating knee braces.

Service: Past Chairman of the Region D Medicare Advisory Committee; member of the BOC Board of Directors.

“I would not be a practicing clinician and Vice President of Ongoing Care Solutions/NeuroFlex if it were not for BOC. The next few years will be critical for O&P, and I am excited about BOC’s expanding role in the O&P community.”

BOC is proud to have walked alongside John in his career.

We are here to support you in your journey, too.
MESSAGE FROM THE CHAIR

This year – 2011 – the Amputee Coalition reaches its 25th anniversary, and, with this first issue of inMotion during this anniversary year, we will both begin the celebration of our past and look forward to our future. Anniversaries not only represent milestones and celebration of achievements, but also thresholds to be crossed – thresholds of new possibilities, new challenges and greater successes. We have much to celebrate and to look forward to as we continue the pursuit of our key aims in our 2015 Strategic Plan – Awareness, Impact, Mission and Sustainability – on behalf of the limb loss community.

In 25 years, the Amputee Coalition has become and remained the leading support and advocacy organization for people affected by limb loss. We aim to celebrate this achievement with an important symbolic act, the designation of April as “Limb Loss Awareness Month,” both at the federal level and in as many states with gubernatorial proclamations as we can achieve. Over these 25 years, through our nationally recognized Limb Loss Information Center, Peer Visitor Program, our excellent publications, including inMotion, and our new media outreach, we have succeeded in raising public AWARENESS of our work and of the contributions our constituents make to improve the lives of people affected by limb loss, including their caregivers and their communities.

We will celebrate our 25th anniversary at our 2011 National Conference, which we hope to be our biggest and best conference yet, bringing new amputees and their caregivers to learn about the newest innovations in prosthetic devices, the challenges and inspirations of living life to the fullest as an amputee, and the medical, social and psychological resources available to achieve these goals. The National Conference has always been perceived by its attendees as an event with great IMPACT on their lives as amputees. Through our new Bridge to Ability Fund – founded in this past year and funded by our national sponsors – we are expecting to impact more new amputees by providing scholarships to the conference to those who may not have the means to attend.

We will also celebrate our 25th anniversary by honoring today’s and yesterday’s war fighters who have lost limbs defending America. We are inspired by their courage and achievements, and we have resolved to address their special needs and to increase the Amputee Coalition’s impact on their path to reintegration into civilian life or continuing participation in the military. To this end, we are especially pleased to have received a grant from the Veterans Administration to develop a special program to train peer visitors for the caregivers of amputee veterans, and we are developing a military advisory group to guide our increasing impact on this special constituency.

As exciting and rewarding as the celebrations will be, we are equally focused on the thresholds we are crossing during this 25th anniversary year and the opportunities they present. As you will learn in this issue of inMotion (page 9) and through other communications from the Amputee Coalition, we are making a major change in our outreach model – changing from a dues-paying membership organization to a constituency-based organization reaching out to our much broader community of people affected by limb loss, their caregivers, support groups and the communities in which they live. Anyone who has visited our Web site, who has expressed an interest in our publications, who has reached out to our call center for help or advice, or who has otherwise shared their contact information with us will now be considered a “friend” or “constituent” and will receive our communications without the burden of a membership fee. We will continue to have professional memberships and will be working to advance our professional program through providing continuing education, our peer visitor clinics, and patient education materials to our professional members.

The thresholds we are crossing are both the size of the constituency we can reach with our message and the technology that makes this possible. The Amputee Coalition will continue its print publications, including our inMotion magazine, but will supplement them with electronic media products. The challenge of the new constituency model will be to SUSTAIN our programs by reaching out to our expanded constituency and seeking their support. We are excited by both the challenge and the potential of increasing our philanthropic footprint.

Of course, every threshold is crossed in a particular context, and we are aware of the challenges presented by the present economic conditions we now face as a nation and as individual citizens. We are confident, however, that as we mature as an organization and as we nurture our expanded constituency, you will be there with your support. So stay with us, grow with us, and together we will create more awareness, we will have more impact and we will sustain the Amputee Coalition’s MISSION for the next 25 years.

Happy New Year.
The Power of One, Community of Many…Expanded

Our goal for 2011 is to grow to 25,000-people strong! To celebrate our 25th anniversary, the Amputee Coalition will launch a historic organizational change by moving from a traditional fee-based membership model to an open community “Friends” organization for people with limb loss, their families and support groups across the country. We want you to be part of this growth and ask that you visit our Web site and update your e-mail and contact information so that we can provide you with the new features and benefits of being a Friend of the Amputee Coalition.

This new “Friends” model will enable us to reach more people and provide more services to all people with limb loss when they need them most, without the barrier of a membership fee. In the coming months you will see many changes in our Web site, materials, our colors and logo, but be assured that you will receive the same high-quality service and resources that you have come to know and trust.

All individuals and their families will automatically become Friends of the Amputee Coalition. This change will provide you and your family with the following resources and benefits.

- More opportunities to meet and network with other people who have experienced limb loss through local and regional events and activities
- A stronger voice and larger influence on all levels within the limb loss community, on Capitol Hill, with federal agencies, collaborators and other national organizations to protect your rights and fight for fair access to quality care
- More opportunities to become involved and give back to the community through an expanded Community Volunteer Program open to all Friends
- Comfort in knowing that you have a lifelong relationship with a national organization that is there for you when you need it to help and support your life goals.

Will I lose any of my benefits if I am a current paid member?
No. You will still receive the discount to the conference and print copies of inMotion. However, you may elect to help save resources and the environment by “going green” now and choosing to receive future issues of inMotion electronically.

How will this change affect support groups?
All support groups, large and small, will be part of the Support Group Network and will be listed on our Web site with full contact information. We will work closely with each group to ensure they have what they need to serve the local limb loss community in their areas.

Does this change affect professional and facility memberships?
No. Our professional community support will continue with professional and facility members.

We hope that these healthcare providers and companies will collaborate with us to ensure that all new patients leave their office with Amputee Coalition information in hand.

This new initiative will provide help and support through the process of rehabilitation and beyond. It will strengthen our community, provide you with more options for resources, and expand the reach of our programs and services to those who need them most. Please visit our Web site at amputee-coalition.org/friends-update to register your e-mail address for benefits and for more information and regular updates on our 2011 events and opportunities. For more information, you may also call toll-free 888/267-5669.
Gearing Up for an Active 2011

Groundwork Laid for Action on State and Federal Initiatives
Over the past 4 months, the Amputee Coalition’s Government Relations Department has prepared for major activity on the 2011 legislative front: state and federal prosthetic parity bill introduction; gubernatorial proclamations to declare April as Limb Loss Awareness Month in all 50 states; and training key advocates for the Amputee Action Network to lead their state’s activities.

Mobilizing Grassroots Support of Parity in State Legislatures
In fall 2010, the Amputee Coalition held organizing meetings to mobilize grassroots support in a number of states where prosthetic parity bills are expected to be introduced. With the help of support groups, O&P societies and enthusiastic advocates, these meetings resulted in strategic planning for 2011. Through live and virtual meetings, the Amputee Coalition’s government relations coordinator, Dan Ignaszewski, spoke to advocates and volunteers about what it takes to get a parity bill through the legislature.

Seven organizing meetings have been held, to date: Delaware, Minnesota, Nebraska, Pennsylvania, South Carolina, Tennessee and Wisconsin. The following states have organizing activities and we hope to see bills introduced: Arizona, Georgia, Kansas, Kentucky, North Carolina and Washington.

Florida Is the First State to Introduce Prosthetic Parity Legislation for 2011
As a direct result of grassroots support and Amputee Action Network efforts in Florida led by Bill Moses, the Amputee Coalition’s Lead Advocate in that state, a parity bill, HB 5, has already been introduced. Rep. Joseph Gibbon’s (D-105) bill would ensure the Florida limb loss community has access to prosthetics.

Federal Parity Legislation in the U.S. Congress
The 2010 midterm elections resulted in a major change in the composition of the U.S. Congress. Although federal prosthetic parity bills were introduced in the House and Senate last year, the healthcare reform bill (Patient Protection and Affordability Care Act – PPACA) took front and center stage.

Inaugural Class of the First Amputee Action Network Completes Training
In fall 2010, the Government Relations Department trained amputees designated as the Amputee Coalition’s Lead Advocates in their respective states. These activists learned the basics of how to pass a parity bill, how to garner and maintain grassroots support, the pros and cons of hiring a lobbyist, setting up advocacy funds, recording support group and volunteer hours and working with the media. This group is excited, and they are currently mobilizing as the legislatures begin.

We need your help and support in 2011! To learn what you can do to advocate for prosthetic parity and gubernatorial proclamations in your state, contact Amputee Coalition Government Relations Coordinator Dan Ignaszewski at 202/742-1885 or dan@amputee-coalition.org.
“...BUT SUPERHEROES FLY”

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Ashley Johnston, second-place finisher on the ninth season of NBC's *The Biggest Loser*, has a fond memory of the show's season finale. Standing behind a life-size poster of herself at her starting weight of 374 pounds, seconds before she burst through it to reveal her slimmed down figure to a national TV audience, she was struck by a profound self-realization.

"I am strong; I did this," she recalls thinking. "I am the girl who fell off the treadmill, who puked throughout the entire season, and I am standing here 187 pounds lighter. And for the first time in my life, I am completely happy with who I am. Coming to that realization was my best moment on the show – probably one of the best moments of my whole life."

**Worried About Survival**

For the 28-year-old Tennessean, reaching that milestone was a matter of life and death. Like many people, Ashley put on pounds over time, rationalizing away the weight gain and failing to recognize her addiction to food.

"I woke up one day weighing 374 pounds, and I said, 'How did this happen?'" she remembers. "On one hand, I was very aware of my life. I knew what I was doing. But on the other, I was doing it subconsciously."

At that size, Ashley couldn't buckle a car seatbelt. She suffered severe sleep apnea and feared she might go to bed one night and never get up. She finally accepted that her life depended on shedding weight.

