January/February 2012
Volume 22, Issue 1

inMotion

All in the Family

The Power of Family Support

Rubber Chicken Soup for the Soul

Adventures in International Adoption

A Publication of the amputee coalition

MESSAGE FROM THE EDITOR

All in the Family

"The family. We were a strange little band of characters trudging through life sharing diseases and toothpaste, coveting one another's desserts, hiding shampoo, borrowing money, locking each other out of our rooms, inflicting pain and kissing to heal it in the same instant, loving, laughing, defending and trying to figure out the common thread that bound us all together."

– Erma Bombeck

Your family – wife, husband, daughter, son, parents, grandparents and beyond – is the most precious resource you have. It's up to all of you to look out for each other.

This issue of *inMotion* explores various aspects of the dynamics of a family with a family member living with limb loss, including observations on raising a child with a disability, advice written by young amputees for young amputees, and the power of family support.

It is no secret that parenting a child can be a challenging prospect at times. But the challenges (and rewards) take on an entirely new dimension when the child lives with a disability such as limb loss or limb difference.

Many individuals promise to love their spouse or partner "in sickness and in health." But chronic medical conditions or a disability such as limb loss can test even the strongest relationships.

Whether the person with limb loss is a child or an adult, and regardless of the cause, limb loss can affect mobility, social and leisure activities, comfort level and mood. These changes can be temporary or enduring, and they vary from one person to the next.

Some people may try to minimize the help they need in an effort to maintain their independence or they are concerned about feeling that they are a burden to those who care about them. Others may worry about not finding *enough* help to meet their needs. There is no single "best" or "right" way to cope.

But how we deal with these challenges and successes defines who we are as individuals and as families. Communication is the key to coping successfully with the emotional, physical and financial issues that will be encountered. In fact, rather than creating division, many families find that handling such issues together can actually deepen family bonds.

Bill Dupes, Senior Editor

inMotion

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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.

inMotion
A Publication of the Amputee Coalition

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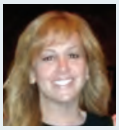

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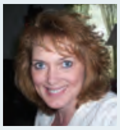

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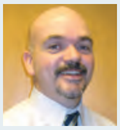

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Advertising Policy

About the Cover

Image of EJ and Cathy Skaife courtesy of Prosthetic Laboratories.


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Quality for life

Longtime COO Finds It Hard to Part With the Limb Loss Community

by Scott McNutt

Time Present

Patricia Isenberg, chief operating officer of the Amputee Coalition since 2002, retired at the end of 2011. But don't say goodbye just yet.

Terming herself "semi-retired," she says, "It is difficult to leave the limb loss community because I have built so many relationships in it; I admire so many people in it."

Asked to continue her work with the Peer Visitor Program training and the Veterans Administration, PALS and peer visitor initiatives, Isenberg is "more than thrilled to do that."

Time Past

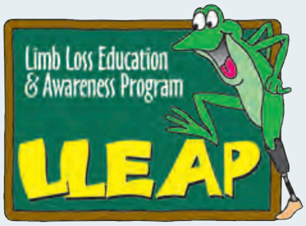
Isenberg joined the Amputee Coalition in 2000. With Bachelor's and Master's degrees in Special Education, a Master's in Clinical and Counseling Psychology and a Minor in Adult Education, she taught at the elementary and secondary levels, worked with institutional care facilities and community action agencies, and was founding executive director of an Alzheimer's day treatment center.

Having just finished 12 years at the Alzheimer's center, in 2000, she was searching for something different.

"All of my work had been in the field of disabilities, mostly working with very severe conditions as well as deteriorating conditions," she explains. "Both emotionally and professionally, that took a lot out of me. So I was looking for a different way to serve the disability community."

The disability advocate found it when she applied to the Amputee Coalition, and when the Coalition hired her shortly thereafter, it gained an innovator who created new programs for the organization and enhanced established ones.

A string of accomplishments followed. Isenberg immediately began developing the Limb Loss Education and Awareness Program (LLEAP), a program for schoolchildren focusing on disability awareness and specifically on the needs of children with limb loss.



At the same time, she worked with members of the Amputee Coalition Medical Advisory Committee to develop a curriculum to educate healthcare providers about the psychosocial, physical and rehabilitation needs of people with limb loss.

Isenberg also saw the need to overhaul and revise the Amputee Coalition's Peer Visitor Program. At the time, training was not standardized, with no national certification for trainers or peer visitors.

"I did it because it was something that needed to be done," she says. "I recognized the gap between where the Amputee Coalition Peer Visitor Training Program was and what national standards for certified training programs should be."

With help from staff and volunteers, Isenberg developed the program materials and created the standardized training protocol. The first Train-the-Trainer seminar was presented in 2002.

"Our educational materials and events target the brain," Isenberg explains. "Our Peer Support Program targets the heart. It's about helping people recover from something devastating – the loss of a limb or the birth of a child who's

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Pat Isenberg and members of the Wounded Warrior Project


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SPECIAL MESSAGE continued

missing a limb. How you recover emotionally from such an event affects how well you recover physically."

Peer support is proven to help that process, she adds.

In 2002, Isenberg became chief operating officer of the organization. Paddy Rossbach had recently agreed to become president and CEO and recognized the pair's complementary skills.

"She was on my peer visitor committee, and we worked on the healthcare provider curriculum," Isenberg says. "We worked very well together. It just made sense."

Isenberg would go on to develop many other programs and products for the Amputee Coalition. Recognizing that the vast majority of people with amputations are age 55 and older, she directed the publication of *Senior Step: A Guide for Adapting to Limb Loss* in 2004.

She also collaborated on several other initiatives, such as the Promoting Amputee Life Skills (PALS) self-management program and its spin-off, PALS Plus, and the organization's continuing relationship with the Centers for Disease Control and Prevention and Johns Hopkins University.

Present in Time Future

Looking back on her time with the Amputee Coalition and ahead to her continuing involvement, Isenberg says, "I'm proud of the work we've done. We've built many strong programs, which I'd like to see grow beyond my time with the organization."

However, she does see more time for herself and her family in the future.

"I'm going to be quilting, traveling and spending much more time with my family," she says. "They've missed me."

MAILBOX

We Want to Hear From You!

To better meet the needs of our readers and potential readers, we recently conducted a survey of our members and convened an editorial board to chart the course of *inMotion* for 2012 and beyond.

Based on the survey results and the recommendations of the editorial board, readers of *inMotion* will be noticing some changes in design and content in 2012 that are aimed at making the magazine easier to read and more reflective of the types of articles that our readers have been requesting. Examples of planned editorial changes include more helpful health tips and an increased emphasis on useful information for living with limb loss.

You can help – we would like to hear from *you*. Please share your tips for performing activities of daily living and your personal success stories of solving challenges. Or just drop us a line to let us know how we're doing or to share a story idea.

inMotion welcomes letters, faxes and e-mail. Mail should be addressed to Amputee Coalition, *inMotion* Magazine, 900 E. Hill Ave., Suite 290, Knoxville, TN 37915.

Our fax number is 865/525-7917.
Our e-mail address is editor@amputee-coalition.org.

All correspondence should include the writer's name, mailing and e-mail (if applicable) address and daytime telephone number. Correspondence may be edited for purposes of clarity and space.


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Help Make the Voice of the Limb Loss Family Heard

by Dan Ignaszewski

The Amputee Coalition's Government Relations Department is starting the new year with ambitious goals and targeted legislative priorities to continue to represent and support the limb loss community. There are opportunities this year to have a significant impact on the future of insurance coverage for prosthetic and custom orthotic devices. Opportunities to ensure elderly and disadvantaged populations maintain needed coverage for their prosthetics in Medicare and Medicaid. There are even ways you can help to raise awareness for the limb loss community, make travel more reasonable and work to ensure fair treatment and access under the Americans with Disabilities Act (ADA). Start 2012 by supporting the limb loss community with your passion and voice and make a difference in your community.

The Amputee Coalition's legislative priorities for 2012 are:

Essential Health Benefits

The essential benefits set is the required benefits for all insurance products sold in the state and federal insurance exchanges. Ensuring that custom orthotics and prosthetics is covered in this essential benefits set is a priority for the Amputee Coalition because their inclusion could greatly improve the coverage of these services throughout the private insurance system, and provide guidance for programs like Medicare and Medicaid for coverage.

Advance Insurance Fairness for Amputees

The Amputee Coalition has worked toward advancing legislation on a state and federal level to ensure coverage for prosthetics and custom orthotics. With the guidance of the Coalition and the hard work and determination of local advocates, 20 states have passed laws, and the effort to pass this federally and in the remaining 30 states remains a top priority.

Reasonable Travel for Amputees

Travel barriers, including the TSA's excessive and invasive screening procedures at airports, continue to be a problem for amputees. The Amputee Coalition will gather information from amputees who travel through airports about their travel experiences, and we will work with the TSA to encourage reasonable and appropriate screening for the limb loss community and work toward establishing effective and viable options for frequent travelers.

Limb Loss Awareness Month

In order to continue to bring attention to the needs of amputees and for prevention of limb loss, the Amputee Coalition will seek a presidential proclamation declaring April as National Limb Loss Awareness Month.

Securing Funding for Limb Loss Initiatives

The Amputee Coalition will work to secure federal funding for resources, services and support to serve the needs of the limb loss community. This includes maintaining current CDC funding for limb loss, as well as looking for other opportunities in partnerships with federal and local agencies, disability groups and broader coalitions.

Working in Coalitions With Other Advocacy Groups

The Amputee Coalition will continue to build upon our relationships and partnerships with a number of organizations and work to include limb loss issues into the agendas of these coalitions. Coalitions of interest include the larger disability community, the

Veterans Administration, the O&P industry, healthcare and public health organizations, the Consortium of Citizens with Disabilities (CCD), the National Health Council and the NCBDDD Disability Coalition, to name a few. We will work together on a variety of issues affecting the limb loss community, including licensure, veterans access, Medicare/Medicaid requirements/audits/cuts, medical device tax, ADA compliance issues and funding for research and services that will impact the limb loss community and/or prevent limb loss.

With these priorities, the Amputee Coalition will continue to be a leading voice representing the limb loss community and be an important leader in the larger disability community. Our voice can become even stronger with the involvement of members like you. The limb loss community is a unique family, and as with any family, there lies a responsibility. Our family needs to be strong advocates. The limb loss family needs to remain together and make our voices heard. Become a friend of the Amputee Coalition. Get involved. Make a positive difference in the lives of your family, your friends and your community.

You can work with your state governor's office to get a gubernatorial proclamation signed in your state to declare April as Limb Loss Awareness Month and work to host activities in April. And you can make sure the Americans with Disabilities Act is being followed and that amputees are guaranteed full participation in society, regardless of disability.

Get involved and become an advocate today. It can be as simple as sending an e-mail or calling your legislative representatives, or you can be more involved by leading efforts to get legislation enacted and signed into law. You can help us tackle the Amputee Coalition's legislative priorities, become a leader in your community and make a change for the better. We look forward to the challenges of 2012 and hope to work with our family in the limb loss community to continue to make a positive difference for you.

EVENTS CALENDAR

NATIONAL BIRTH DEFECTS PREVENTION MONTH

nbdpn.org/national_birth_defects_prevent.php

JANUARY 1 TO MAY 15

Biking for Brains
Ride Across America
Coronado, California
woundedwarriorproject.org

JANUARY 14

First Volley Adaptive
Tennis Clinic (OPAF)
Cherry Hill, New Jersey
opfund.org

JANUARY 29

Taste to Educate
cancerforcollege.org

JANUARY 31

San Diego Triathlon Challenge
San Diego, California
challengedathletes.org

AMERICAN HEART MONTH

heart.org

LOW VISION AWARENESS MONTH

preventblindness.org

NATIONAL HEART FAILURE AWARENESS WEEK

February 12-18
abouthf.org

NATIONAL WISE HEALTH CONSUMER MONTH

aipm.net/wise

FEBRUARY 3

National Wear Red Day
(National Women's Heart Day)
www.nhlbi.nih.gov/educational/hearttruth

FEBRUARY 4

Wheelchair Lacrosse Clinic
Deni and Jeff Jacobs
Challenged Athletes Center
San Diego, California
challengedathletes.org

FEBRUARY 12

First Dance Clinic (OPAF)
Crystal Lake, Illinois
opfund.org

FEBRUARY 12

Miami Tour de Cure
Historic Virginia Key
Beach Park, Florida
diabetes.org

FEBRUARY 12

Ides of March Concert
Stafford, Texas
woundedwarriorproject.org

FEBRUARY 25

Bay Area Cycle Challenge
San Francisco, California
challengedathletes.org

FEBRUARY 25

Relay For Life
Thousand Oaks, California CA
cancer.org

FEBRUARY 26

Amputee Bowling Day
Columbus Square Bowling Palace
Columbus, Ohio
Marc Rohner
mrohner@juno.com

HUMOR:

Rubber Chicken Soup for the Soul

by Terrence P. Sheehan, MD

Life can throw some interesting challenges our way – some positive, some not so positive, depending on one's perspective. Marriage, a new baby, a new job, retirement, cancer, limb loss, etc. – all are life-changing events. Change is a disruption of what was; no matter how you look at it, it can be stressful. How we respond to change defines the experience and shapes the outcome.

A number of studies have demonstrated relations between the number of recent life changes and subsequent poor health, disease and accidents, depressed moods, anxiety and various forms of emotional disruption. There is also considerable support in behavioral research literature that humor reduces the harmful impact of stressful experiences, particularly the level of mood disturbance.

We could learn a lot from children about coping with life's challenges. Their natural joy and boundless energy and curiosity endow them with the resilience to roll with the changes. The Greek philosopher Heraclitus, whose teachings maintained that strife and change are natural conditions of the universe, perhaps said it best: "We are most nearly ourselves when we achieve the seriousness of the child at play."

Laughter Is the Best Medicine

The notion that humor possesses therapeutic properties can be traced back at least as far as the ancient biblical maxim that "a merry heart doeth good like a medicine" (Proverbs 17:22). Of course, humor and laughter won't "cure" a person with limb loss or limb differences, but they can be useful tools in handling challenges on a daily basis.

So how do you get to the "funny part" after limb loss? First, share your experience with family and friends, but, more importantly, find others who have experienced similar loss (peers) and share with them. You need to express the pain, anger, grief and frustration before you, and only you, can define "what's so funny" after limb loss. If you are overwhelmed by the loss, speak with your doctor; other avenues may be helpful, such as talk therapy with a psychologist and/or medication for anxiety and depression. Just as humor can lift your spirits and change your body's chemistry, depression can disrupt the chemistry of emotion modulation to the point that medication may be needed to jump-start the system into "feeling" better.

In my experience working with people with limb loss, I've found that the response just after surgery sets the tone of the initial rehabilitation phase. It is, therefore, important to present a new amputee with a group of knowledgeable, compassionate people, both professionals and peers, who can provide a vision of "what can be." This team process of goal setting and vision attainment can't occur if the person is sent to a nursing home or directly home. The team process is an exciting event in which the challenge of change meets the resilience of the human spirit. It takes time, hard work, painful adjustments, tears and frustration – and a lot of laughs.

Yes, laughs – from quiet giggles and chuckles to sidesplitting belly laughs. For all of the people whom I've had the privilege to work with after their limb loss, humor has played an important role in reducing stress, drying the tears and celebrating our humanity.

It's All in How You Look at Things

Humor may have evolved as a uniquely human strategy for coping with stress. Humor can be regarded as essentially a sudden shift in cognitive perspective. It is this flexibility to shift perspective that allows us to distance ourselves from the immediate problem, to view it from a different angle and, therefore, to reduce the often paralyzing feelings of anxiety and helplessness.

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The philosopher Epictetus once said, “Men are disturbed not by things, but by the view which they take of them.” A modern-day philosopher, Billy Joel, can also be quoted from his lyrics, “I’d rather laugh with the sinners than cry with the saints; the sinners are much more fun.” Laughter is fun, and it involves letting go of the woe. It restores our sense of control and allows us to connect with others through shared – often difficult – experiences. Limb loss is no laughing matter, but the pain of loss and the hard work of rehabilitation can be cushioned by humor. It allows us to step out of ourselves to appreciate and accept our lack of perfection (our humanness), giving our weary hearts a restful moment.

Support: It’s All in the Family

Two weeks before I got married, I was sitting in the living room of my future in-laws’ home, bonding with my future father-in-law, Charlie. Charlie abruptly paused in our conversation to stand up and go to the kitchen sink. There, he proceeded to spit up bright red blood. No warnings, no complaints, just plain hemoptysis (a fancy medical word for spitting up blood). I had just officially finished medical school a few days earlier, and I had enough sense to know this was not a good thing. Actually, I knew that this was cancer unless proven otherwise.

The wedding was fabulous; Charlie walked down the aisle with “my girlfriend” and danced with his little girl (his seventh child) without a hitch. He had his lung removed while we were on our honeymoon. Needless to say, this was a stressful situation, but natural humor bubbled throughout that whole period, and the memories are cherished and filled with great laughs today.

“Dad” had his share of ups and downs during his recovery; he became sluggish, worn out from chest pains, loss of appetite, shortness of breath with just walking to the bathroom, etc. He declined household duties and invitations out of the home, explaining that he had only one lung. But his wife and family wouldn’t put up with such an excuse and pushed Charlie back into life. He became known as “One-Lung Charlie” within the family, and there is still a chuckle to this day when using this reference. He regained his appetite for food and life, developing the stamina to walk several miles each morning and to return to work. With his family’s support, he beat the cancer with few tears and many laughs.

Rubber Chicken Soup for the Mind and Body

The fact that we usually feel better when we laugh suggests its therapeutic properties. There has been support for the emotionally therapeutic value of humor as a coping mechanism, as a relief of tension, as a survival mechanism and as a defense against depression. I read many pieces of behavioral research on humor in preparing for this article (none of them funny, but interesting, nevertheless). The focus was on understanding how humor benefits us in stressful situations. The higher the research subjects scored when measuring their sense of humor, the less depression of mood was produced by negative life events.

Humor appears to have a positive physiologic impact as well. Laughter initiates a complex system of exchanges between physiologic and psychological processes. The objective measures of heart rate, respiration and oxygen exchange increase during laughter as the body “revs up” physiologically. Indeed, the writer Norman Cousins once quipped, “Hearty laughter is a good way to jog internally without having to go outdoors.” His autobiographical account is a case in point. Suffering from an extremely painful disease, Cousins found that 10 minutes of belly laughs had a soothing effect, providing at least two hours of pain-free sleep without other pain medication. This suggests that laughter may stimulate the production of endorphins and other pain-modulating substances within the central nervous system. Cousins’ apparent complete recovery from this disease provides anecdotal evidence of the beneficial effects of humor and laughter on the physiological mechanisms of the body.

Plan to Be Spontaneous Tomorrow

There is a spontaneous nature to humor, but just waiting for it to happen is not enough. It’s not a passive process. You need to actively look for humor, find or create it, make it your own and share it. A patient I work with does a comedy routine in his senior living community. During each of our visits, he tells me many jokes, occasionally bordering on the risqué. He prepares and shares his humor. I perpetuate it by sharing it with patients and colleagues (when appropriate).

You’ve probably noticed that laughter is often contagious, if you allow it. If you’ve ever observed a group of children inexplicably collapse with laughter, you know what I mean. It starts with one child trying to stifle a giggle and failing miserably, and it quickly spreads like ripples in a pond. If you’re fortunate enough to experience such a moment, allow yourself to jump in and join the fun. Be a proud parent of your inner child. Rediscover and embrace it. Run with it. Just be sure to look both ways before you cross the street.

A Family Travel Survival Guide

by Debra Kerper

The new year has just begun, but it's never too early to start thinking about and planning your next family vacation. Spring break is just a couple of months away, and summer will be here before you know it! Planning ahead is even more important when a family member has special needs to be taken into consideration.

If you are traveling with a child, there are some tried and true destinations that will provide an outstanding experience for all. Disneyland and Disneyworld never disappoint, and visitors of all ages can take advantage of the excellent access provided in the parks as well as in the resort hotels. Be sure to request a Disney Access Guide from the Guest Relations Office prior to heading off on your adventure. The guide will give you detailed information on which rides are suitable for wheelchairs and where to enter the ride. Park employees will stop a ride so that someone with mobility issues can enter and exit the ride safely. There are even some rides that are fully accessible to wheelchairs and allow the user to remain seated without having to transfer.

San Diego is one of the most accessible cities you can visit and is full of wonderful venues to explore. The city offers an Accessible San Diego guide, which can be ordered online at asd.travel. Be sure to visit the world-famous San Diego Zoo and SeaWorld while you're there. If your child or other relative uses a wheelchair or scooter, purchase your tickets at the guest services booth and one caregiver will be given free admission.

Cruises are always a great choice for anyone who has special needs, and they're a perfect way for a multigenerational group to spend quality time together while still having the opportunity to pursue their own interests. All major cruise lines have excellent children's programs and will go out of their way to include all children. Ask your travel agent to contact the access department so the head of the children's program will be aware of any special needs your child may have. Parents are given pagers and are contacted immediately if their child needs them.

Start making lists of everything you will need to bring with you as soon as you decide that you will be taking a trip. If this is the first time you or a family member is traveling as an amputee, you may want to ask your prosthetist for advice on what type of prosthetic supplies to pack. Extra liners and socks are a must, as well as any tools you may need to make adjustments. Don't forget any medicated creams and ointments you use, as well as antibacterial and alcohol wipes. People with diabetes should pack an ample supply of test strips, needles and syringes, meter batteries

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TRAVEL & ACCESSIBILITY continued

and proper snacks to combat drops in blood sugar levels. You never know if you may be sitting on a runway for a long time due to weather or other conditions. Organized parents will have children who are easy to travel with. Don't forget their favorite toys, pillows, blankets and snacks in addition to medical supplies!

Older amputees who are less experienced travelers tend to be more stressed at the prospect of traveling to an unfamiliar destination. Many adults with a recent amputation will feel that their world is changed forever, and many of the activities they previously took for granted will no longer be possible, not the least of which is their ability to travel. Information and education is the key to seeing the world with reduced mobility. Various types of mobility aids, including wheelchairs, scooters, walkers and canes, can make travel easier. There are companies that will deliver mobility aides to your hotel room or cruise ship cabin and other companies who provide luggage delivery ervices. Don't hesitate to call ahead and ask lots of questions about access and accommodations. Become familiar with Transportation Security Administration (TSA) guidelines for people with special needs and medical conditions.

People with disabilities do not have to remove their shoes, and you should never have to remove your prosthesis. TSA has recently implemented a telephone hotline (855/787-2227) to answer questions for people with disabilities; the line is in operation 9am-9pm EST. It is recommended that you call this number 72 hours prior to travel. Travelers can also ask for a supervisor if they have questions about the screening procedure when they are at the airport. For more information, refer to the TSA Web site and check out the section that best describes your situation at www.tsa.gov/travelers/airtravel/specialneeds.

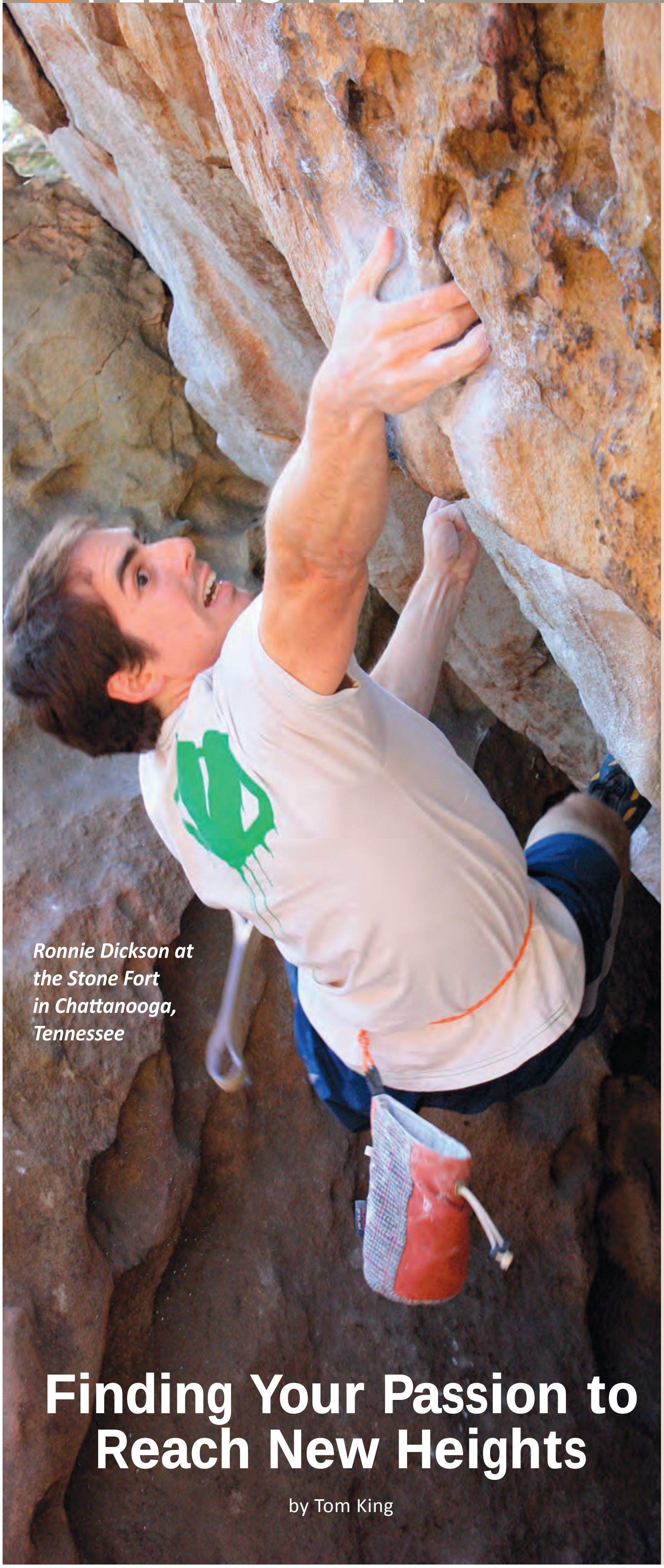
And don't forget to visit the Amputee Coalition Web site for more tried and true travel tips!