"It wasn't about missing out on fun things; I was worried about my survival," she says.

The young esthetician – a self-described “party girl” – knew she ate and drank too much, but dieting never worked, despite trying “everything out there possible.” With her health – and perhaps her life – on the line, Ashley was ready to take extreme measures to confront the insecurities that led to her overeating. So she and her mother, Sherry, tried out for *The Biggest Loser,*
in which teams compete to lose the most weight, both individually and as a group, under the care and guidance of a team of no-nonsense professionals on an isolated ranch.

Revelations
The Johnstons were not initially selected but were invited back later. The rest, as Ashley puts it, “America knows. There’s nothing unrevealed now. I left it all on the ranch.”

Sherry was eliminated midway through the season (she continued to lose weight, going from 218 pounds to 138), but Ashley made it to the end, shedding 187 pounds (49.83 percent of her body weight), more weight than any other female contestant to that point.

The winner, Michael Ventrella, trimmed 264 pounds, or 50.19 percent of his body weight.

Although there may be nothing unrevealed now, something was revealed to Ashley at the season’s start: She had diabetes. Her father struggled with diabetes in his later years, but Ashley had never been diagnosed with it, despite her obesity. The news was shocking. When she learned that diabetes was reversible with weight loss, she was even more determined to drop the pounds.

“I don’t want to have the struggles my dad had,” Ashley says. “And I didn’t want to take any more years off my life than I already had – I was 27, and they told me I had the inner body of a 57-year-old. After that, I monitored my blood sugar, and as I lost weight, I actually got to see me healing myself of diabetes. I felt almost lucky to have something wrong with me that I could fix, not with drugs, not with surgery, but with changing my lifestyle.”

The Mental Battle
Ashley now gives talks on her experiences. While many want to know her diet secrets, she says that shouldn’t be the focus.

“Everybody wants to know, ‘What do you eat?’ I understand that,” she explains. “It’s simple: You count your calories (she generally eats 1,200-1,400 calories per day), you eat a well-balanced diet and you exercise – but ‘simple’ is not easy, because it’s a mental battle. It’s about a lifestyle change and figuring out how you got to the weight you are.”

She attributes her lack of success dieting over the years to not confronting the underlying reasons for her eating addiction. She had never fully faced painful experiences, such as her father’s death from cancer when she was a teenager. Rather than face stressful subjects, Ashley would “stuff them,” or eat to repress them, just as those addicted to nicotine...
And for the first time in my life, I am completely happy with who I am. Coming to that realization was my best moment on the show – probably one of the best moments of my whole life.

Healthy responses to stress allowed Ashley to combat her addiction and transform her life.

“When I’m stressed out, all I want to do still is eat a carb,” she observes. “But now I find different ways to release that stress. Instead of eating, I’m working out – I take a great kickboxing class – and I feel even better when I’m done.”

The Hardest Test
Ashley acknowledges that she was fortunate to have the assistance and guidance of physicians, psychologists and trainers on The Biggest Loser. Yet, since leaving the show, she’s kept the weight off. She did it by simplifying her life (she calls it “decompressing”).

“I’m grateful for being on the ranch, where my job was to heal myself, but you still have to figure out how to decompress your life when you get home,” she explains. “When I got home, it was like a time warp. I was very different, but nothing else was different. I came back to the same room that I left, to the same clutter, to friends that weren’t living a healthy lifestyle. I had to find balance in my life.”

So she reduced her stressors and temptations. She moved out of her mom’s house – a decision she terms “great for both of us” – got her own house, reduced time spent with friends following unhealthy lifestyles and surrounded herself with people who want to live healthy, happy lives. But these changes don’t mean her life is without challenges.

“This is reality; this is the hardest test,” Ashley says. “I’m working full time. I’m traveling – I’m still conquering (maintaining healthy habits) and traveling. That’s hard. But I don’t have all those other mental problems holding me down anymore.”

Giving Back
Ashley currently works as a spokesperson for The Biggest Loser’s new activewear clothing line, BL Body. And she’s mapping out how to give back to her fans.

In addition to doing inspirational speaking engagements, Ashley is crafting a plan to fulfill numerous requests to help fans with diet plans and workout routines. She has pitched the idea of doing it through a combination of personal visits and videoconferencing, which has received enthusiastic support.

“The response was overwhelming,” she says. “Hundreds of people were ready to sign up. I’m just trying to figure out how I can do all of this. I’m working on trying to give back to everyone.”

Identifying her stressors, confronting them, forgoing the emotional crutch of eating and instead developing healthy responses to stress allowed Ashley to combat her addiction and transform her life.

“I found comfort when I was full,” she explains. “I was happy for that moment. It was a vicious cycle because then it was, ‘Omigod! I’ve eaten all this, and I’m gaining all this weight!’ To stuff that feeling, I would eat more.”
"It's not that Fourroux does one thing well, they do Everything well!"

It was the whole process that truly blew me away.

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Brandon Rowland
Bi-lateral BK Amputee

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Illustration and article by Scott McNutt

Save yourself! Only you can help prevent diabetes and its devastating complications

Like the invading alien pods in the 1956 science-fiction movie classic, “The Invasion of the Body Snatchers,” risk factors that contribute to type 2 diabetes (including a sedentary lifestyle, poor eating habits, high blood pressure and cholesterol, family history, genetics and age) make diabetes a silent, insidious threat. Without proper care, diabetes can consume your body from the inside, working its way up your nerve endings, ravaging your limbs, and leading to amputation. If you’ve already had an amputation because of diabetes, and you don’t take action to control the disease, it can infiltrate your organs and take control of your life – or end it.

Unlike the alien pods, however, risk factors for diabetes can be detected and combated. Eating sensibly, exercising and avoiding smoking are reliable defenses against diabetes. If you’re at risk for the disease, you can minimize its effects by staying alert for warning signs, such as fatigue, sudden weight loss, frequent urination, wounds that won’t heal, hunger and extreme thirst, blurry vision, tingling or numbness in the feet, and sexual dysfunction. If you exhibit these symptoms, consult your healthcare provider immediately.

If diabetes has already infiltrated your body or you believe you’re in danger of being affected, you must keep it from taking control and putting you at risk for amputation and many other devastating health problems. The Centers for Disease Control and Prevention (CDC) estimates that 7.8 percent of the U.S. population, or 23.6 million Americans, currently have diabetes (including 5.7 million with undiagnosed diabetes). This is up from 18.2 million in 2003. As this number rises, diabetes continues to be the leading cause of nontraumatic lower-limb amputations (LLAs) in the U.S.

In 2008, more than 50,000 Americans lost a lower limb due to diabetes-related complications, representing nearly half of the LLAs performed in the U.S. Members of minority groups, including Hispanic/Latino Americans, African Americans, American Indians/Alaska Natives, and older Americans are at especially high risk. About half of all diabetes-related LLAs occur among people age 65 or older.
For people with diabetes who have undergone amputations, current data is not encouraging. Studies show that people with diabetes who undergo an amputation are at significant risk of additional amputations within 5 years, and as many as one in three may be dead after 10 years.

The Amputee Coalition (amputee-coalition.org) is fighting amputations from diabetes complications with the most effective tool available: knowledge. Experts contend that anywhere from one-half to four-fifths of all diabetes-related amputations could be prevented by people being aware of diabetes' effects and taking measures – such as getting their feet examined regularly – to prevent them. All people with diabetes, whether they have undergone amputation or not, should develop daily self-management practices. Early detection and treatment are the keys to preventing amputation.

Diabetic neuropathy (loss of sensation in the feet and legs) and poor circulation in the lower limbs are two of the main complications from diabetes that lead to amputation. Poor circulation causes skin and tissue to be easily damaged and interferes with healing, while loss of feeling allows damage to go unnoticed until wounds have become infected and ulcerated. Fortunately, most ulcers that lead to amputation can be prevented through daily foot inspection and care, foot-care education, wearing proper shoes and early recognition and treatment of any suspected trouble areas. All people with diabetes should undergo annual foot examinations to identify high-risk foot conditions. Healthcare providers of people with diabetes should be able to conduct simple screening exams of the neurological, vascular, dermatological and musculoskeletal systems.

If no action is taken to stem this disease's looming threat, the CDC forecasts that up to 33 percent of all Americans will have diabetes by 2050 – an epidemic that could overwhelm the U.S. healthcare system. If you're not currently at risk for diabetes, you can curtail its invasion by not smoking and following healthy diet and exercise regimens. If you're at risk, contribute to the fight by stopping or not starting smoking, losing weight if you're overweight, eating right, exercising and following your healthcare providers' advice. If you already have diabetes, make sure that you apply your daily self-management practices and visit the appropriate healthcare providers regularly and follow their advice. Taking these steps will help prevent "The Invasion of the Body Fatteners" from devastating your life.
While people come to limb loss by many different routes, they often face similar problems along the path to healing and rebuilding their lives. Regardless of whether the loss is of an upper or lower limb, and whether it is caused by illness or injury, the experience will undoubtedly change a person’s life.

The first year following an amputation is critical, and it can be an especially difficult period, both physically and emotionally. While the loss is felt acutely by the amputee, it is also extremely difficult for the person’s closest family members to accept the loss and adjust to new daily routines.

The time needed for healing and rebuilding will vary with each person – often depending on physical health, age, available support systems, emotional outlook, and other factors. It is also important that individuals have a roadmap to help them achieve the most successful recovery possible.

This section – a partial roadmap – includes tips for the first 12 months after limb loss for both upper- and lower-limb amputees; information for bilateral upper-limb recovery; stories of physical and emotional survival; information about gait training for lower-limb amputees; and overviews of current pain treatments and skin conditions that can threaten recovery.

We hope that the experiences of the amputees and experts who have contributed to this section will help you reach many of the important “landmarks” on your individual path to recovery.