Travel Tips Checklist

- ✓ Always pack medication and necessary medical supplies in your carry-on. Never pack medication in your checked luggage.
- ✓ Have a list of your medications and dosages and how it is taken. Give a copy of this list to someone who is traveling with you.
- ✓ Airlines may not charge to transport medical equipment as long as it is not packed with any personal items. Pack all supplies in a separate bag and label as "Medical Supplies."
- ✓ If you encounter any problems with airport personnel, ask to speak to a Complaint Resolution Officer (CRO). Airlines are required by law to have a CRO available in person or by phone at all times when airline counters are open.
- ✓ If you use a travel agent, be sure to use the services of one who understands and is familiar with your special needs.
- ✓ Pack a smile and a good attitude and enjoy your trip. The world is waiting for you!

Finding Your Passion to Reach New Heights

by Tom King



Ronnie Dickson at the Stone Fort in Chattanooga, Tennessee

Photo courtesy of George Yaeckel

Ronnie Dickson, an above-knee amputee with a passion for adaptive rock climbing, will share his story and his passion with the NYU Support Group in New York City, thanks to a $500 grant from the Amputee Coalition's Support Group Network Grant Program.

The grant for the NYU Support Group was part of $10,000 in grant money that was available from the Amputee Coalition. The grant sizes ranged from $100 to $500. Amputee Coalition Volunteer Coordinator Kim Henshaw says that 27 grants were awarded in 2011.

Ronnie, 24, lives in Orlando, Florida, and for two years has been making prosthetics at Prosthetic and Orthotic Associates. He loves to share his rock-climbing skills with the amputee community across the country. "I started rock climbing 5 years ago, and it changed my life," he says. "It's such a positive experience, and I enjoy sharing that with amputees and letting them know that you can accomplish anything you put your mind to."

At age 5, Ronnie was diagnosed with Trevor's disease, a bone disorder that causes growth plates in the limbs to expand unevenly. Growth in his left leg lagged behind the right leg. When he was 10, he had surgery on the leg to lengthen the bones. It worked – for a while. Then large tumors began growing in his knee and ankle, eventually altering his range of motion. When he was 18, he made the decision to have the leg amputated above the knee instead of enduring a series of corrective surgeries that he says may or may not have helped.

Looking forward to speaking to the NYU Support Group, Ronnie says, "I will share with them my experiences as an amputee, but I want to convey to them that everyone can find their passion as well and to go for it. Rock climbing is intimidating, but if I can do this, then you can do anything. In these days, as an amputee, there are lots of opportunities out there for you to find what you love and develop your passion for it, whatever the sport or the activity."

The prosthetics and orthotics graduate of St. Petersburg College in Florida adds: "We are all capable of much more than we could ever dream of. It just takes the vision and the belief that it is possible. I realized the only limits we have are those we impose on ourselves. It may not be

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rock climbing. It may be something else. But you've got to find what you love to do and just do it."

The NYU Support Group, which meets monthly at the Rusk Institute of Rehabilitation Medicine, has between 150 and 200 members, according to Dr. Jeffery Heckman, medical director of the Amputee Rehabilitation Program at Rusk. The group has been meeting monthly for 3 years.

Ronnie will be doing his climbing in a facility in Brooklyn, Heckman says. "We are about building self-esteem, and having Ronnie here to tell his story and show us his story will be very inspirational," he adds.

If you would like to learn more about the NYU Support Group, you can visit their Web site at amputee-support.med.nyu.edu.

Photo courtesy of Devaki Murch

Ronnie Dickson bouldering in the New River Gorge, West Virginia

Spreading the Word

With the help of a film crew from Louder Than 11, a rock-climbing promotion organization based in Charlotte, North Carolina, Ronnie is featured in an inspirational video of his climbing that he hopes to distribute to amputees. Amputee Climbing: The Ronnie Dickson Project, vimeo.com/13934033 Video Link

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Dream On

Love and support inspires success

by Amy Di Leo

With love, anything is possible and that love can come in many forms. It can be the support of parents who help a child achieve his or her dreams when the world says, "you can't." It can be a community coming together to help a couple rebuild their lives after a terrible accident. Or it can be the love of a woman who helps a broken Iraqi War veteran find himself again.

There is an old song called "Love Me and the World Is Mine." Nothing rings more true in the stories of Tony Memmel, Jimmy Ardis, Cathy and EJ Skaife, and Bobby Lisek.

Jimmy Ardis and Tony Memmel experienced a powerful supportive love starting at very young ages. In fact, it helped them achieve their dreams – Tony's, to become a professional musician; Jimmy's, to be a cross-country truck driver – both men doing so without their left arms.

When Tony Memmel was born in the mid-1980s in Waukesha, Wisconsin, he was born without his left forearm. Though he says his parents were "pretty shocked" because no ultrasound showed it, he explains, "My arm was pretty much a nonissue most of the time. I wasn't coddled. They made me figure things out on my own and didn't give me much special treatment … my support system forced me to be strong and to learn independence."

That "tough love" approach seems to have worked. Tony says he was a skilled athlete and musician and was popular in school because of his attitude. "Upon first impressions, some people wondered how to treat me, but I showed them what I was capable of, and I've always maintained a pretty positive demeanor," he explains. "From an early age, I began teaching others around me how I was going to live my life."

Although Tony's parent's showed him that a prosthesis was an option, Tony preferred not to use one. He learned to play baseball, figuring out how to hold a bat and quickly switch his glove off and on his right hand to field and throw. He also made the high school baseball squad and was captain of the high school soccer team. He also dabbled in street hockey, basketball and any other game the neighborhood kids were playing.

Tony has had an affinity for music his whole life, but he developed a strong interest in guitar at the age of 13. That's when he found his mom's old instrument in a closet and started playing around with it.

Tony says, "I learned that I could actually buy a left-handed instrument, so one night at dinner, I revealed to my mom and dad that I wanted to really learn how to play and that left-handed models would make it possible. My parents met me with some skepticism. They expressed their concern that my interest could very well be a passing craze and that they weren't going to buy

Pictured above:
Tony and Lesleigh Memmel

me an expensive guitar 'just to collect dust in the corner of my room.' So I proposed we split the cost. I had to raise about $250 to reach my side of the deal, and I did. I saved all of my birthday and Christmas money. I babysat like there was no tomorrow and added many new chores to my workload to earn the necessary cash. I finally earned my guitar toward the end of 8th grade. [It was] a midnight-blue Fender Stratocaster."

A completely self-taught guitarist, Tony learned by emulating other players' techniques and picked up chords from an old book he found in his mom's guitar case. "My current method of using Gorilla Tape to secure a pick to my arm took me about 8 years of tinkering to develop," he explains. "I tried many different tapes, glues (which I don't recommend) and adhesives to get the feel I was after, and Gorilla Tape has been the answer."

Today, Tony is a professional singer/songwriter who plays guitar, piano and harmonica in his three-piece Americana folk rock band. Tony has been called "the best one-armed guitarist in Wisconsin." He is a classically trained vocalist who has earned a Bachelor's degree in music from the University of Wisconsin, Oshkosh.

Tony met his wife, Lesleigh, on his first day of college. Lesleigh recalls, "He walked in [to chamber choir class] and I said he could sit next to me, and we were instantly very good friends. We started dating a while later, and here we are." Lesleigh says music is a big part of their relationship. Lesleigh sings backup and plays piano and keyboards in the band; a friend, Brian Farvour, plays drums and percussion.

Lesleigh works full-time as a registered nurse, but her schedule enables her to tour with the band. They have toured throughout the country and have an upcoming spring tour. More information on Tony, his touring schedule and his music can be found at tonymemmel.com.

In the same way Tony's family supported him in his youth, Lesleigh helps him to thrive today. "Lesleigh is indeed a major support for me," he explains. "She contributes a great deal to my business, to my music, and to my home life. We are a complete team and I don't know where I'd be without her."

And the feeling is mutual. Lesleigh says, "I love being married to Tony. He's always been my best friend, and he's such a good leader – for our family, the band, everything. He's a hard worker, and he's so passionate about what he does. I respect, love and support him with my whole heart."

Jimmy and Debbie Ardis

Overcoming Obstacles

Like Tony, Jimmy Ardis of Sumter County, South Carolina, had a dream, and no one was going to stop him from achieving it. At age 6, Jimmy was diagnosed with cancer and his left arm had to be amputated. Jimmy explains that, much like Tony's parents, "From the start [my mom and dad] helped me to understand that I had a choice to make: I could sit back quietly and be known and pitied as the boy with one arm, or I could step up, accept the cards I'd been dealt and become known for my personality and other talents. I chose the latter."

Jimmy goes on to say that he's sure people notice that he doesn't have an arm, but he knows that's not what defines him. "Anyone who knew me [when I was younger] will tell you that through school I became known much more for my outgoing, boisterous, 'life of the party' personality. Even as a child, I never met a stranger, and after conversing with me, most people didn't, and still don't, notice my 'disability'; rather, [they see] my willingness to try just about anything." For Jimmy, that means hunting, fishing, shooting pool, bowling, dancing, riding a mechanical bull and golf.

Jimmy adds, "Obviously, there were certain hurdles I had to overcome, but I played sports – baseball and football. I learned to move the baseball glove very quickly from catching to throwing. In fact, the only thing that gave me a problem, and still does, is tying my shoes. Other than that, I've learned to adapt and do anything I want."

The biggest "want" in Jimmy's life from the time he was a boy was to be a long-distance truck driver. He started driving trucks in 1976 and in 1979 applied to the trucking program at Sumter Technical College. That's where he started hitting roadblocks.

"[I] was told that because of my 'condition' I would need to jump through many hoops. In fact, at the DMV I was singled out and told that I would never be able to get my commercial driver's license (CDL). I didn't let that stop me. I called my state representative, who put me in touch with Elizabeth Dole, then Secretary of Transportation. The result was [that] a CDL exam was set up for me and I passed. I then had to get a medical waiver." Jimmy ultimately graduated first in his class of 35 at Sumter's trucking program.

Today, 35 years later, Jimmy is one of the safest drivers you will encounter on the road, with 4 million miles of driving without a reportable accident. In January 2012 he was given a safe driving award by the Owner-Operator Independent Drivers Association. Jimmy has been told that he is the only amputee in the country to have earned that recognition.

The organization's assistant manager of business services, Kip Hough, said in a statement: "Jimmy Ardis' life is a classic American story. He has been subjected to great adversity, but through a strong heart and great perseverance, he made his dreams come true. His shining example of safety represents the ultimate goal of all truckers. With one arm, Jimmy has accomplished what many drivers haven't. His achievement would be impressive even for someone without a disability."

Perhaps part of the reason Jimmy was able to achieve this amazing feat and other personal achievements is because his family only looked at his abilities. He explains that his parents and grandparents "made every effort to support me." Since Jimmy didn't know any other amputees, his role models included older family members and actor John Wayne, who "portrayed rugged men who could rise above anything life dealt them." Jimmy adds, "That was the kind of man I wanted to be and hope that I am."