For more information on surviving with limb loss, please contact the Amputee Coalition at 888/267-5669 or visit the Web site at amputee-coalition.org.
What You Might Expect During the First 12 Months as a Lower-Limb Amputee

by John Peter Seaman, CP, CTP

As a recent amputee, you’re not alone if you feel clueless about what to expect during your first year as an amputee. While there are no set guidelines that will fit every amputee’s individual situation, there are some generalities that may apply. One certainty is that you will see your prosthetist many times during your first year as an amputee, possibly as many as 15 to 20 times, if not more. For this reason, you should do everything in your power to find a prosthetist that you are comfortable with.

Following your amputation, you and your residual limb will start your respective psychological and physical healing processes. Depending on how fast your limb heals, you should expect to have your stitches/staples removed within 3 to 4 weeks of your surgery. You should start pre-prosthetic physical therapy soon after your amputation, working on your upper body strength and your lower limbs to maintain good range of motion in your hips and knees and strength in your leg muscles. You should also start desensitizing your residual limb by rubbing it and manually moving your tissue around with your hands to loosen any scar tissue that might develop inside your limb. You will also meet your prosthetist multiple times, first for a consultation/evaluation and then to be fitted with a “stump shrinker” (an elastic stocking) that will start shaping your residual limb for initial prosthetic fitting.

Once your incision has completely healed, your stitches have been removed and your doctor has provided a prescription for a preparatory prosthesis, you will meet with your prosthetist to be measured and “cast.” Depending on how your prosthetist works, he or she will either cast your residual limb or create a digital image of it by scanning or taking pictures of it. Once your prosthetist has a positive
model of your limb, it will be used to create a diagnostic (check or test) socket for test fitting purposes. This socket will be connected to a knee (for transfemoral amputees) or just a pylon (for transtibial amputees), which in both cases will then be connected to a prosthetic foot. When you see your prosthetist for a test fitting, this might be completed in one visit or it could take multiple visits. Once a diagnostic socket is deemed to fit “comfortably,” your preparatory socket will be fabricated and connected to your other prosthetic componentry, resulting in your first prosthesis. Adjustments to this prosthesis may be required during the first month or two that you wear it, leading to follow-up visits to your prosthetist. After you are fitted with your first prosthesis, your doctor should provide a prescription for physical therapy. Usually, you will see a physical therapist two to three times a week for 1-hour sessions. These sessions are important to ensure that you develop good habits while you relearn how to walk, using a prosthesis. You will typically start walking using a walker as you work to regain strength, balance, endurance and confidence.

Your residual limb will continue to go through physiological changes as you use your prosthesis more, typically resulting in volume loss. If your rehabilitation process proceeds well, you might see your prosthetist on a monthly or bimonthly basis during this time period. It might become necessary for your prosthetist to fit you with a socket replacement during this timeframe due to significant volume loss in your residual limb, which can cause your original preparatory socket to become too large and adversely affect its fit. If so, you may be test fit again before you are fitted with another downsized laminated socket. This process can take a few visits to your prosthetist to complete. Be aware that every socket you are fit with will feel different, which may require some getting used to and possible adjustments following fitting. If your rehabilitation has proceeded well to this point, you might not need continued physical therapy.

By now, your residual limb may have stopped shrinking and reached a somewhat mature state. At this point, your physician might prescribe that you be fit with your definitive (final or permanent) prosthesis, assuming your preparatory socket no longer fits intimately. This may require test fitting again and additional visits to your prosthetist before a new laminated socket is fabricated. Your prosthetist will also incorporate componentry into your definitive prosthesis that matches your current and/or potential level of activity, assuming your activity level has changed since originally being fit with your preparatory prosthesis. You may have progressed through the use of a variety of assistive devices (walker to a 4-prong cane to a single-prong cane) to the point where you can ambulate without an assistive device. However, not all lower-limb amputees are able to function safely without the use of an assistive device, depending on their overall health, determination and confidence. Be aware that for some amputees, prolonged use of an assistive device can enhance safety and reduce the potential for falls.

As you approach the end of the first year since your amputation, you will hopefully have become fairly comfortable with life as an amputee: You will have mastered using a prosthesis – putting it on (donning), taking it off (doffing), making adjustments to the number of socks being worn, etc.; your phantom pain will have subsided and your phantom sensations will have lessened or become more tolerable; you will have found that you are able to do many of the activities of daily living (ADLs) that you did prior to your amputation, but possibly in different ways; and you will have established a good relationship with your prosthetist, who you’ve seen many times during the past year and will continue to see on a regular basis in the future.

If you have any questions about this article, please contact John Peter Seaman at jpseaman@aol.com.
Tips For Enhancing Your Success as a User of a Lower-Limb Prosthesis

by John Peter Seaman, CP, CTP

Even for the most experienced wearers of lower-limb prostheses, using a prosthesis can result in daily inconveniences, if not worse. So what can recent amputees do to enhance their experience after being fitted with a prosthesis? First, accept that successful prosthesis use involves a 50/50 effort between the amputee and his or her prosthetist. Second, amputees need to understand that their prosthetist, in most cases, is not a miracle worker. In simplest terms, the prosthetist’s role is to assess the amputee’s physical potential, select appropriate prosthetic componentry, and provide a tool, in the form of a prosthesis, for the amputee to use to achieve his or her desired ADLs (activities of daily living). Once this is accomplished, it is up to the amputee to do the many things necessary to maximize the benefits offered by a comfortably fitting and properly functioning prosthesis.

Listed below are 10 of the more important things you can do as an amputee to help ensure that your experience as a prosthesis user is maximized.

1. **Be compliant** – Properly clean the inside of your liners after wearing them, examine your residual limb each day to be sure you don’t have any issues that need to be addressed (skin breakdown) and, when needed, wear prosthetic socks to enhance your socket fit. You might also want to wear a shrinker while you sleep to help shape your residual limb and reduce swelling overnight, especially if you are a recent amputee.

2. **Don’t procrastinate** – If you have an issue with socket fit, comfort or prosthetic function, schedule an appointment to see your prosthetist right away. Don’t let what seems like a small issue grow into a major one, especially if you have diabetes and have skin breakdown that could become infected or your prosthesis is not functioning in a safe manner.

3. **Establish personal goals** – Set some goals involving physical activities that gradually increase your prosthesis use as time goes by. Don’t be satisfied with today’s level of activity. Constantly stretch yourself and strive to achieve more each day while being safe.

4. **Wear and, more importantly, use your prosthesis every day** – As a new amputee, you may wonder how long
you should wear your prosthesis each day. A standard answer would be, “As much as possible.” If your prosthesis fits comfortably, you should be able to put it on in the morning and wear it until you go to bed at night. Also, by wearing it all day, you will be more inclined to use it more regularly. Your prosthesis will not do you any good if it is sitting in a closet collecting dust.

5. **Become experimental** – As an amputee, you will have to learn how to successfully use a prosthesis, and, yes, it requires work on your part. Your residual limb will not fit in the prosthetic socket the same way each day or even throughout the day. You need to be sensitive to what you are feeling in the socket and learn what you can do to effect positive changes in your socket fit, like adding or taking away full-length or partial-length prosthetic socks or removing and redonning a liner that has slipped due to a build-up of perspiration.

6. **Exercise regularly** – As a new lower-limb amputee, you have lost some musculature in your affected leg, so you have fewer muscles to use when standing, walking or running. You’ll need to strengthen those remaining muscles to stand in a stable manner and walk with an efficient gait. This will take several weeks or months and require a lot of effort. Working with a physical therapist soon after your initial prosthetic fitting to shorten the learning process is highly recommended.

7. **Control your diet** – As a lower-limb amputee, in many cases, you will initially be less active than you were prior to your amputation. Such a sedentary lifestyle will often result in your gaining weight. It is important to understand this and to adjust your nutritional intake to match your activity level so that you do not gain appreciable amounts of weight during this period of transition. If your weight fluctuates significantly after being fitted with a prosthesis, intimate socket fit can be compromised.

8. **Accept and embrace your situation** – Everyone deals with amputation in his or her own way, some more smoothly than others. The sooner you can come to grips with the fact that you’re an amputee and that your life has not ended, the better. Most lower-limb amputees are able to return to very full lifestyles after they become accustomed to using a prosthesis and understand that being a successful prosthesis user can be just as dependent on dealing successfully with mental adjustments as physical ones.

9. **Strive for independence** – Immediately after your amputation, it is normal to seek out and receive assistance from family members or friends to help you during this transition. However, at some point – the sooner, the better – you should strive to become as independent again as possible. With a comfortably fitting and properly functioning prosthesis, you should be able to do many, if not all, of the things you did before becoming an amputee.

10. **Focus on the future** – Few, if any, amputees are thrilled with having become amputees and having to rely on a prosthesis to live their normal lives. Those who do well accept their situation and make a conscious decision to not let it get in the way of living life to the fullest. Don’t be misled, however; not every day as an amputee will be a walk in the park. Often, you’ll need to exhibit an immense amount of patience and perseverance. However, if you focus on the positives in life versus dwelling on the negatives, with sincere effort and determination, you should be able to live a long, fulfilling life as a prosthesis user.

Please forward any questions or comments to the author at jseaman@aol.com.
Your life has changed – you’ve lost an arm. Now what? What will you be able to do? How will others see you? Will life ever be “normal” again? While it is overwhelming to face so many unknowns, be reassured that there are many people and organizations that can help guide you and your family along the path of recovery and rehabilitation. Over the next 12 months, your life is likely to include several recurring themes: medical care, emotional challenges, prosthetic care, and occupational and physical therapy.

**Medical Care**

The starting point for your rehabilitation is medical care. A few days after surgery, your medical care transitions from suture and staple removal to wound care and pain management. Once you leave the hospital, you will become more responsible for monitoring the physical aspects of your recovery and reporting this to your doctor at regular follow-up visits. At some point during the first 3 months, your surgeon will probably transition your care to a physical medicine and rehabilitation (PM&R) physician, or physiatrist. The PM&R physician focuses on pain management and medications and is your main referral source for emotional healthcare, prosthetic treatment, occupational and physical therapy, social services and return-to-work issues. Your relationship with this physician will likely continue throughout your life, so take the time to build a good rapport. The other professionals who become part of your care team will work closely with this physician to manage your rehabilitation. While you are the central decision-maker on your team, the PM&R physician is the director that gets you the services you need.