Jimmy's wife, Debbie, knows he is. The couple met dancing at a local Country-Western bar, and they have been married nearly 20 years. Jimmy says of Debbie, like many truckers' wives, "Over the years she has spent countless days and nights by herself and never fails to be understanding when I have to miss an event or activity because I'm on the road. When I roll in, she's there with a smile and hug." But what sets Jimmy's wife apart and why he calls her "the greatest wife in the world" is the support Debbie gives to him.

"I don't know how I would do this without her," explains Jimmy. "...because, unfortunately, I'm still scrutinized in the trucking world daily by customers, truck drivers and the general public. I'm used to it, and I try not to let it bother me. In fact, I feel it makes me an even better driver. Let them look, because what they'll see is a man who takes pride in his work and who is living his dream each and every day."

For Debbie, the feeling is mutual: "[He] is always there for me. Jimmy is not only a great truck driver but is a wonderful provider. There is nothing we need that he doesn't make sure we have. Additionally, he makes every effort to arrange his schedule to be at my various work events; nothing made me happier than to see his smiling face just beaming when I received the South Carolina Community Educator of the Year award in 2008."

Debbie says she doesn't worry about her husband any more than she would worry if she were a soldier or police officer's wife, and because of Jimmy's impeccable safety record, she's definitely not concerned with his driving abilities. In fact, she explains, "He's accomplished more with one arm than most people do with two."

Having Each Others' Backs

Cathy and EJ Skaife of Platteville, Wisconsin, were inseparable. Before May 2008, when they weren't working, if you saw EJ, you saw Cathy. That often meant Cathy riding on the back of EJ's Harley-Davidson Road King on trips through their small town, poker runs or bike rallies in Sturgis, South Dakota, Daytona, Florida, or a cross-country camping trip. That was until a tragic Mother's Day accident nearly 4 years ago.

As the couple rode home from a 150-mile motorcycle trip, a pickup truck pulled out of a field road and collided with them. The accident left both Cathy and EJ with multiple injuries. Cathy spent 99 days in the hospital; EJ spent 81, including 12 days in the Trauma and Life Support Center not knowing whether his wife of 38 years was alive. Cathy and EJ each ended up with right leg amputations. EJ also needed a prosthetic left eye. EJ has screws, plates and rods holding together his pelvis, femur and left arm. Cathy has a rod in her wrist. She also had multiple skin grafts.

Before the accident, Cathy was the caregiver, the cook, the cleaner and the one always helping everyone else, so accepting help from others after the accident was difficult for her. But once she was back home and adjusting to life with a prosthetic leg, she allowed her family – and eventually her community – to help.


Cathy and EJ Skaife

"Our families are wonderful," Cathy says. "Both of our families have been there to help us in so many ways. My parents moved in with us for 6 weeks to take care of us. Then each of our sisters and brothers would take turns living with us on the weekends. Our community was great to us. A landscaping business in our town called and took care of our yard work for 4 months. Another business took care of snow removal. They wouldn't take a dime for it. Food was delivered to our house weekly for months. We now are on our own but if we do need help, all we have to do is call and anyone will come and help."

She adds that adjusting to being an amputee is "quite interesting" and that the carefree and busy life, with each holding full-time jobs, managing the household, gardening, yard work and hobbies, has drastically changed. "Now we don't take anything for granted, and [we] enjoy life from

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morning to night. We don't plan anything anymore. We just play it by ear and never hesitate to go somewhere when anyone calls. We've slowed down and enjoy life each day [because] you never know what tomorrow will bring."

EJ returned to work part-time but his injuries made his duties as a machine operator too difficult to do, and he's since retired. He relearned hunting because he was left-eye dominant, but he's already successfully got two deer since the accident. He's also back on a Harley. Now, instead of a big bike, he rides a trike. Cathy only recently has felt more comfortable getting on the back, but she has returned to working at the restaurant where she's worked for more than 30 years.

Cathy says they can still do everything they did before the accident, but in a new way. She says they no longer hurry and they count their blessings every day, but most importantly, they support each other every step of the way.

A Lifesaving Love

"Hope." That's the most important thing that Bobby Lisek of Billings, Missouri, says his wife, Mary Grace, gives him. Wounded in Iraq in December 2004, the retired Army Sergeant says his fellow soldiers saved his life that day in Sadr City, but it wasn't until months later that he actually started to live again.

Bobby's war wounds included an above-knee amputation of his left leg, massive injury to his left arm, and major head and face trauma, including traumatic brain injury (TBI) and getting his teeth blown out. He also had to cope with the emotional loss of one of his buddies, Sgt. Yihjyh L. Chin, who died that day on the battlefield.

Mary Grace explains that when she first met Bobby in the spring of 2005, he was having a hard time, socially and emotionally. He had only been home from Walter Reed Medical Center for about 2 months, and he still lived with his parents, spending much of his days in his room or going to one of many medical appointments. He was a patient at the dental office where she worked.

"The first thing he ever said to me was that he would marry me some day," remembers Mary Grace. In July 2006, after persistent pleas from Bobby, the couple started dating. That September, he asked her to marry him.

Wanting to support and help her husband, Mary Grace spoke with brain injury specialists, who educated her on how to help Bobby function around the house and keep up with appointments. She helped to teach him "life is what you put into it."

Lasting Memories Photography, Republic, MO

The Lisek family

"If I didn't have my bride, I'd be lost. She does so much for me," Bobby shares. Besides caring for him and taking care of their home so he can spend time with their two daughters, it's the pep talks that Mary Grace provides that enhance his life, Bobby explains. "She knows when to take the girls and go and she knows when I need them around. She tells me, 'Keep your head up, you're doing good.' She makes me smile."

For the past 5 years, the Liseks have been active with the Missouri chapter of Disabled American Veterans (DAV). Dan Claire, DAV's national director of communications, says, "Bobby and Mary have always been willing to put their relationship out there – good or bad. What I see is that, despite their obvious challenges, Mary shows what being a good caregiver is all about, and you can almost feel the deep love and respect they have for each other."

Mary Grace says of her husband, "He gives me so much joy. I never met anyone that could make me laugh and smile so much in one lifetime. He gives me a complete heart and soul. Before I met Bobby, I always felt so lost and broken; it seemed like I could never find my way. With him it takes no effort, the way is just there. If I feel lost or broken, he just takes me by the hand and shows me the way, all the while whispering how much he loves me."

Paying It Forward

Supporting others is also what each of these inspirational people do – all of them know the importance of giving back and mentoring. Tony Memmel says he receives a great deal of support from members of the hand and limb difference community through groups that weren't around when he was growing up. One, The Lucky Fin Project (luckyfinproject.org), is based in Michigan.

"The Lucky Fin Project is totally awesome!" Tony exclaims. "It serves as an international resource for people with limb differences and their families. I've received many e-mails and Internet correspondences from members. Some people share stories about themselves or their children; others say they've found hope in my music and story."

Tony says he connected with the Texas-based Hands Down Support Group, which is associated with the renowned Texas Scottish Rite Hospital for Children, while on tour with his band through the region last year.

"Ultimately, through these groups, we're all helping each other out. I'm grateful to [be connected with] them both," he says.

Jimmy Ardis' favorite project is the Trucker Buddy program he started at Saint Ann School in Sumter. Jimmy explains, "Among my many activities, my absolute favorite is when I have the opportunity to share my life's struggles and successes with schoolchildren in my home county."

Jimmy's routinely asked to visit various schools to give presentations on truck driving as a career as well as giving "inspirational" talks on how important it is to never give up on your dreams. Jimmy says that his talks always include an explanation that anything worth having is going to come with lots of struggles.

Shortly after Bobby Lisek's first daughter was born, he got a call from the founder of Camp Hope (camphopeusa.org), a retreat for war-wounded active and retired military personnel in rural southeastern Missouri. Bobby was invited to experience Camp Hope, a place where wounded members of the Army, Navy, Air Force and Marines could go to heal through nature and bond with one another. After arm twisting by his wife, he went. As Mary Grace recalls, "Bobby left angry, and he returned calm, soft-spoken and so, so happy. It was like God had touched his soul."

Cathy says they can still do everything they did before the accident, but in a new way.

From that moment on, Bobby became an advocate for Camp Hope. He tells all the soldiers and other wounded military personnel he meets, "When you go to Camp Hope, your bad memories will stay there. You leave them at the gate."

Since EJ and Cathy Skaife's accident, they have become advocates at University of Wisconsin Hospital in Madison for recent amputees who are having difficulty with their limb loss. Cathy says they enjoy speaking with patients: "We try to explain to them what to expect when they are released from the hospital – the starting process of getting their prosthetics. We try to assure them they will get to the point where we are right now."

The Skaifes also talk to rehab therapy students to help them better understand the patients with whom they will be working. But Cathy says they're most passionate about speaking with driver education classes.

"These young kids are fearless, and we're trying to show them what can happen while you're driving," explains Cathy. "We show the classes pictures from [our] accident, and we also take off our prostheses to show them our legs."

Cathy doesn't remember anything about the accident, but EJ remembers it all, down to the sound of the saddlebags scraping the pavement and the smell of gasoline. Cathy says her husband recounts the story in intricate detail as the young new drivers listen intently.

Cathy explains, "In a way, this is also therapy for us. My husband still gets emotional when he talks about the accident. But if EJ and I can save just one family from going through [what we went through], it will be worth it."

On the side of the road between University of Wisconsin Hospital in Madison and Cathy and EJ's town of 9,000, there is a billboard with a picture of Winston Churchill and a quote: "Never, Never, Never Give Up." Cathy first saw that billboard on the journey home after nearly 3 months in the hospital, and she says the sign spoke to her. Cathy and EJ, Bobby, Jimmy and Tony certainly live that mantra every day.

Related Resources

Caring Today
caringtoday.com

Family Caregiver Alliance
caregiver.org

Family Caregiving 101
familycaregiving101.org

National Family Caregivers Association
nfcacares.org

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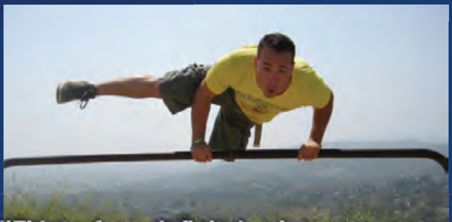

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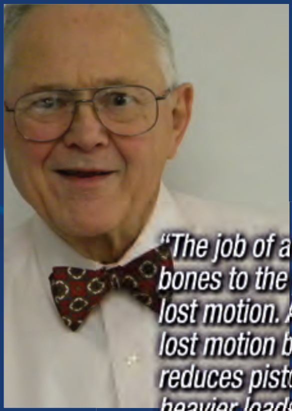

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– Scott Schall, Optimus Prosthetics

"My ability to move is much better. It doesn't feel like I'm carrying something. The HiFi is a part of me. It's solid; it has me. And it's a wonderful thing!"
– Terrance Wortham

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Recovery

A mother and daughter's reflections on the long journey back

by Carolyn McKinzie

I had 3 emotionally grueling weeks to prepare myself for the amputation of my right lower leg in 2001. It had been 2 ½ years and nearly a dozen surgeries since both of my legs were crushed in an auto accident. But complete healing of my fragile bone would never happen, so here I was.

My years of nursing experience proved helpful in my physical recovery, but mentally I had no idea what to do with myself. No support services were offered or even available to me in my area back in 2001. So, I thought, surely I was capable of "handling it."

Within 6 months I was walking on a prosthesis, unaided; I had a barely detectable limp. But despite my physical progress, something still didn't feel right. I began to feel that I didn't fit in or belong anywhere. I felt that I should be able to return to my old self now that the struggle to recover from the accident was over. I had married a few months after my amputation, but for all the wrong reasons. After just 3 months of marriage, I asked my husband to move out. I started drinking a lot, and I made new friends. It was easier being around people who hadn't known me before all of this because they had no expectations of me. I would go off on weekends and leave my 15-year-old son. He drove and had a car, and he was gone a lot; in my mind, that made it OK for me to be gone.

One Sunday afternoon I returned from a weekend away to discover my son and all of his things were gone. He'd gone to live with his dad, who lived a few miles away. I was shocked and devastated, but instead of pulling myself together and being the mom he needed, I fell deeper into that big black hole.

My family was at a loss; they had no idea why I was struggling, and I couldn't seem to find the right words to tell them. They just didn't understand – trauma changes you. It changes your personality. I had been experiencing one trauma after another with each painful surgery following my accident. I found it easier to avoid my family. I felt that they were disgusted with me, as I was with myself. I recall a phone conversation with my sister in which she said, "It's been almost a year; you ought to be *over* it by now!"

I wasn't prepared for that, but I realized at that moment how little my family understood about the emotional journey I had been on for so long. I segregated myself from them and I felt excluded from many family functions because of the resulting tension. I felt shunned, alone and completely misunderstood.

& Reunion

Things stayed that way for a couple of years, until I discovered the Amputee Coalition and started getting some insight into my feelings and behavior. I was happy to learn that I wasn't so crazy after all!

I also found great therapy through writing. Getting my thoughts and feelings on paper helped me realize what my issues really were. I learned how to verbalize and rationalize my feelings, and that helped dramatically in how I was able to communicate that to others so they could understand it all too. I learned that it's OK to say, "I don't know how to handle this." It's OK to let them see you cry! The heavy drinking seemed to fix itself, and one by one, I re-established the strained relationships with my family.

I speak publicly to various groups about my experience in becoming an amputee. I am a [Hanger] certified amputee peer visitor and a peer trainer. I love providing support to new amputees and their families – something I didn't have when I needed it most.

My son, now grown, lives just a few miles away from me, and I see him several times a week. I never realized how much I had missed that. My family understands me better now, as I do them. It's been a bumpy road, but the lessons learned made it a purposeful journey for all of us.

From my mother, Ann Berry

For 2 ½ years following Carolyn's automobile accident, she and her doctors tried numerous times with surgery to mend her injured limb. During those surgeries, I sat and waited for the surgeon to tell me that this time, at last, his work would be successful. But that never happened.

As Carolyn's mother, I wanted her leg to be restored to the perfection that it was when she was born. But she appeared to accept, as I did not, that she could only wait after each surgery to see the result. The hoped-for result never came and eventually the amputation was scheduled. On the day of her surgery, many family members waited together at the hospital. The surgery that so radically altered my daughter's life didn't take that long – how could that be? Until I saw her, I didn't have to face the realization that her right leg below the knee was gone. There it was – right in my face as I looked into her room from the hospital corridor. Her right leg was elevated with a pillow under the knee. An ACE bandage started above the knee and was wrapped ever so neatly down her leg – which ended abruptly several inches below the knee.

Could this be real? Where my daughter used to have a lower calf, an ankle and a foot, there was nothing. Carolyn appeared calm. How could she be? I decided I also needed to be calm, for her. Soon she would have a prosthesis, and her mobility would return! But no, it doesn't work quite like that. For a long time she suffered and struggled in silence, and so alone. But I only saw the physical challenges. All the while, Carolyn was uncertain about who she was and where she fit in, socially, no longer being just like everyone else.

Finally there was a light on her horizon in the form of the Amputee Coalition. With the help of that organization, she gained strength, knowledge and support and started to climb mountains. As an amputee who found little or no emotional support early on in her quest for understanding, finally she had a buoy to hang on to.

I am proud of her accomplishments in her career as an LPN, a peer counselor and author, all pertaining to helping and teaching others to cope. Carolyn has come a very long way.

Still, Carolyn is my child – my youngest. On snowy days, I hope she is home from work safely. I assure myself that others are watchful when she is nearby. I always want to know that the driveway at her father's and my house is clear for her to park closest to the door. I can't help it – I'm her mom.

Related Resources

Amputee Coalition National Peer Network
amputee-coalition.org/npn_about.html

"Caregiver Tips: Journaling"
amputee-coalition.org/senior_step/journaling.pdf

Journal Therapy
goodtherapy.org/journal-therapy.html

5 Lively Kids in Ohio

One Family's Adoption Adventures

by Carolyn Cosmos | photo courtesy of Rob and Deborah Amend

The director of the orphanage was kindly but skeptical. Although Rob and Deborah Amend had made the long journey to the Ukraine hoping to adopt a special needs child, and they had read about Anna, her file hadn't fully described her condition. The director was doing that now, face-to-face with the Ohio couple.

Anna was completely missing her right arm and her legs were different lengths, he said. He doubted the American couple would want this child in the end, and he didn't want Anna hurt again.

"She very smart," the director said of the 3-year-old. "She'll know why you're here and she's been rejected before. We don't want you to meet her."

"But we insisted," Deborah Amend says.

And the director relented.

"As soon as we saw her, we said, 'This is our daughter,'" Deborah recalls.

Four weeks later, the three were on their way home to join the family's two older sons by birth, Ben, then 6, and Justin, age 4. The parents had cautioned the boys about Anna: They must be gentle. She would need time to adjust. She would be fragile. They must be careful.

"But little kids don't react to disabilities the way many adults do," Deborah says. "They knew she was missing her arm but they didn't make much of it. The first night she was home the boys were wrestling and Anna took this great leap and she jumped on them – she just piled right on top of them and joined in!"

A few days later, the Amends found her on the second floor of the two-story playhouse in their back yard. She'd climbed up on her own. "She doesn't take big risks," Deborah explains. "She knows what she can and can't do. But she's very athletic."

So athletic that Anna has become a champion swimmer.

Because the Amends had Ukraine contacts through their church, they did not use an adoption agency. They did an "independent adoption" instead, one where "you choose your own child." With all international adoptions,

Related Resources

Adoption Information

Adoption.com
Detailed discussions of international adoption options and countries, with blogs and information about adopting children with special needs. Comprehensive discussion of financial issues, including agency fees, tax benefits, and raising money for an adoption.
International.adoption.com
Special-needs.adoption.com

U.S. Department of State Bureau of Consular Affairs

Intercountry Adoption
An authoritative overview of the international adoption process with up-to-date country information that includes any recent changes in requirements, lists of accredited adoption agencies in each state, and a guide to getting a visa for an adopted child.
adoption.state.gov

November 2011 Report on Intercountry Adoptions
This annual report offers the latest adoption statistics and information per country, such as the number of adoptions last year, median cost and how long it presently takes to complete an adoption.
adoption.state.gov/content/pdf/fy2011_annual_report.pdf

The Amend Family

A Dress for Anna: The Story of the Redemption of the Life of a Ukrainian Orphan, by Deborah J. Amend, Tapestry Books, 2009.
amazon.com

Video: Making Amends: An Adoption Story
In this video, featured on the *700 Club*, the Amends discuss the family's international adoption journey.
tinyurl.com/7s24h46 Video Link

however, Deborah explains, "You have to be approved by three entities: the state you live in, the federal government and the country you go to."

The couple contracted with an Ohio social worker to help with the process. According to the U.S. State Department, international adoptions typically take a minimum of 5 to 6 months and a maximum of nearly 2 years. Anna's adoption, which started in 2001, took about a year.

Anna's adoption cost the Amends approximately $10,000, which is on the low end. With home study costs, agency fees, country adoption fees and travel, costs generally run higher, toward $25,000.

Deborah is a freelance writer, a former music teacher and college instructor and Rob Amend is a librarian. "We didn't have the money," she says. However, friends, family and their church community pitched in – and the couple did odd jobs. Then an insurance check arrived out of nowhere. In short, Deborah says, "God provided."

The Amends eventually adopted two other daughters from overseas, both with special needs – and special talents: Saya, age 9, from Kazakhstan, and Alyona, age 7, from Ukraine. Saya has radial club hand, Amend explained, short forearms and four fingers on each hand, and Alyona, or Aly, has a joint disorder and uses a wheelchair.

"But we forget about the disabilities most of the time," Deborah says. "All the kids have school, friends, church."

Family life is busy: martial arts, dance lessons, theater and raising ducks and chickens for 4-H are part of the mix. Ben, now 15, plays guitar and keyboards and writes music; Justin, 13 and thoughtful, likes to draw. Anna has her swimming and likes to sing as well, while Saya is a dancer and Tae Kwon Do enthusiast. Aly is learning to swim as well as play piano, her mom proudly says.

"While it's not easy, we're so thankful we chose to adopt children with disabilities," Deborah says. "The girls are mature compared to other children their age, and they deal with stress well." She adds, "They have taught us how to live in a way that's completely different and we all have such rich, full lives."

Left to right, back: Rob, Deborah and Ben Amend. Front: Anna, Saya, Aly and Justin Amend.

10 Tips for Growing Up

by Melissa Shaw, Beau LaFave, Mia Lax, Li Jackson, Nicole Fuller and Debra Gardner

1. It gets easier.

Whether you were born missing a limb or you became an amputee later on, you can count on one thing: It will get easier as you get older. You'll get used to it, and you'll find most people are more accepting of your difference. In fact, that difference becomes more and more a part of what makes you *you*.

2. Your attitude will affect how others perceive and treat you.

There's no getting around the stares and questions. People are going to be curious. The more comfortable, relaxed and confident you are with yourself, the more others will treat you with respect. A quick matter-of-fact explanation puts others at ease, and once they know your story, they're likely to stop focusing on your arm or leg. In fact, once people get to know me, they often "forget" about my arm (and try to hand me stuff, for example).

3. Give yourself permission to feel what you feel – being different isn't always fun.

No matter how positive and well-adjusted you are, you're likely to have moments when you just don't feel like answering questions. I've had plenty of times when I was irritated by people's ignorance and rude questions. I still get annoyed at the airport when I have to go through extra screening, and I don't like it when people react to my arm with overflowing pity and apologies. (Sometimes I'll be writing or carrying something and someone will ask, "What's wrong with your arm?" When I say it's a prosthesis, they'll say things like, "I am so sorry. That must be horrible for you!") The truth is, that stuff does get to me sometimes, and it can be a bummer to deal with physical pain, such as heat rash. I've found that I feel a lot better when I talk to my friends or family and just give myself permission to feel sad or frustrated. Those feelings won't last, and it's just plain lonely to act like nothing ever bothers you.

4. Don't limit yourself.

It may sound corny, but there's really nothing you can't do if you're persistent enough and determined enough. Whether it's a sport, a hobby or a job you want, there's a way to make it happen. You may have to do some research and try different approaches, but you can find a way to pursue anything that interests you. There are great resources (like the Amputee Coalition) and people who are willing to help modify equipment or tools for you if you seek them out. Don't sell yourself short by not trying.

5. You have nothing to prove.

As much as it helps to know you can pursue any activity or sport you want, it can also be exhausting to go through life feeling like you've got something to prove. Everyone loves stories about people who triumph over adversity and do the impossible. But, honestly, there's nothing you need to do to "make up for" your difference. All you need to do is be yourself and pursue your own dreams. Who knows, maybe you will inspire others in the process without even trying. As Christopher Reeve said, "A hero is an ordinary individual who finds strength to persevere and endure in spite of overwhelming obstacles."

6. Tell your family and friends how to support you.

Chances are that your parents, siblings or friends may try to read your mind and guess how you want to be treated. They may act like nothing at all is different or they may do a lot of things for you.

as an Amputee

At different times you're going to need and want different kinds of support. You can help by telling them how to help. My dad always went out of his way to treat me like any other kid (which I appreciated). But there were a couple of times when he lost sight of what I wanted in his eagerness to make things "normal" for me. Once he took me on a water-skiing trip and spent half the day trying to help me get up on the skis. I got a face full of water and one very sore arm. I'm sure if I really wanted to, I could have learned to be an excellent one-armed water-skier, but I was having fun just hanging out and getting towed around on an inner tube. He didn't realize it, but he was pushing more for the sake of other people than for me. It took a while for me to learn to speak up in those situations, but it was worth it. It's especially hard to say something to the people who love you and only want to help, but they will appreciate the direction.

7. Only *you* can decide if a prosthesis is right for you.

It never ceases to amaze me how opinionated people are about prostheses, especially when they aren't amputees! I've had people tell me everything from, "If I were you, I wouldn't care if I looked different! I'd never wear a fake arm!" to "If I were you, I'd get a bionic arm and never take it off!" Only *you* can decide if a prosthesis makes things easier or harder for you. It's different for everyone. You may even find yourself changing your mind at different times or for different activities.

8. People who don't accept your difference are not worth your time.

I can count on one hand (and not just because I only *have* one hand) the number of times I've had someone blatantly snub me because of my arm. The vast majority of people are going to see past your difference. You may encounter a few turkeys who get hung up on it. Those people tend to be incredibly self-conscious and insecure (even though they don't always show it). The bottom line is, they aren't worth your time or energy. If a person doesn't want to be your friend or date you because you're different, you're better off without them. I try to consider myself lucky to have a way to filter them out.