**Emotional Challenges**

Limb loss has a significant emotional impact on both the individual and his or her family. It is important to understand the range and intensity of feelings you may experience during the first 12 months, and perhaps longer. Many people overlook or avoid the opportunity to talk with a counselor and address the reality of the grieving process. Emotional recovery is a highly personal experience with no set timeframe. Some people feel that they quickly reach a level of acceptance following their injury or surgery.
only to find themselves pulled back into feelings of grief when they least expect it. Establishing a comfortable, honest dialogue with a licensed counselor, social worker, psychologist or support group should occur within the first 3 months of your recovery.

**Prosthetic Care**

Most new amputees are referred to a prosthetist after their surgical sutures or staples have been removed. In some hospitals, an immediate post-operative prosthesis (IPOP) is applied by a prosthetist in the operating room so that from the moment a person awakens from amputation surgery, he or she is wearing a prosthesis. In either case, it is important to understand that you will probably be working with a prosthetist for the rest of your life. To get the best possible outcome, be sure the prosthetist you choose has extensive upper-limb experience.

In one of your earliest meetings with a prosthetist, while your residual limb is healing and creating new circulation pathways, you may be fit with a “shrinker” that is made from fabric or silicone. It looks like a sock but its function is to help reduce swelling in the residual limb, compress the tissue and build tolerance to pressure. Even after you begin wearing a preparatory prosthesis, you will continue to use a shrinker during the first year when you’re not wearing a prosthesis.

The first month of your recovery is often when you learn the most about integrating a prosthesis into your life, before you get used to doing things without a prosthesis. The prosthetist you select will spend a significant amount of time discussing your goals, learning about your history, and teaching you about prosthetic options and components. It is vital to establish open communication and trust with your prosthetist. Help him or her understand your life by discussing your work, family and recreational activities.

**Occupational or Physical Therapy**

An occupational or physical therapist will play a key role in guiding your rehabilitation. The therapist and the prosthetist work together to create a treatment plan that moves you through the three phases of therapy: pre-prosthetic, interim-prosthetic and post-prosthetic. During the first month, the focus is on preparing you to wear a prosthesis. In the second or third month you begin learning to use a preparatory prosthesis and work on repetitive drills and controls training. More complex tasks are added after you receive your final prosthesis and are moving toward the 12-month mark.

Building a positive working relationship with your therapist gives you a secure place to practice both new and familiar tasks before trying them in the real world. This will help build confidence with your body and with the use of your prosthesis. Let your therapist know the goals you have for your recovery and stay open-minded about trying different exercises and prosthetic components to accomplish your goals. After the first 12 months of therapy have been completed, it is important to remember that you can revisit therapy later, when you try new activities or prosthetic components.

One year after losing your arm, you will have learned a great deal about adjusting to life as an amputee and a prosthesis user. You will have discovered new ways to approach both simple and complicated tasks. And, most importantly, you will have a team of supportive people – professionals, family and friends – that will continue to help you set and reach new goals in your rehabilitation.

*Photos courtesy of Advanced Arm Dynamics*
Bilateral Upper-Limb-Loss Rehabilitation
An Occupational Therapist’s Perspective

by Shawn Swanson Johnson, OTR/L

Upper-limb loss is a rare occurrence. Consider this fact: for every incident of upper-limb amputation, there are 30 incidents of lower-limb amputation. Bilateral upper-limb loss is even rarer, and is extremely challenging, as there is not a remaining arm to perform daily self-care tasks.

The loss or absence of both hands or arms places the individual and his or her family in a very difficult situation. Yet specialized, long-term rehabilitation can help people regain their ability to care for themselves, participate in leisure activities or hobbies, drive a car and return to work. The guidance of a multidisciplinary team that includes both an occupational therapist and a prosthetist who specialize in upper-limb rehabilitation is essential. Other factors that contribute to better outcomes include a strong support system of family and friends and a positive, motivated attitude on the part of the limb-loss individual.

Initial Concerns and Challenges
One of the most challenging aspects of bilateral upper-limb amputation is that for some period of time, the patient is likely to be completely dependent on someone else for his or her most basic and personal needs. Using the bathroom, bathing, getting dressed and eating are all important aspects to address early on in rehabilitation. Occupational therapy is the best way to start regaining some independence prior to receiving a prosthesis. Occupational therapy also prepares the individual to become a prosthetic user, which will increase his or her options for self-sufficiency. It is important to note that patients should be taught how to perform daily tasks both with and without prostheses.

Early occupational therapy in both unilateral and bilateral upper-limb loss addresses the following issues: wound care, scar management, edema management, desensitization, range of motion and psychosocial concerns. For bilateral limb-loss individuals, early occupational therapy will also include a unique focus on stretching and strengthening the lower limbs and strengthening the core of the body. Balance and fall recovery are also addressed, as these patients do not have arms to help them with balance or to protect them when they fall.

Prior to receiving a prosthesis, there are numerous tools and techniques that can help facilitate independence. These include but are not limited to:
- A universal cuff that slips around the residual limb and can hold a fork or spoon
- Eating utensils that swivel and are easier to grip or provide the appropriate angle to bring food to the mouth
- Bidets, which remove the need for toilet paper management
- Devices such as gooseneck clamps and suction cups to hold personal grooming items like shower brushes, hair dryers and toothbrushes
- A “dressing tree” that makes dressing
easier with a system of hooks placed in strategic places on a wooden or PVC stand
• A mouth stick that enables a person to flip switches and press buttons or keyboards
• Speakerphones or voice-activated cell phones
• Electronic, hands-free devices that help the individual call for help and control his or her home environment, such as lighting, room temperature, appliances and TVs.

While these tools are helpful in the home environment, some are not easy to take along when reentering the community or traveling.

Getting Familiar With Prosthetics
Becoming a fluent user of bilateral upper-limb prostheses takes time. How much time depends on the complexity of the injury, the length of the residual limbs, and the individual’s overall attitude and level of motivation. It is not unusual for it to take 1 to 2 years or even more to become comfortable and capable.

It is preferable that the prosthetic sockets are pre-flexed with radial deviations of the forearm and wrist that help position the arms toward the center of the body. Additional components that allow for elbow, wrist or shoulder movements are added to the prosthesis as the individual is able to tolerate the additional weight and complexity.

Prosthetic training for bilateral upper-limb-loss individuals requires a special approach where each arm is trained independently. The residual limb that is longer or more mobile becomes the dominant arm and hand. Prosthetic training should occur on the dominant side first, with the entire process repeated separately on the non-dominant side. Finally, training continues with the individual wearing both prostheses and attempting bimanual daily tasks.

Learning to put on and take off the prostheses – donning and doffing – is an important part of prosthetic training. The occupational therapist (OT) works with the patient on learning to don and doff the prostheses without the assistance of another person. No matter the level of limb loss, independence with this task is possible.

The OT also helps the patient learn to actually use the prostheses in a particular method or sequence of steps that include controls training, repetitive drills and bimanual functional skill retraining. Controls training includes basic movements like opening and closing the terminal device (hand or hook), operating the wrist, flexing and extending the elbow, and manipulating the shoulder joint. After consistency and accuracy are achieved with speed and device positioning, repetitive drills begin. This includes repetitively grasping and releasing items of various shapes and sizes and moving them in different areas around the body. It also includes learning to pre-position the terminal device to pick up objects in an anatomically correct way rather than twisting or bending the body in awkward or harmful ways. After the patient has demonstrated consistency and accuracy with repetitive drills, it is appropriate to move on to bimanual functional skill retraining. This includes basic gross motor skills like folding a towel and progresses to fine motor skills, such as manipulating buttons.

Living in a New Way
Adapting to life with bilateral upper-limb loss usually happens over a period of months or years, not weeks. Smaller day-to-day accomplishments lead to more independence over the long run. If it is financially feasible, home modifications, especially in the bathroom/shower, are extremely beneficial. Smaller
day-to-day accomplishments lead to more independence over the long run. If it is financially feasible, home modifications, especially in the bathroom/shower, are extremely beneficial. Smaller modifications around the house, such as changes to drawers, handles, doors, containers and light switches, are easier to make and also less expensive.

Most individuals have a hobby, job or other activity they want to return to. Whether it’s shopping for groceries, working in the yard or driving a car, there are bilateral upper-limb amputees who have found new ways to do these and other activities. Being able to drive again is a reachable goal, and, by working extensively with a driver rehabilitation specialist who has experience with bilateral upper-limb-loss individuals or those with a spinal cord injury, it is often possible to become a licensed driver.

In closing, consider these key points that have emerged from healthcare practitioners over years of working with bilateral upper-limb-loss individuals:

- Most individuals are motivated and inventive/creative in how they adapt.
- Having a strong support system is a vital part of being successful.
- It is essential to have a backup set of arms in the event of repairs and maintenance on the primary prostheses.
- Having multiple terminal devices gives the patient the ability to complete a variety of daily tasks, much like a box of tools is helpful to a handyman.
- Using electric prostheses on both sides is becoming more common, versus the traditional approach of using body-powered on the dominant side and electric on the non-dominant.
- Attendant care is typically required and ranges from part-time to full-time.
- If individuals choose not to wear prostheses and use their feet or other parts of their body for various activities of daily living, anecdotal evidence shows that they will develop problems with their neck, back and especially their hips.

All photos courtesy of Advanced Arm Dynamics.