9. Reach out to others.

I was in my 20s before I met another person who was missing an arm like me. My first year as a counselor at the Amputee Coalition Paddy Rossbach Youth Camp was an awesome experience. Since then, I've been hooked on staying in touch with all the friends I met there. It felt so great to hang out with other people who shared my experience and to have people I could ask about stuff (like adaptive sports, protecting my "good" arm, etc.). Whether you're a new amputee or you were born that way like me, it can really help to reach out to people who know exactly what it's like.

10. Laugh when you can.

Humor can be one of the greatest gifts for those of us who go through life looking different from other people. If you can crack jokes, and even learn to laugh at yourself, you will make other people feel at ease and find it easier to get through the natural ups and down you'll face. Besides, you have infinitely more potential for practical jokes than other "normal" people.

Together Again

Post-amputation intimacy: An amputee's case-sensitive investigation

by Elizabeth Bokfi

Suddenly they were coming at me from all directions: behind me at the mall, in front of me in grocery store line-ups and, piercing my eyes with their perfection, from within magazine pages at Walmart.

Long before reaching my peripheral vision, their sound – woodsy, clanging or ratcheting – would seduce my determination into finally looking. Across the ceramic-tiled mall floor they clanged, in all their tanned-calf adornment: sets of high heels. Beautiful specimens, all those muscular calves walking past. "Don't hate me because I'm in heels!" they silently screamed at me, as I seethed inside my prosthetic limb.

Now a flat-heel convert, the trigger had been set. My mind strained to remember The Evening Gown; The Mini Skirt Above a Set of High Heels; The High-Heeled Cowboy Boots My Levis® Used to Slip Over. In my opinion, The High Heel has power enough to turn even a potato sack into a glamorous evening gown.

As one negative thought shot to another in a contagious frenzy, my memory landed at long-ago nights of abandoned sexual inhibitions and micro-wispy barely-theres, pre-residual limb. Dangerous territory for an amputee barely off the ward.

At the tender age of 41, it's my heart and brain that matters to men, I tell myself over and over; then again, there's only so much heart and brain a man can take before testosterone rears its head.

To ameliorate my fledgling self-esteem, I turn the tables and imagine myself at the testosterone end of things. How do amputee *men* feel about *their* desirability and performance in the boudoir? While some women can fake it, there's no faking it for men.

Like any upheaval in a couple's life, amputation, whether the result of trauma or illness, can affect couple intimacy. In addition to the physical stress placed on the body by the actual accident or illness, amputees may also experience stresses related to body self-image and self-esteem. Physical pain aside, insecurities over physical appearance, desirability and sexual performance may infiltrate and threaten the intimate relationship between couples.

Body Image and Self-esteem

Often self-perceived as a mutation, amputation may negatively impact a patient's body image, which in turn affects his or her self-esteem. Depression over visual deformity, the inability to perform daily routines that were once simple tasks and dependency upon others contribute to feelings of loss of control, loss of lifestyle and loss of self.

Men tend to equate the loss of a limb with loss of manhood; for sexually active women who want to continue to seduce and have men's attention, the impact on body image can be especially devastating. To what extent the amputee's body image and self-esteem play a role in a couple's intimate life depends upon factors such as the level of acceptance of the situation, whether the amputee is male or female, and age.

Sexuality

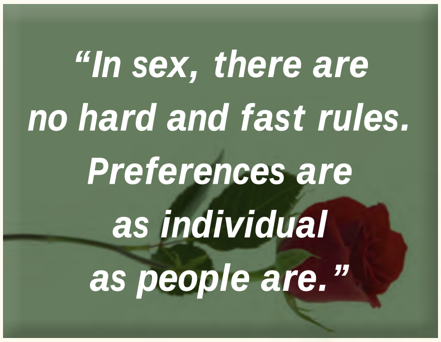
Every person who has a physical disability will experience, to some extent, physical restriction. Combined with a negative body image and a lowered self-esteem, intimacy levels in relationships are ultimately affected. It's important to address issues surrounding amputee sexuality. The lack of information on the topic leads to the conclusion that society has difficulty linking human sexuality to disability. Perhaps if society viewed the disabled as *physically challenged*, and not *unable*, there would be less of a nonsexual stigma attached to people who are, in fact, physically challenged. For some reason, walkers and sex toys are an unlikely combination. When a person becomes physically challenged, does his or her sex life need to end?

Humans are a sexual species. Whether we are consciously aware of it or not, our primary instincts tend to be sexually driven. It begins at birth. We have a need to touch and be touched. At some level we all have a need for approval and acceptance, and humans, however deeply buried it may be, have a need for intimacy.

The amputee may experience a wide range of emotions and anxieties over his or her sexuality, post-amputation. For men, anxiety over sexual performance is a major concern. Women may feel they are less attractive visually. Medications can affect libido. Heavily medicated patients may experience decreased sexual desire, slower body function, the inability to achieve and/or maintain erections, and failure to achieve orgasm. Adaptive changes to sexual positions may also be necessary to facilitate physical comfort. Partners to amputees may also experience difficulties of acceptance when it comes to a lagging sex life. Understanding, adaptation and acceptance are keys to gaining confidence in the bedroom, post amputation. After all it's more than just sex – it's sharing; intimacy; emotion. Beyond just physical pleasure, sex is also about exchange and bonding. Emotionally supporting the amputee spouse and giving them sexual space by demonstrating less demand is very important. Adaptation becomes a necessary component to succeed in all facets of the amputee's life: emotional, social and physical. There are no easy hurdles.

For men, the desire for sex is still there, dependent upon whether or not the amputation is upper- or lower-limb. For those with upper-extremity amputations, it is worse. Not only are they affected visually by the missing limb, but they also have difficulties physically. For many, because a large part of sex involves touch, they experience difficulties when trying to satisfy their partner when they only have one arm, for example. It becomes a challenge – balance, touch, everything. Male wheelchair users tend to feel less a man – if they are able to stand [during the act of intercourse], they tend to a have better self image.

For women, age comes into play. Older women, in their 70s and 80s, tend to care less. Many want autonomy at that age, and acceptance comes more easily.



"In sex, there are no hard and fast rules. Preferences are as individual as people are."

Mature women with spouses – 40- or 50-year-olds that have good relationships with good communication – are just happy to be alive. They know they are loved, regardless of the amputation. For some younger women, sex may become less important as they immerse themselves in their career or profession. However, some women that have lower-limb loss are very affected. Legs comprise a large part of a woman's sexuality. It all depends on how she defines herself. Does she define herself as a mother, career woman or wife?

Let's Talk About Sex, Baby

Amputees and their partners may feel embarrassed about discussing sexual concerns with each other. Fears over having their feelings and needs trivialized may prevent open communication. Using a healthcare professional as a liaison helps to break the ice.

Sometimes partners of amputees are afraid of hurting the residual limb during sexual interaction. Healthcare professionals can give information to that spouse through the physiotherapist or health practitioner. Nurses are also able to discuss couples' concerns.

Keeping an open mind can help couples through challenging transitions. The use of sexual aids such as vibrators, erotic literature and even fantasy might help couples reintegrate sexual activity in their lives. The use of sexual paraphernalia, once considered only for the sexually adventurous, may be used by couples as practical tools.

Sexual positions that were once comfortable may now need adapting. Leg amputations make standing positions challenging. Side-lying positions might be more comfortable, where removal of the prosthesis eliminates uncomfortable pressure points created from inadvertently twisting inside the socket. Ordinary pillows may also be used as support platforms to facilitate sexual activity between partners.

Although sex may need to be put on the back burner immediately following surgery, it can slowly be integrated back into the conjugal relationship as pain, swelling and general physical discomfort subsides. In-depth discussion beforehand about fears and anxieties may help to relax both partners. Placing emphasis on nonsexual contact such as massage and nonsexual caressing helps to relieve "performance pressure". The absent expectation of sexual success (orgasm) in any relationship paves the way to a trusting, comfortable atmosphere, which ultimately is conducive to good sex, whether couples have physical limitations or not.

Setting the mood is also very important. After years of being in a committed relationship, it's easy for couples to keep the candles packed away, to grab sex on the go, and if they're too tired from the day's activities, to forego sex altogether. It might help to view reconnecting as an opportunity to rediscover passion for each other.

In sex, there are no hard and fast rules. Preferences are as individual as people are. Some like their bagels toasted, some don't. So, in what position does that leave me? For now, in flats, and in no position at all.

Courtesy of Hanger Prosthetics & Orthotics

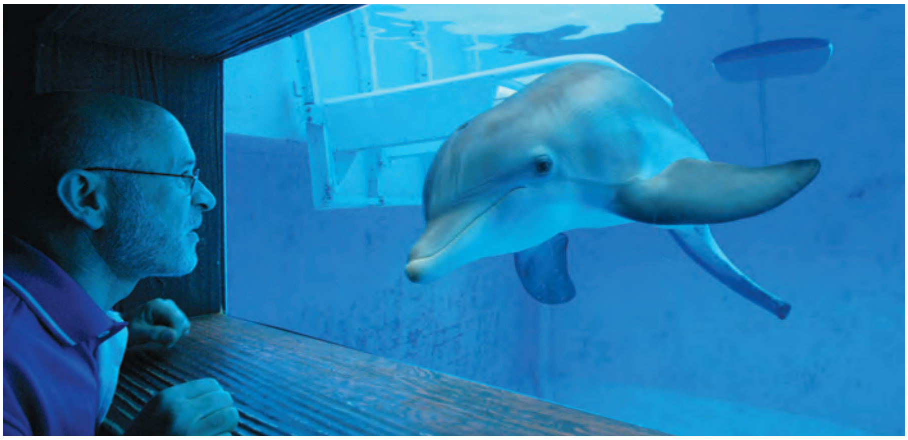
The Tale of a Tail That Inspired the World

by Jennifer Bittner

It's the stuff of movies – literally. A baby bottlenose dolphin survives days entangled in a crab trap off the Florida coast, only to lose her tail to the severity of her injuries, facing what seems to be insurmountable obstacles to recovery.

If you haven't seen one of the many national news features on *NBC's Today Show, The CBS Early Show,* or *The Oprah Winfrey Show* celebrating this "little dolphin that could," your children may have learned about Winter through #1 *New York Times* bestselling children's author Craig Hatkoff's book, *Winter's Tail: How One Little Dolphin Learned to Swim Again* or the co-released Nintendo DS game. And if Winter's inspirational account still eluded you, it's likely you heard about her aspiring celebrity status by way of Hollywood and its 2011 box office smash hit *Dolphin Tale*, starring Morgan Freeman, Ashley Judd and Harry Connick, Jr.

Behind all of the news coverage, glitz and glamour is a charming, fascinating and undeniably adorable amputee dolphin who, simply by living each day, has become a worldwide inspiration. While appreciated by people of all types, Winter's plight and ensuing triumphs have resonated particularly strongly within the limb loss community.



Courtesy of Hanger Prosthetics & Orthotics

Kevin Carroll, MS, CP, FAAOP, with Winter the dolphin

"We have seen young children to senior citizen amputees melt when around her, as they begin to realize that if this little dolphin can fight through, so can they. The effect is real, and larger than life," says David Yates, CEO of Clearwater Marine Aquarium (CMA) where Winter resides, and co-producer of *Dolphin Tale*.

Despite heroic rescue and rehabilitation efforts following her entanglement in December 2005, Winter lost her tail to severe injuries. The need for a prosthetic tail quickly became apparent as Winter adapted to an unnatural and gravely damaging side-to-side swimming style.

Coordinating with an expert team of trainers at CMA and veterinarians from Harbor Branch Oceanographic Institute, Hanger Prosthetics & Orthotics Vice President Kevin Carroll, MS, CP, FAAOP, and Sarasota, Florida-based clinician Dan Strzempka, CPO, volunteered countless nights and weekends to successfully develop a prosthetic tail for Winter. To address the challenge of Winter's sensitive, scarred skin tissue, they turned to scientists to help create a special material called WintersGel™ that provides the necessary cushion Winter needs to comfortably thrive with her new prosthesis.

"Not only has Winter provided an emotional release for amputees, the result of our clinical work with her has advanced prosthetic options for humans," says Strzempka. "We may have helped Winter with a tail, but what she has done for the amputee community and the prosthetic field is invaluable."

According to Yates, CMA receives daily visits from members of the limb loss community: "You won't find a day without a number, and sometimes a large number, of amputees visiting CMA."

Many amputee support groups, associations and children's camps make visits to CMA a regular part of their programs, as Yates and Winter's team, led by trainer Abby Stone, go above and beyond to engage amputee visitors and their families.


Courtesy of Hanger Prosthetics & Orthotics

Hanger prosthetists Kevin Carroll, MS, CP, FAAOP, and Dan Strzempka, CPO, fit Winter with her prosthetic tail

One such patient who has been forever changed by her personal encounter with Winter is 13-year-old Megan McKeon from Clovis, California. McKeon first met Winter in November 2009 when visiting CMA with a camp for pediatric amputees. At the time, McKeon wasn't wearing her prosthesis as often as her parents and her medical team would have liked.

"When I spent time with Winter, I felt inspired and excited. I think if she can wear her tail, then I can wear my leg. And she doesn't let anything stop her," McKeon says.

Carroll witnessed their first meeting: "Megan was clearly touched by Winter and would not leave her tank. Likewise, Winter was totally enthralled with Megan. It was like they were communicating with each other."

Carroll adds, "The bond between Winter and the people she meets is unconditional – there is no judgment. There is an unspoken level of understanding, often a kindred spirit-like connection, if you will."

Other amputee visitors to CMA have commented that the popularity of Winter's story has brought the topic of overcoming amputation and physical challenges to the forefront of everyday conversation.

"Winter's story highlights the fact that no matter how big your challenge might be, anything is possible if you surround yourself with the right people," Strzempka explains.

To learn more about Winter, visit SeeWinter.com *and* WintersGel.com.


Courtesy of Clearwater Marine Aquarium

Winter and Megan McKeon shared a bonding experience, inspiring Megan to overcome her resistance to wearing her prosthesis


WintersGel™

Why Can't I Wear My Old Shoes?

by Pete Seaman, CP, CTP

"Why can't I wear all my old shoes?" This is a common complaint voiced by new lower-limb amputees when learning to use their first prosthesis. The short answer is: because different shoes have varying thicknesses of heels and soles, changing the shoe you wear on your prosthesis can adversely affect its alignment.

When you are fit with a prosthesis, your prosthetist sets its alignment (assuming the continued use of the shoes you wore that day) to optimize the spatial relationship between your prosthetic foot, knee (if you are an above-knee amputee) and socket. These alignment adjustments, made in both the sagittal plane (anterior to posterior or front to back) and the coronal plane (medial to lateral or side to side), affect the function and comfort of your prosthesis and can also affect the efficiency of your gait when walking.

For example, if you wore a pair of athletic shoes when you were fit with your prosthesis, your prosthetist made alignment adjustments based on the heel and sole thickness relationship of that particular pair of shoes. Your prosthetist will typically try to adjust your prosthesis so that its pylon is vertical at mid-stance (when your foot is flat on the ground) when viewed from both the front and the side. When you change shoes, the relationship between your footwear heel and sole thickness can also change; this may affect your alignment enough to make your gait less efficient and possibly make you unstable when standing or walking.

Based on this example, if you changed your footwear from the athletic shoes you were originally fit in to a dress shoe with a thinner heel, your prosthesis would tilt backward when standing. On the other extreme, if you wore a shoe with a taller heel than the original athletic shoes you were fit in, your prosthesis would tilt forward. Either of these situations could adversely affect your gait and stability because your prosthetic socket, knee (if applicable) and foot would no longer be in proper alignment.

So what can you do to successfully wear a variety of footwear? The first, and easiest, option is to wear shoes that have similar relationships between the thickness of the heel and sole as the shoes your prosthesis was originally aligned in. The key is not the heel height alone, but the relationship between the heel thickness and the sole thickness under the ball of your foot. For example, if your athletic shoe heel thickness is 1-1/4" and its sole thickness is 1/2", then the "heel/sole differential" for that shoe is 3/4". That 3/4" difference between the thickness of your shoe's heel and sole is the constant factor that you need to reproduce when purchasing new shoes or trying to use old shoes.

Another possible option is to insert heel wedges of varying thicknesses into your shoes, depending on the heel/sole thickness differential as compared to the original pair of athletic shoes you were fit in. However, based on this example,

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Pylon tilting backward due to insufficient heel height

Near-optimal vertical pylon orientation

Pylon tilting forward due to excessive heel height

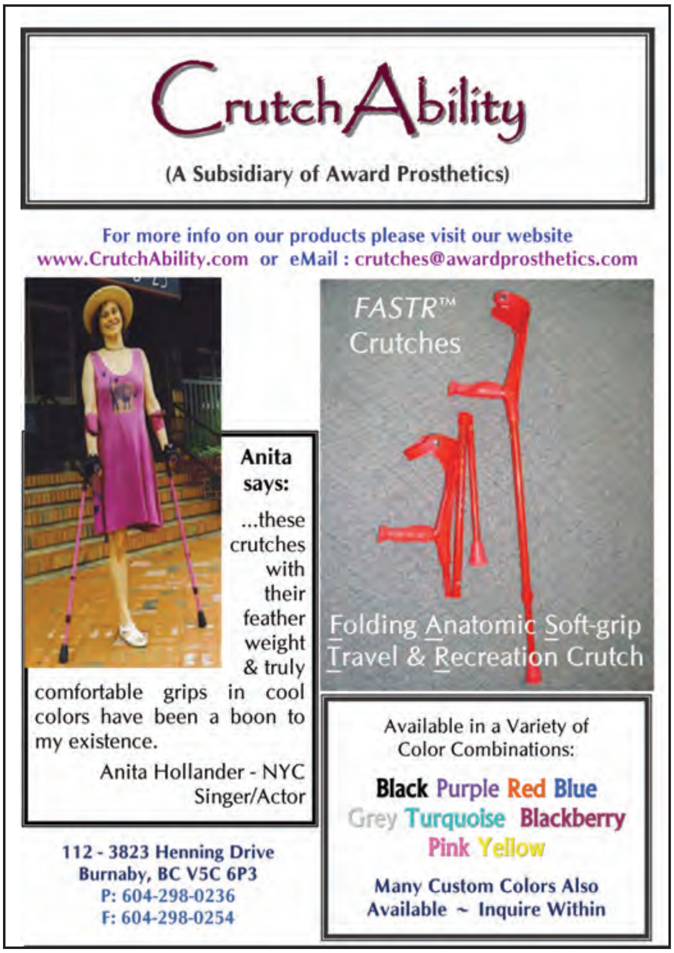
Photos provided by Pete Seaman

heel wedges will only work if the shoes you are trying to wear have less than the 3/4" difference between the heel and sole thicknesses of the shoes that your prosthesis was originally aligned for. Inserting a properly sized heel wedge will act to reestablish the 3/4" difference between your heel and sole thickness, resulting in proper alignment.

A final, and more extreme, option is to have your prosthetist fit you with a prosthetic foot that has an adjustable-height ankle. There are several such feet available that can provide up to about 1-1/2" to 2" of heel height adjustability; however, this option is not for everyone. Some of these feet have weight limitations, and some insurers will not cover the expense of an adjustable ankle for the foot, as they do not consider it "medically necessary." Check into these potential roadblocks with your prosthetist. The most important thing to consider with this type of foot is that you will need to be able to properly set its adjustment whenever you change shoes. This can involve depressing a button on the side of the ankle or inserting and turning a key or wrench into the back of the foot. This process can become frustrating, as it may be difficult to set the ankle at the precisely correct angle for each different pair of shoes you choose to wear. Remember, if you cannot get this adjustment correct, it will cause you to walk less efficiently, less comfortably and possibly with less stability.

The easiest, but perhaps less stylish, option is to wear the same footwear every day. The next best choice is to find shoes with similar heel/sole thickness relationships as those you were originally fit in. Another option is to experiment with heel wedges of different thicknesses. And your final option is to try a foot with an adjustable heel height. Your willingness to experiment with options is critical in making these decisions. If you don't want to be bothered, then keep it simple, but if you're game, get busy. And remember, it's always best to consult with your prosthetist if you have footwear issues or questions.

Please contact the author with questions or comments at jpseaman@aol.com.



How Proper Physical Therapy Can Aid Your Recovery

by Scott Waite, DPT

Appropriate physical therapy is crucial to both the physical and emotional lives of people who must live with a residual limb after amputation. Without it, patients are in store for a wide variety of additional problems during and after their recovery. The use of a prosthesis to improve amputees' functional abilities is becoming more of the norm than ever, and the time between the amputation and receiving a prosthesis should be used wisely to ensure the patient's long-term well-being. In addition, physical therapy is important for people who already have a prosthesis but who spend long periods without using it due to health problems, a poor fit or residual-limb issues (skin breakdown, neuropathy, revision surgery, etc.).

Whatever the reason, if an amputee goes a reasonably long period without a prosthesis with the intention of using one in the future, certain precautions should be taken to enable proper functioning of the limb once the prosthesis is used.

In fact, even if amputees decide never to use a prosthesis, appropriate physical therapy is very important for their overall physical well-being. It can help them maintain and improve their circulation, skin health, strength and endurance, and it can help them decrease their risk of developing contractures (shortened muscles or tendons).

Through proper care, physical therapists can play a vital role in helping patients achieve their desired goals. Unfortunately, there are a limited number of physical therapists around the country who specialize in the full rehabilitation of amputee patients. It's in patients' best interest, however, to try to find one in their area. It is ultimately the patient's responsibility to research and find the right therapist. Talking with your physician, calling local hospitals or visiting therapy clinics will help you find the rehabilitation clinic that best suits your needs.

The goal of physical therapists is to provide the best care for their patients and to help them return to their previous level of function without causing any harm. Unfortunately, when physical therapists first see patients who have not had proper training before receiving their prosthesis, it's highly likely that these patients will have increased physical limitations as a result.

An amputation is a traumatic event to the body, and recovery time varies from person to person. When patients have an appropriate amount of physical therapy, their physical therapist may have the opportunity to see them more often than any other medical professional and should be able to monitor their residual limb and incision area. Occasionally, a residual limb can take longer than normal to heal, become infected or have undesirable skin pressure problems that could be either alleviated or controlled with such professional observation.

During the first couple of months after surgery and before patients receive a prosthesis, their residual limb is shaped by using such things as an elastic bandage or a shrinker. If the shaping material is too tight, it can cause circulation problems,

Related Resources

Move Forward
moveforwardpt.com

Below-Knee Amputee Exercise Program
www.sld.cu/galerias/pdf/sitios/rehabilitacion/b-k-amp-stage1.pdf

Below-Knee Amputee Exercises
livestrong.com/article/127979-below-knee-amputee-exercises/

Exercises Above the Knee for Amputees
livestrong.com/article/119840-exercises-above-knee-amputees

Keep Moving: Exercises for People With Lower-Extremity Amputations
amputee-coalition.org/senior_step/le_amp_exercises.html

pressure sores or a misshaped limb. If the material is too loose, it will not shape the limb properly.

Further compression may, therefore, be required; the bandage may have to be wrapped more tightly or a smaller shrinker may be needed. The person's physical therapist should check the condition of the limb for proper shaping.

Part of the healing process should involve residual-limb massage to assist in desensitizing and toughening up the limb in preparation for using a prosthesis. Different types of massage are needed, depending on the healing stage of the limb. A physical therapist can determine which type of massage is appropriate at the time and teach the patient the proper technique.

Residual-limb tightening and even contractures can easily occur due to decreased use of the limb and constant static limb positioning. In fact, constant static positioning of a person's residual limb with minimal activity is probably the most common reason contractures are so prevalent in amputees. A general definition of a contracture is skin, fascia (connective tissue), muscles, tendons or joints that prevent normal movement of the related tissue or joints, such as when a knee or elbow joint is unable to be straightened completely.

Instruction regarding proper residual-limb positioning, stretching and range-of-motion exercises is very important in decreasing the risk of contractures. Education in ways to prevent contractures is much easier and much more effective than trying to increase joint motion after tightening or a contracture has occurred. Although a prosthetist can make accommodations in the alignment of the prosthesis to help problems primarily involving hip and knee contractures, there will still usually be limitations once a problem has occurred. In addition, proper body mechanics will tend to be more difficult to achieve.

For any limb to function properly, it must have a certain amount of motion in various directions. New amputees should be instructed in the necessary movements required by their residual limb and other pertinent joints. This will improve circulation, increase efficiency and ultimately enable proper prosthesis use. Because prosthetic devices are designed to be very functional and are primarily based on "normal" body movements, it is important to keep or improve limb motion. Measuring limb motions can help in determining deficiencies, which physical therapists can then focus on to improve.