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**Additional Resources**

**Workshops**

*International Society for Prosthetics and Orthotics (ISPO)*

*Skills for Life 3*, October 12-16, 2011

The program will feature a series of workshops devoted specifically to issues faced by individuals with bilateral upper-limb loss. Presenters will include therapists, prosthetists, physicians and others living with bilateral upper-limb loss. usispo.org/skills_for_life.asp

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**Videos**

*The Use of Upper-Extremity Prostheses* by Art Heinze

armamputee.com

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Aaron
Bilateral C-Leg wearer
Minneapolis, MN
Great Partnerships.
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Molly French, ever the doting teacher, never missed school for anything – certainly not for something as minor as a cold. But when her cold got worse and her energy flagged, Molly’s colleagues had to practically force her to see a doctor. The kids in her classroom were shocked that their dedicated teacher was sick enough to miss school.

The doctor told Molly she had a virus, and said to get some rest. “Did I listen?” she jokes. Well, she might have, but the next day was class picture day at school, and she knew the kids couldn’t have their class picture without a teacher, so she went.

That weekend, though. Molly didn’t get off the couch, and by Monday her husband Jamey said she needed to see the doctor again. He knew she was really sick when she not only agreed, but told him to grab her emergency lesson plans because she was too weak to write a new plan. Her students may have ended up with a class picture of Mrs. French, but little did anyone know that that would be her last day as a teacher and that the next 3 weeks would be a battle for her life.

**Critical Care**

This time, on the way to the doctor, Molly began experiencing trouble breathing. Unfortunately, when she first went, she wasn’t exhibiting the classic signs of strep throat, which by now had turned septic. To complicate matters, her breathing problems were due to a deadly condition called Adult Respiratory Distress Syndrome (ARDS), which was brought on by the sepsis. This came with a grim statistic: no more than a 5 percent survival rate.

Thanks to Jamey’s childhood friend, Troy, a respiratory specialist at the University of Michigan Medical Center who lived 2 hours from Molly’s hospital in Dayton, Ohio, she is able to share her story. She tells of the night when Troy, hearing the news that Molly had ARDS, drove straight to see her – against Jamey’s wishes – after working his long shift. “Jamey said, ‘He didn’t listen to me as a kid,’ but I’m glad he didn’t listen,” says Molly. Troy knew how grave her situation was, but he didn’t tell Jamey at first. When Troy arrived at Good Samaritan Hospital in Dayton, he didn’t have any privileges, but the doctors worked with him on the medications and ventilator settings.

Then the critical moment came when Jamey had to decide whether to keep Molly at Good Samaritan or fly her to the University of Michigan hospital where Troy knew she would have a better chance of survival – if she could survive the flight. Jamey chose Michigan. “We joke that as Buckeyes, Jamey sent me to the land of the Wolverines,” kids Molly, referring to Ohio State and University of Michigan college team rivalries.
Waking Up to a New Life

Not only did Molly survive the flight, but when she came out of her coma, Jamey knew she was the same person he had married. Molly says: “I looked at the calendar on the wall and said, ‘That calendar is wrong.’ He said, ‘No, honey, it’s not.’ And then I shot up in bed and said I needed to do my lesson plans!”

As she was weaned off of her IVs, there came another difficult decision: amputation. The doctors had done everything they could to save her legs, but they told her that she would always have to wear leg braces and be at risk for injuring herself, considering the level of damage due to the sepsis and ARDS. The quality of her life was at stake. She agreed and chose amputation. Shortly afterward, they also amputated her thumb and index finger on her left hand.

In the aftermath, her life was all physical therapy – 6 to 8 hours a day. Molly had to have hand therapy because her muscles had tightened up due to the lack of oxygen. “My hands were completely closed, and I couldn’t open them,” she recalls. To open her hands again, the therapists had to pry her fingers apart. “I just cried, it was so painful.”

The Journey to Acceptance

As most amputees experience, this was not the end, but the beginning. Now that Molly had survived her illness and its painful aftermath, she had to orient herself to surviving the emotional aftermath and learning one of the hardest lessons of her life: accepting help from others. People naturally wanted to extend their financial support, something she and Jamey would have been glad to do for others going through a hard spell, but it was devastating to come to the realization that their finances were in peril. “As Jamey put it, ‘First Molly was on life support, but now our checkbook was on life support,’” says Molly.

It was such an important lesson that it has now become part of their message in talks they give to churches, schools and organizations to help others in the aftermath of trauma. Their message is simple, and they call it the Steps to Hope: (1) Prayer, or for someone who doesn’t pray, they recommend reflecting on what’s happening in their life; (2) Be grateful; and (3) Let people help you. Molly also tells new amputees the thing she knows is hardest to hear – because she has been there too. “I tell them that they have to be patient,” she says.

Molly wasn’t always patient in her process to return to normal life. She couldn’t return to teaching full-time because of a spleen condition that makes her unable to fight off infections – which was discovered after her illness. As a result, she can’t be around kids all day. Nevertheless, volunteerism sustains her, both at her school and church, and now as a support group leader.

“Being so close to death just made me look at my life differently,” says Molly, who still has bad moments but never lets them ruin a whole day. “The bottom line is every day I am just thrilled with the fact that I can breathe,” she says. “I wish everybody could feel that way in their lives.”

Jamey French is the Amputee Coalition’s development director. He was hired in 2010. Photo provided by Jamey and Molly French
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The Importance of Gait Training

by Scott Cummins, PT, CPO, FAAOP

It is the goal of most every lower-limb amputee to walk “normally” again. In the context of this article, “normal” is defined as a symmetrical gait pattern that falls within the “average” range in terms of posture, step length, rate of speed, limb positioning, etc. But being a lower-limb amputee presents many different challenges when it comes to ambulating safely and without exerting excessive energy. Generally, the higher the amputation level, the more we can expect to see gait deviations, or what some would call limps. This is because with each segment of the anatomy that is lost to amputation, more muscle, sensory receptors and leverage are also lost. As a result, the person with a higher amputation level typically has a less stable and less energy-efficient gait pattern compared to a person with a lower amputation level.

Almost all lower-limb amputees will benefit from gait training at some point in their recovery to help normalize the gait pattern. It is widely accepted that recent amputees have the most to gain because using a prosthesis is such a new challenge. Aside from pre-amputation exercises done under the supervision of a physical therapist, the initial training is provided by the prosthetist as part of the care during the fitting of the prosthesis. This care includes aligning the prosthesis to ensure that the components or parts of the prosthesis are positioned in such a way as to optimize the gait pattern. At the same time, initial gait instructions are also provided by the prosthetist so that the person wearing the prosthesis is able to stand and walk with enough stability to ensure safety. This process usually starts in the parallel bars, often using a gait belt just in case the new amputee loses his or her balance. At this stage, it is best to involve a physical therapist for regular gait training sessions. Once it is determined that stability is consistent, the parallel bars can be traded in for a
walker or crutches. Eventually, many prosthetic wearers will progress to a single cane or even no assistive device at all! It should be noted that using some type of assistive device is not a sign of disability; instead, its use indicates that the person can be more functional with the extra stability it provides.

Even amputees who have worn a prosthesis for years can benefit from gait training. This could be in the form of occasional visits to the therapist for a “tune-up” or it could be to learn a new skill such as walking step-over-step up stairs, walking on uneven terrain, or even running. It is important that the prosthetist and therapist remain in close communication when gait training is occurring since any changes to the prosthesis will affect the gait pattern, and vice versa. This becomes critical when considering the sophistication of today’s prosthetic components and their need to be adjusted more carefully. Also, quicker gains can be made if the amputee has at least a basic understanding of how the prosthesis and its components work.

Gait training provided by an experienced physical therapist is available in a variety of settings. For the new amputee, training with the recently fitted prosthesis will probably occur in a rehab hospital or skilled nursing facility (SNF). Here, the basics will be covered, including such things as side-to-side weight shifting, marching in place, balancing on one leg, and side-stepping. These techniques are usually performed with the parallel bars, often with the use of a full-length mirror so that posture and foot position can be observed. Sometimes, the training will take place in the amputee’s home by a visiting physical therapist. Although there is no access to parallel bars and other equipment, some view the opportunity to learn in a familiar environment with real obstacles as a worthwhile tradeoff. Another option is to travel to an outpatient physical therapy clinic to receive gait training in a more progressive setting. Here, the focus is usually on more advanced tasks such as walking without an assistive device, climbing stairs, traversing inclines, and walking at varying speeds. Some amputees will eventually master uneven terrain, walk while carrying bulky items, or even learn to run. An exercise program will also be prescribed to increase strength and range of motion. This will improve the chances of reaching the functional goals.

Many different techniques can be incorporated into the gait training sessions, but two seem to stand out. The first involves the teaching of “splinter skills,” where the gait pattern is broken down into a sequence of events that are practiced individually before putting them all together to build the gait pattern. The second technique is more of a “whole walking” approach so that the gait pattern is practiced all at once with little concentration on the individual events, instead relying on the body’s natural tendency to find the most stable and energy-efficient way to walk. The physical therapist and prosthetist may try either or both of these strategies to get the best outcome.

Communication and teamwork between prosthetists and physical therapists go a long way in helping amputees reach their goals with a prosthesis. A person’s ability to ambulate with a prosthesis partially depends on confidence, and that can be developed with practice. Unfortunately, insurance coverage sometimes tends to limit treatment options, but it is important that a person is willing to advocate for the best care – then make the most out of the opportunity by working hard and working smart.

Photo courtesy of Next Step Orthotics & Prosthetics, Inc.
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Goin’ to Kansas City: visitkc.com
by Sarah J. Sullivan, PhD, and Dawn M. Ehde, PhD

As children, we come to know the unpleasant sensation we call pain through scraping knees, stubbing toes and bumping elbows. In these cases, pain is typically short-lived and easily mended with some help from a caring adult. In contrast, as many of you reading this article know, following an amputation, pain is sometimes severe and can be long-lasting. This article offers some general information about chronic pain in people with amputation, introduces how the brain is involved in the experience of pain, and describes a cutting-edge approach to treating chronic pain that may be able to help reduce pain and its impact on your life.

Pain is experienced by virtually all people with amputation at some point in the healing process. In fact, studies have found that up to 90 percent of people experience pain after amputation. For some, pain resolves as the wound heals, but for many people, pain becomes a chronic issue. Chronic pain is defined as pain lasting longer than the expected healing time of injury or pain lasting longer than 6 months. For many, pain after amputation comes and goes, whereas for others, pain is present nearly every day. So, if you’ve had surgery some time ago and are still living with pain on a regular basis, you are not alone.

For a number of reasons, chronic pain following amputation is particularly complex. It can come and go without warning and can occur in a number of different locations, including the residual limb and other parts of the body, particularly the opposite, non-amputated limb, hips, back and neck. One study found that 70 percent of people had pain in two or more locations after limb loss. In addition, many people experience what is called “phantom pain,” pain perceived in the part of the limb that is no longer present. Phantom pain is considered to be neuropathic because it results from injury to the nervous system itself as opposed to musculoskeletal pain, which results from direct injury to skin, muscle or bone. Finally, more than just unpleasant to live with, chronic pain can be related to a number of other problems, including difficulties with mood, sleep, relationships, employment and enjoyment of life. For these reasons, it’s important to let your healthcare providers know about any pain you’re experiencing so that they can help you address the problem.

Just as chronic pain is complex, so too must treatments for it address different areas of your body, mind and daily life that pain may affect. Even in the simple scenario of a child who falls and scrapes a knee, “treatment” will likely involve a number of layers: perhaps some antiseptic and a bandage, comfort from a family member, problem-solving about how to avoid future falls, and support for the child in moving on with the rest of the day. As an ongoing and complex health challenge, chronic pain after amputation requires an even more multi-layered approach to treatment.

The good news is that researchers and healthcare providers are working on developing new treatments to combat chronic pain. Some of these treatments involve medications or procedures, while others involve strategies that you can learn to use on your own. Strong evidence now exists that several “talk therapies” offer many people both pain relief and reduction in the negative toll that pain can have on other areas of life. But wait – how can talking make pain better? Does this mean that pain is all in your head? Absolutely not. Pain is a real experience that should be taken seriously. But, for a moment, think about someone having surgery under general anesthesia. Typically, surgeons perform acts, such as cutting the skin, nerves and bone, that would be painful if the person were conscious. Yet, because the patient is unconscious due to anesthetic, the person experiences no pain. This example shows us that the conscious mind is crucially involved in the experience of pain. Fortunately, this role that the mind plays in the experience of pain points to pos-
a Weapon in the

Possible strategies for alleviating pain – without general anesthetic!

How can we harness the mind to reduce the experience of pain and its impact on quality of life? Researchers have investigated a number of approaches for using the mind as a weapon in the fight against pain. Self-management is one such treatment that is delivered with words instead of a needle or pill. Rather than an intervention that is delivered to a patient, self-management is an intervention in which an individual with pain actively participates and guides treatment based on the specific and unique nature of his or her pain and life situation. For instance, one person may be bothered by difficulty sleeping due to pain, another person may be bothered by pain while at work, and yet another person may experience both of these problems. Self-management interventions allow you to work with a therapist to learn about strategies that address the specific challenges you face. For example, whereas learning healthy sleeping habits promotes sleep quality, learning about appropriate activity pacing supports coping with pain at work. Furthermore, different strategies work better for different people, and your therapist will work with you to figure out what works best for you: One person’s sleep may benefit from establishing a bedtime routine and another’s may benefit from avoiding afternoon naps. No one is in a better position than you to become an expert on your pain and the best way to manage it. Self-management interventions involve arming yourself with the latest knowledge about chronic pain and how it can affect different areas of your life. In addition, you work with a therapist to identify strategies that already work well for you in managing pain and try out new pain management strategies as well. For instance, you may already have found that regular exercise helps you manage your pain, but you might also notice that you sometimes overdo it and that your pain is worse at these times. A self-management therapist can support you in continuing your exercise program and, at the same time, in learning strategies for avoiding overdoing it or under-doing it. Self-management interventions have been tested and shown to be effective in large research studies where treatment was delivered by a trained therapist in person on either an individual or group basis. The research community is working hard to understand more about how and why chronic pain develops and the most effective ways to address it. Self-management interventions offer an opportunity to combine the wisdom you’ve acquired through firsthand experience with chronic pain with the latest scientific information about chronic pain in a treatment where you work with a trained therapist to tailor a plan that is right for you.

Studies have demonstrated that self-management is an effective treatment for people who have chronic pain due to something other than amputation, such as chronic headaches, back pain and jaw pain. Self-management is also being used to help people with other health problems, such as diabetes or hypertension, to manage the diseases and their effects. However, self-management interventions are often delivered in person; access to this kind of treatment can be difficult for some people, particularly those living with limb loss. Therefore, researchers are exploring how to increase the accessibility and convenience of self-management interventions. One such study is the University of Washington’s Telephone Intervention for Pain Study (TIPS). This study is comparing two different telephone-delivered self-management interventions for people with disability pain, including pain after limb loss.

Chronic pain is a health issue that many amputees encounter and is one that can have far-reaching effects on a person’s life. Although living with chronic pain presents many challenges, there are steps that anyone can take to manage pain. In addi-

Chronic Pain
tion to the other treatments that you’re already working with your healthcare providers to implement, self-management interventions can offer new strategies for reducing chronic pain and the impact it has on your life.

Related Resources

American Pain Foundation
painfoundation.org

American Psychological Association – Psychologist Locator
locator.apa.org

University of Washington Telephone Intervention for Pain Study (TIPS)
rehab.washington.edu/research/studies/pain.asp

Pain Management and the Amputee
amputee-coalition.org/fact_sheets/painmgmt.html

American Medical Association – Doctor Finder
(Find a pain medicine or physical medicine and rehab specialist)
https://extapps.ama-assn.org/doctorfinder/home.jsp

TIPS Study
Every TIPS participant receives eight 60-minute treatment sessions conducted over the telephone by one of the study’s clinicians who is a trained clinical psychologist. Because we’re interested in understanding and comparing two different approaches to self-management delivered by phone, participants in the study are randomly assigned to one of two self-management treatment interventions. Both treatments involve educating you about pain and discussing the impact of pain and different ways to manage it in hopes of decreasing your pain and its impact on your life. Furthermore, both treatments are commonly used in pain clinics and have been used in the past to treat pain in amputees. Participants are encouraged to think about and use the information they’ve learned outside of treatment to help manage pain between sessions and even after the treatment has been completed. For more information, please call 866/928-2104 or e-mail tipstudy@uw.edu.

Promoting Amputee Life Skills
The Amputee Coalition’s Promoting Amputee Life Skills (PALS) program is an eight-session self-management course for people with limb loss. The PALS program teaches people with limb loss important self-management skills, including new problem-solving skills, to better manage the effects of limb loss. It is provided in a group format so that amputees can learn from one another, in addition to learning from the course leaders. In a joint study by the Amputee Coalition, Johns Hopkins University Bloomberg School of Public Health, and the University of Washington, the PALS course was found to have a significant effect on the quality of life of people with limb loss. Of those participants who completed the PALS course, 70 percent reported that the PALS program helped them better manage their mood; 58 percent reported that it helped them manage amputation pain; 74 percent reported that it helped them manage other problems associated with limb loss; and 76 percent said PALS helped improve their quality of life. Additionally, 95 percent said that they would recommend PALS to a friend with limb loss, and 73 percent said that PALS was more important than other available services in managing limb loss.
Identifying and Managing Skin Issues With Lower-Limb Prosthetic Use

by M. Jason Highsmith, DPT, CP, FAAOP, James T. Highsmith, MD, and Jason T. Kahle, CPO

Fitting a prosthesis is complicated because parts of the human body are used for tasks for which they are not designed. The skin/prosthesis interface is at fault for many complications. Here, a synthetic material, such as silicone or plastic, is in constant contact with the skin. Skin is not well-suited for this type of material contact. Skin problems are one of the most common conditions affecting lower-limb prosthetic users today. Skin problems are experienced by approximately 75 percent of amputees using a lower-limb prosthesis. In fact, amputees experience nearly 65 percent more dermatological complaints than the general population.

Abnormal mechanical and thermal conditions are introduced in a prosthesis, such as socket contact against the skin. This can traumatize tissue by excessive tension, friction or heat. Additionally, the skin reacts to increased temperature with perspiration, which is unable to evaporate because of the closed prosthetic environment. This results in more heat and moisture softening the skin, thereby disrupting normal integrity (maceration). Pressure is another mechanical issue introduced in a prosthetic socket. Certain parts of the human anatomy are well-suited to disperse pressure, such as the fat pad of the heel. With amputation, the normal pressure-distributing anatomy is missing or altered. Therefore your prosthetist must use anatomic areas not well-suited for weight-bearing pressures. Improper socket fit can increase pressure and accelerate skin breakdown. Pressure sores can often be corrected with minor prosthetic adjustments. However, sometimes pressure areas can be more significant and require recovery time out of the prosthesis and/or a complete new socket fit.

Irritant contact dermatitis and allergic contact dermatitis are two more common problems affecting prosthetic users. Either of these can occur when the skin is exposed to a material that creates a skin aggravation. If a known irritant or allergic component exists in the patient’s prosthesis, it should be switched to another material. Furthermore, both conditions can be treated with topical steroids or a barrier cream. Several over-the-counter (OTC) topical preparations are available for these conditions, such as hydrocortisone and zinc oxide. Untreated, dermatitis can lead to chronic inflammation, cellular damage and carcinogenesis (cancer). Therefore, we urge all
prosthetic users to see a physician when they have failed conservative therapy or have a lesion that won’t heal. It is imperative that these lesions are evaluated so that various forms of cancer can be ruled out.

Avoiding skin complications begins with good hygiene and daily skin inspections. Clean all parts of your prosthesis daily that contact your skin. The reverse is also true: Inspect and clean all parts of your skin daily that contact your prosthesis. Don’t rely on feeling a problem as your primary means of detecting skin problems. Many patients are desensitized and can’t feel damage to the skin. The best inspections make use of a mirror or a spouse who can view all aspects of your limb. Every amputee’s needs are unique, so discuss your inspection needs with your provider.

If you encounter a skin problem that you are unable to resolve or that will not heal, then the first step is to see your prosthesis. The prosthetist can then determine if the problem can be resolved prosthethically or through other conservative means. If not, the prosthetist may refer you to your primary care physician or a specialist (see flow diagram).

Skin issues are very common among amputees. Because amputees require an unusually high demand from their skin, and because not wearing a prosthesis is often not an option, they sometimes dismiss the importance of hygiene and monitoring of their skin. Skin issues need to be taken seriously. A simple skin breakdown can lead to more severe problems, such as infection, cancer, osteomyelitis (bone infection), and ultimately revision surgery. Start with your prosthetist to determine, and hopefully resolve, the problem. If your prosthetist cannot find a solution, you may need to consult a specialist, such as a dermatologist.

Photos provided by James Highsmith, Jason Highsmith and Jason Kahle

* Polysporin® is recommended over Neosporin® due to a high incidence of allergic contact dermatitis. Consult your dermatologist for more information.
PARTICIPANTS NEEDED FOR RESEARCH STUDY OF ELECTRICAL NERVE BLOCK FOR CHRONIC POST-AMPUTATION PAIN

We are looking for volunteers to take part in a study of an electric nerve block application for patients suffering from chronic post-amputation pain.

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For more information about this study, or to volunteer for this study, please contact:

Dr. Amol Soin
The Ohio Pain Clinic
8934 Kingsridge Dr.
Suite 140
Centerville, OH 45458

Phone: 937-434-2226
www.ohiopainclinic.com

This study has been reviewed by, and received ethics clearance through, the Copernicus Group Institutional Review Board.
As my 8-year-old slid into the back seat of my car, I carefully glanced in the rearview mirror to get a peek at his face, not wanting to be caught trying to get an idea of his mood. Wes had just left his therapist’s office after an hour of grief counseling. He had lived through some pretty hard times in his young life, and the effects had been taking a toll on him.

Wes was only 4 years old when I contracted a rare form of Strep A bacteria, called necrotizing fasciitis, or what is commonly termed “the flesh-eating bacteria.” As a result of contracting this life-threatening illness, I lost the lower parts of both legs and feet, and my right hand. I was in the hospital for 3 months and in rehabilitation for 9 weeks. Half of Wes’s fourth year was spent with me in the hospital. Now, while he was still trying to cope with his feelings surrounding my illness, and subsequent disability, he was faced with his dad’s newly diagnosed cancer.

My husband, Michael, was diagnosed with terminal cancer 2 years after my illness rocked our little family. Wes was trying to make sense of it all in his 8-year-old brain. His heart had already been beaten and bruised by almost losing me permanently, and now having to deal with a very ill father was almost more than he could bear. Grief counseling seemed like a much-needed part in his troubled life.
As I looked at his face in the mirror, I could see that he didn’t seem as “rough” as he sometimes did after emerging from his therapist’s office.

“Wes,” I began.
He looked up at me. “Yeah?”

“When we get home, I need you to go over to Johnny’s house and get Colin.”

Colin was Wes’s 4-year-old brother. He was playing at a neighborhood friend’s house, while Wes and I were at his appointment.

“Why do I have to do everything?” came his mumbled, whiny reply from the back seat.

I took a deep breath and gathered my thoughts before I spoke.

“Wes, I know that dad and I expect a lot from you sometimes, and I’m really sorry, but here’s the deal. Your dad is sick and in bed, and I can’t get up the steps at Johnny’s house to ring the doorbell.”

I went on to explain that we were a family, and that families are a team.

“When one of the team members can’t do something, the other members come in to help out,” I said. “That’s what families are all about.”

For the first time since my illness, my son began to speak to me about how he felt when I was in the hospital.

“I’m so angry that those doctors took your legs!” Wes said.

“I know, honey,” I said, trying to soothe the pain, “but they had to, to save my life.”

“I was sick too, when you were in the hospital,” he replied.

“You were?” I asked.

“Yes,” he began in a small, shaking voice, “my head hurt, and my stomach hurt, and my heart hurt.”

Fighting back my tears, I replied, “But look at us now, Wes! We’re here, and we are strong! You are the strongest and most courageous kid I know.” I glanced again in the rearview mirror, needing to see if my words had connected with his heart. I noticed a small transformation taking place in my back seat. Wes was sitting up straighter, and a smile was beginning at the corners of his mouth.

“Yeah, I am strong, aren’t I, Mom!”

“Yes you are, Wes, and that’s what being a survivor is all about,” I told him.

“And, you and I, Wes, we are survivors!”

As we pulled into the driveway, Wes unbuckled his seat belt and loped across two lawns on his way to retrieve his brother. I sat for a moment in the front seat of my car, amazed at the healing that had just taken place in the confines of my car. Both of my boys emerged from Johnny’s front door, in a dead heat, racing for our house. Two beaming little faces lifted my spirits and warmed my heart. I shook my head slightly, got out of the car smiling, and walked to my front door.

*Photos courtesy of Cindy Charlton*
One Prosthetist’s Solution to

by Todd Norton, CP, LP, FAAOP

After years of seeing below-knee amputee patients come in wearing their prostheses incorrectly, I decided that I needed to do something differently. It became evident to me that the literature I was giving my patients didn’t include what I consider to be the most important information about how to use their prosthesis: donning and doffing, sock management and hygiene. Furthermore, patients didn’t appear to be retaining the verbal instructions I was giving them.

One reason why patients have such a difficult time grasping seemingly simple concepts became obvious: We are overwhelming our patients with a lot of information. I was surprised to see that, for instance, in 5 minutes of sock management instruction, there are 40 sentences that cover what patients need to know about the subject. That is a lot of information in a short period of time. No one could be expected to remember most of that information, much less all of it. And all of it is important!

In researching the extent of the problem, I found some studies that supported my hunch. According to John Frederick Jr.’s study, *A Survey of Prosthetic Sock Ply Management of Transfemoral Amputees: Patients’ Knowledge of Sock Management and the Relationship to Educational Needs of Amputees*, “Sixty-seven percent of amputees who come in for an adjustment are not wearing the correct number of plies of socks.” Also, according to Caroline Nielson’s study, *A Survey of Amputees: Functional Level and Life Satisfaction, Information Needs, and the Prosthetist’s Role*, “Forty-four percent of amputees wish they were receiving more instructions with their prosthesis.” Furthermore, Scott A. Hrnack’s study, *Literacy and Patient Information in the Amputee Population*, addresses the problem of the medical literacy gap: “The 12 most common brochures we give patients are written on an 11.5 grade level, while the average person’s medical literacy level is only a sixth grade level.” Together, these studies help confirm that there is a need for more appropriate information for patients. The effect of this problem is that prosthetists often see their patients wearing their prostheses improperly.

To solve this problem, I began to search for a way to educate my patients by demonstrating the concepts of proper prosthetic use in a practical way, and in a way that would help them retain the information. As a prosthetist, I believe that patients are ultimately responsible for their success with their prosthesis, but I wanted to find a way to empower my patients to be successful without overwhelming them.

The result was that I created a DVD called *Using a Below Knee Prosthesis*. Of course, it is not a substitute for prosthetic instruction, but I have found it to be an effective tool to assist in better educating patients. The DVD also stresses to patients (no fewer than eight times) to “discontinue use of their prosthesis and call their prosthetist” if they are having a problem. Prosthetists may find it useful in their practice, not just for the value of educating their patients but also for educating therapists, doctors and caregivers. The DVD can also result in significant time savings to both prosthetists and patients alike.

On my last day at Northwestern, one of my instructors offered this parting advice to the class: “Give back something to the field.” I hope, at least in some small way, this is what the DVD does.

*DVDs are available through Prosthetics 101, LLC’s Web site: prosthetics101.com. Future DVDs planned by Prosthetics 101 are an above-knee version, a Spanish language version and updated versions of each.*

*Editor’s Note: For videos on introductory amputee care, you may also visit the Amputee Coalition’s Web site at amputee-coalition.org/video/introductory_amputee_care.html or call 888/267-5669.*
Most people probably cannot imagine a life-threatening situation happening to them if they are healthy, and most people probably cannot imagine a situation in which their healthcare provider makes a life-threatening mistake. When Surriya Waheed entered the hospital for a stent connecting from her kidney to her bladder, she never imagined that it would cause her to become a bilateral lower-limb amputee and lose eight fingers at the knuckle. The journey was physically and emotionally painful as Waheed came to grips with the reality that she would not be the same active, mobile person she had been. The ordeal would have been too much for her to handle without the support of family and friends.

Waheed, born in Pakistan in 1944, immigrated to the U.S. in 1971 shortly after marrying her husband, who had a postgraduate medical research appointment. She was an avid traveler and managed a successful travel company. Her medical problems began when she experienced pain in her right kidney and difficulty in urinating. She was told that she needed ureteropelvic junction (UPJ) surgery due to scar tissue in her kidney. Although English is her second language, Waheed asked many questions and was not intimidated by the medical specialists. She had experience with medical terminology from dealing with her diabetes, and her husband and son are also doctors.

Soon after having the stent inserted, Waheed felt sick and had pain urinating. She was initially advised that the pain was normal, but when she later went to the hospital, a team of doctors discovered that she had developed urosepsis, blood infection caused by urinary tract infection. “I call it the ‘mother of all infections,’ since it was not responding to any of the medications the doctors gave me,” she says. “I have never felt so sick in my life.” Waheed’s body was fighting off a deadly infection, and she began to develop gangrene. She was put into a medical coma and woke up 2 weeks later without her legs or fingers.

Waheed felt that something had gone wrong with her medical treatment. She wondered how a healthy person like her could have a relatively simple surgery and end up nearly losing her life. Thus began the long journey of investigating her case. She pored over her medical records and hired an attorney to find out what really happened. A key factor in her case was an untested urine sample, which contained the bacteria that caused the urosepsis. Her case eventually went to trial, but the defendant offered a settlement before the verdict to cover her prosthetic and caregiver expenses.

With this traumatic journey behind her, Waheed is now trying to move on with her life. “When I walked into the hospital for the scheduled surgery and I came back without my legs, I had no idea what I would do and how I would live my life because I was so sick,” she says. “I made up my mind that I cannot live my life lying down in bed. I have to do something for myself.”

Part of this journey of recovery involved writing and self-publishing a book about her experience, titled Beyond My Imagination: Living Tragedy with Tolerance and Patience. “This was a very cathartic thing for me to do,” she acknowledges. “I want others to know that they can stand up for themselves to doctors who may not always be doing their best job.” Waheed has spoken to support groups about how to take action for themselves to ensure they receive proper medical care. The experience was and still is painful for her to accept, but Waheed is determined to make the most out of her situation and have a good life.

Surriya Waheed formed the Life for Limb Loss Charitable Foundation to support people with all kinds of disabilities. For more information, you may contact her at surriyawaheed@hotmail.com.
The Definition of Humor

hu • mor (hyōō’ mər) n. 1. The quality that makes something laughable or amusing; funniness.

On Derrick Lewis’ 35th birthday in 2007, his right foot went completely numb. The first he heard about peripheral arterial disease (PAD), the disease that caused this mysterious numbness and eventually took his right leg, was when the doctor removed a nickel-sized blood clot from behind his right knee. Four years later, he is still learning about the disease and realizes that if he knew very little about it, others at risk probably don’t know much about it, either. Since then he’s decided to help inform the public about the ravaging effects of PAD. Not only is Derrick a patient advocate for the prosthetic company New Life Brace and Limb, but he also puts his passion for helping others to use through his humor.

Despite a tragic encounter with this quiet, yet insidious disease, Derrick’s perspective is lighthearted. He approaches life – amputation and all – with humor. While in the hospital, he joked with others as a way to connect with them and to heal from the pain of losing his limb. He would frequently laugh with the nurses and physical therapists about being an amputee. They laughed along with him and told him that he should incorporate his funny ideas onto T-shirts for others to enjoy.

That was all the coaxing he needed. After Derrick received his first prosthesis and was able to return to some semblance of normal life, he created his own Web site for custom T-shirts for amputees: Ampuwear.com. He currently has four designs, but new T-shirts are coming soon. Derrick is also the cofounder of a Web site called Ampufreedom.com. With each of his endeavors, he hopes to inspire. He tells other amputees: "Losing a limb doesn’t mean you have to stop living."

Do amputees comment on your shirts?
I usually get positive responses like, "Hey, man, I love that shirt!" Or else I can hear them laughing as they pass me by: So far, I haven’t come across anyone who was offended by my shirts. I guess I’m not the only one with a crazy sense of humor!

How do you know when you have a good idea?
I always had a sense of humor even before losing my limb. I guess that sense of humor went up a notch after my amputation. I usually test out a new idea by printing a shirt and wearing it around town when I visit amputee patients at the local hospitals. I also post a picture of the new shirt on my Facebook page and see what type of response I get.

What do you tell new amputees who might be scared or upset and not in the mood for a laugh?
I tell them to keep their heads up; life isn’t over because you lost a limb. Every day, we are faced with obstacles and setbacks, and sometimes we just have to pick ourselves up and continue with our mission in life. Plus, I was always told that laughter is the best medicine.

Tell me more about Ampufreedom.com.
This is a site dedicated to amputees and others with disabilities. The site allows amputees to socialize with others like them. They can communicate through blogging, live chat and uploading pictures and videos.

After my amputation, I searched the Web for information pertaining to amputees. I came across numerous amputee social sites and I wasn’t impressed. So I brainstormed ideas back and forth with my father-in-law, and Ampufreedom.com was born. I’m hoping Ampufreedom.com can provide helpful information and the support needed to overcome their loss.

Derrick Lewis can be contacted by e-mail at ampuwear@yahoo.com. You can also find him on Facebook (Derrick Lewis) and on Twitter (@ampuwear) (@ampufreedom).
There are SOME things you simply CAN NOT control.

But there are some really important things you CAN …

... like keeping your family healthy and safe. The American Diabetes Association has a free booklet that can help you take control. It’s called “Planning For a Healthy Life” and it’ll help you do just that, with information on everything from healthier eating choices, choosing a doctor, and managing your finances … to planning for a secure retirement.

This booklet is for everyone who wants to live a long, healthy, happy, active life. Because the American Diabetes Association is concerned about the overall health of all Americans – not just people living with diabetes.

To get your free copy, call 1-800-DIABETES or go to diabetes.org/lifeplanner.

Order yours today. And take control of your life.
inMotion’s new Classified section provides another affordable advertising option, perfect for your advertising needs, including:

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inMotion 2011 Classified Ads

Rates

Up to 50 words................................. $100
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100–150 words............................... $200
Black & White Photo/Logo............... $50

Kim Phillips
Advertising and Marketing Assistant
888/267-5669
KPhillips@Amputee-Coalition.org

Classified ad contents are the sole responsibility of the advertiser and are not changed/edited in any way by inMotion staff. All advertising material is subject to Amputee Coalition approval. The Amputee Coalition reserves the right to determine the suitability of all ads submitted for publication and to reject those that do not meet the editorial standards of our Communications & Public Relations Department.
**The Alpha Select Locking Liner: Controlled Pistoning**

The Alpha Select Locking Liner combines many frequently requested liner traits into one product. Controlled pistoning is one of the leading liner characteristics desired by wearers of locking liners.

The one-way stretch fabric used in Alpha Select Locking Liners effectively controls pistoning without the use of a traditional rigid distal matrix, which can potentially irritate residual limbs. The one-way stretch fabric also provides tissue compression without uncomfortable pressure on the limb. Additionally, the fabric stretches circumferentially, allowing for easy donning of the liner for a variety of limb shapes.

The Alpha Select Locking Liner features a unique accordion umbrella that is sized to each liner to maximize comfort and fit. The shape of the accordion umbrella blends into a patient’s anatomy for an almost unnoticeable feeling.

For more information, ask your prosthetist or visit Ohio Willow Wood at www.owwco.com.

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**New SleeveArt® Style**

You asked for it, so we got it! Digital Forest Camouflage is the newest addition to our collection of more than 70 styles. Available as a prosthetic cover or a laminating sleeve, Digital Forest Camo is a cool design.

SleeveArt® prosthetic covers are fabricated from spandex. They stretch to fit over your prosthetic leg or arm. Available in various widths and lengths, there is a right size for anybody. They add a slippery feel to the prosthesis and eliminate the problem of pants clinging. Our laminating sleeves can be used by your prosthetist to create a permanent design on your new leg.

For more information, please visit our Web site at sleeveart.com. If you don’t have access to a computer, just call Joanne at 954/646-1026 and she will mail you a flyer.

Fred’s Legs, Inc. • Dania Beach, Florida

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**President of Amputee Support Group Counts on the LegSim for Easy Mobility**

My name is Mary Petrarca, and I am the president of EnMotion, a CNY amputee support group. I have been an avid user of the LegSim for the past 4 years, since my prosthetist helped me get one. The LegSim has literally been a lifesaver. I have had issues with sores and a poorly fitting prosthesis for years and when unable to wear my prosthesis, I could always count on the LegSim. The LegSim is always a perfect fit. I can go shopping, do dishes, laundry, housework, cook or even carry my grandchildren while using my LegSim.

It is lightweight and so easy to use. I have comfort knowing it stands ready by my bedside in case of any emergency.

I was up and walking with it in no time at all. I would highly recommend this to everyone who is an amputee to make your life so much easier.

Call 313/735-1659 or visit LegSim.net to see videos.


“Health Awareness Events.” May/June, p. 58.

“Health Events Calendar.” Sep/Oct, p. 15; Nov/Dec, p. 16.


“Staying Fit With Limb Loss.” Jan/Feb, pp. 32-33.


“Staying Fit With Limb Loss.” Jan/Feb, pp. 32-33.

“Online Therapy and Social Interaction.” May/June, pp. 53-54.

“Online Friends, Strangers and Stalkers.” May/June, pp. 55-56.


“Staying Fit With Limb Loss.” Jan/Feb, pp. 32-33.

“Ask the Physical Therapist.” Jan/Feb, pp. 33-34.


“Climber Aims to Inspire ACA Campers.” May/June, pp. 40-41.


“How to Be a Good Patient.” July/Aug, pp. 18-19.

“How To Finish or Not To Finish.” Mar/Apr, pp. 34-35.


“Upper Extremity.” July/Aug, pp. 52-56.


“Phantom Pain and the Brain.” May/June, pp. 36-37.


“Online Therapy and Social Interaction.” May/June, pp. 53-54.

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Need a new prosthesis? A prosthetist? A funny T-shirt? If so, visit the Amputee Coalition's new online 1-Step Products & Services Information Center. Visit amputee-coalition.org and look for the 1-Step Products & Services Information Center at the top of the navigation bar of our home page. Visit Today! The center is growing daily, so come back often.

Amputee Coalition Confidentiality Policy

The Amputee Coalition has a strict policy of confidentiality for all individuals on the Amputee Coalition’s database and mailing lists. As part of our mission to educate our members, the Amputee Coalition works with its partners, sponsors, and other allied health organizations to provide information on the latest technology, healthcare practices and reimbursement issues that affect this community. THE AMPUTEE COALITION DOES NOT RENT OR SELL THE MAILING LIST AT ANY TIME. All correspondence sent to our mailing list is through a secure mail house and is never released in any way to any organization or company outside the Amputee Coalition. If you do not wish to receive this information, contact the Amputee Coalition and we will activate an opt-out option on your database record. You will continue to receive your magazines but will not receive any healthcare or product updates. If you have any questions regarding the Amputee Coalition’s confidentiality policy, please contact us at 888/267-5669.

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For more information go to AOPAnet.org, AMPUTEE-COALITION.ORG, or ARMSANDLEGSARENOTALUXURY.COM.