If amputees are to regain as much functional independence as possible, the residual limb must be as strong as possible to assist with prosthesis control. In my experience with prosthetic training involving upper or lower limbs, I've observed that patients have a difficult time using their residual limb properly. Early intervention to "wake up" an amputee's residual limb with strengthening, neuromuscular reeducation and stabilization exercises is critical for establishing the residual limb as a functional part of his or her body. For example, people with an above-knee amputation sometimes have difficulty establishing the functional mobility they need to use their prosthesis to its full capability. Gaining control of the residual limb through appropriate strengthening can determine how well they are able to use their prosthesis. Depending on the area of the amputation, certain muscle groups, such as hip extensors, quads, hamstrings, gluteals, abdominals, triceps, biceps and rotator cuff muscles, are important for increasing strength, especially in preparation for prosthesis use. Getting appropriate physical therapy from the right therapist at the right time and in the right amount can help you avoid all of these problems. When it comes to physical therapy, an ounce of prevention is certainly worth a pound of cure.

Navigating the Distance Between Venus & Mars

From the dawn of time, we have speculated on the physical and emotional similarities and differences between men and women.

Historical, philosophical debates have led to reams of research on the subject. Today, medications that were tested only on men are no longer assumed to have the same effects in women. Professionals no longer consider women as defective or deviant if they don't follow the male path of psychological development. But it was considered the norm for years, even by some women in the psychoanalytic field.

Even as we learn to better study our differences, much tension remains surrounding our failures to fully understand and appreciate them. So our biases as men or women creep into how we see many situations. We also deal in stereotypes, where we assume all men or all women are alike. We sometimes forget that we're far more different as individuals than we are alike according to our gender.

"Women get sick; men just die."

There is, however, usually at least one grain of truth in stereotypes. Furthermore, research continues to document gender differences in generalities. For example, women are much more likely to go to the doctor and be admitted to hospitals than men. Yet, although they have been labeled the "weaker sex" for generations, they outlive men on average, lending weight to the old saying, "Women get sick; men just die." The culprit? Research shows the need for men, especially young men, to include dominance over others in their definition of masculinity. This means they are not supposed to be (or even appear to be) vulnerable to others. One recently published study of Scottish men concluded, "It's caveman stuff, but that is to a certain extent how guys still operate," in describing their subjects' reluctance to seek help.

The big difference between the sexes in seeking help extends especially into the emotional health arena. Women are twice as likely as men to suffer from depression or attempt suicide. However, they are also far more likely than men to report depressive symptoms. Studies also show most of their suicide gestures are not a true wish to die, but a desperate attempt to force change in their circumstances. They reach out to others, including healthcare providers, for support. This is thought to be the reason why three out of four actual suicides are "solutions" chosen by men, not women.

In her book, *Challenged by Amputation: Embracing a New Life*, the late Carol Wallace, an amputee, summed up gender differences by saying that men "hibernate and stew and keep it all in," whereas "women are compelled to discuss everything."

Men don't cry.

Wallace's quote doesn't suggest that men have fewer emotions than women – only that they address them less often. They are more likely to deny them, even to themselves, as they try to diminish the power that emotions hold over our choices. This denial leads men who have experienced trauma to unrealistically declare themselves "over it" simply because they don't have access to their feelings. But the energy consumed by this denial leaves them disconnected from themselves and others. This leaves men with fewer tools with which to heal emotionally. Many returning veterans, mostly men, have great difficulty in accepting that war, by its very nature, is a trauma that takes its toll on one's humanity. When these veterans can't talk about this truth, and the feelings that go with it, they are far more likely to be afflicted with problems such as clinical depression and post-traumatic stress disorder.

In a heart-wrenching episode of *The Wonder Years*, a show about growing up in the '60s, a loving mother was tortured over not being able to comfort her son after being hurt in a football game. The pre-adolescent child was struggling with his own desire to be held and comforted by his mother, but he realized he was now "old enough" that he needed to avoid looking like a "sissy." In her empathy, the mother knew he needed to grow up in this manner, meeting the demands of a society that defines men as being independent and needing no such help. Otherwise, he would be an outcast among his friends. Recent news stories have described the brain-damaging consequences of this attitude in football players, who suffer concussions but continue to play, denying their obvious symptoms to themselves and others.

Redefining normality.

One of the most important elements of trauma that demands attention while recovering from limb loss is the disruption of what is termed "body image." Body image disturbance is the anxiety over how we imagine we look – not through our own eyes, but through the potentially judging eyes of others. We may be taught that beauty is skin-deep, but in this realm we all want to be seen as "normal." We are taught from childhood to believe this is necessary for us to be accepted by others.

One of the many benefits of attending an Amputee Coalition National Conference is the opportunity for people with limb loss to be as part of a majority for a change. This allows them to redefine what is "normal," an incredibly empowering experience. In the words of one peer visitor, "Where else can you take your leg off and pass it around for others to look at? And where else will you not be embarrassed as people tease you playfully when you knock over chairs trying to maneuver your prosthesis to get into your seat?"

Men and women both struggle over body image. Although women with lower-limb loss seem to have an obsession with shoes that men do not share, men have other "vanity" and sexuality concerns in common with women. The primary difference is (as you might have guessed) men don't discuss these concerns with others. Studies also show that men are more concerned than women with the "functional" aspects of a prosthesis that let them continue working and engaging in strenuous activities. Women, while valuing function, are more concerned over the form, or "aesthetic," aspects of prostheses that look more realistic and help preserve their sense of femininity.

But enough about me – how do *you* think I look?

Excessive concern over appearance has historically been interpreted as "vanity" in women. It is true that there are women (and equally true that there are men) who admire themselves obsessively, with or without a mirror, as if this is *their* universe – they just allow the rest of us to live in it. These individuals often monopolize entire conversations, speaking admiringly only of themselves while criticizing others. This emotional disorder is called narcissism; it indicates a "false self," masking a deep insecurity about one's true value and ability to deal with the ordinary anxieties of life.

However, women's obsessive returns to the mirror have historically been driven by shame, not narcissism. Women are checking for defects, not admiring themselves. "Do I have lipstick on my teeth?" "Have I smudged my eye makeup?" "Is my slip showing?" Forms of shame like this are universal to any "second class" group of people who have been devalued by a group with more power. In the political arena, it's called "internalized oppression," the unfortunate consequence of trying to adapt to a culture not of one's making, called the "dominant culture." The inability to deal with this shame may explain the higher rate of depression among women.

No man (or woman) is an island.

As women have gained voice in defining our society's values and in making rules that reflect these values, there have been some cultural shifts. For example, what was once considered weakness or dependency in women has begun to be seen as the recognition of others' importance in our lives. Cooperation has replaced competition and the desire to dominate others as a means of interaction in many successful groups and organizations. This follows the truism that, as human beings, we are social creatures; therefore, relationships are central to peaceful coexistence. And to our health and well-being.

Related Resources

Anxiety Disorders Association of America
adaa.org

HealthyMinds.org

MentalHelp.net

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THE OHIO STATE UNIVERSITY COLLEGE OF SOCIAL WORK

Save the Date

April 21, 2012

Synch it to your Smartphone. Mark it on your calendar. Use an old-fashioned Post-it note!

Amputee Coalition Limb Loss Education Day is coming to Atlanta, Georgia, April 21, 2012, at the Gwinnett County Fairgrounds.

Join the Amputee Coalition for the first event in an exciting new educational series: Amputee Coalition Limb Loss Education Days.

The Coalition is partnering with Children's Healthcare of Atlanta and OPAF's McKeever's First Ride to host our first Limb Loss Education Day event in 2012. This special event will feature:

- Gait Analysis Clinic
- Sessions by limb loss experts
- Networking and fun with your peers.

Limb Loss Education Days are a component of our 2012 educational programming. With these 1-day programs, the Amputee Coalition will reach people with limb loss where they live to begin building stronger limb loss communities across the nation.

Stay tuned for more information about the Amputee Coalition's 2012 Educational Programming Calendar of Events, including additional Limb Loss Education Day events, webinars and new podcast releases.

Come learn with us in Atlanta!

For more information:
conference@amputee-coalition.org
888/267-5669

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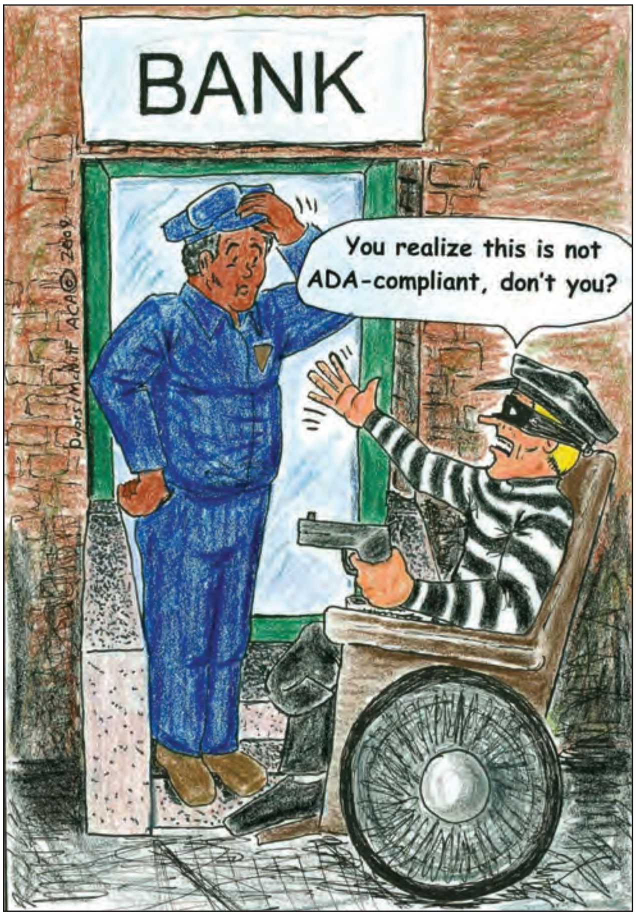

POLICY

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.

amputee coalition

ADVERTISER INDEX

A Mother's Thoughts on Parenting With Limb Loss

by Peggy Chenoweth | photo provided by Peggy Chenoweth

I will never forget my emotions when my son Robby was born. I suppose I experienced the same apprehensions felt by new mothers since the beginning of time. We were handed a little blue bundle by the nurse who, for some reason, expected us to know what to do. In reality we were clueless, inexperienced and utterly terrified. The fact that I was navigating through this wild adventure of parenthood with an amputation merely compounded my fears.

During the first few months of motherhood, I fretted obsessively about how my limb loss would affect my son. I worried about everything, from carrying him safely while wearing my prosthesis to keeping up with him at the park when he was older. More than anything, I agonized about how having an amputee mommy would impact his peer relationships. The thought of his being taunted because of my disability broke my heart.

When Robby was 6 months old, I awoke with an epiphany: I couldn't do anything about my little boy having a mom with one leg, but I could be the best mother possible by demonstrating that one can flourish and thrive with limb loss. In that moment, my perspective changed and much of my anxiety evaporated. I decided to turn being an amputee parent into a challenge – to prove to my son and to society that limb loss doesn't have to be a handicap.

Being a parent with an amputation has not been without challenges. Sometimes prosthetic and limb issues have sidelined me. Robby has learned what it means when I have a "bad leg day" and has heard, "Momom needs to take a break and take my leg off" on more than one occasion. He has seen that my abilities exceed any limitations caused by my disability. He has never known me without a prosthesis. For him, having an amputee parent is nothing unusual and is simply part of life.

Because he has been exposed to my limb loss since he was born, Robby isn't fazed when he sees an individual with a prosthetic or disability. When we are in public and he sees another amputee, my little boy thinks nothing of introducing himself and informing his new acquaintance about "Momom's special leg." I rarely have to struggle with an icebreaker when he's with me.

Despite my worries during the first few months, my son is not ashamed of my limb loss and prosthetic use. Earlier this year I found him stuffing my prosthetic leg into his little backpack. He wanted to take my leg for show and tell because he was supposed to bring an item demonstrating what he wanted to be when he grew up.

While all of the cubbies in his classroom were overflowing with plastic fireman hats, baseball bats, stuffed dogs and toy chalkboards, my child's cubby had a leg jutting out. Robby's presentation earned raves from his classmates and teachers. He sat in front of his peers, holding my leg, and explained that he was going to build prosthetics to help people walk and run. He described the "really cool robot hand" that he saw and explained how he is going to build those arms someday. I was told that he talked for nearly 10 minutes about his ambitions!

By growing up with an amputee parent, Robby has a unique perspective on the world. Because of his experiences, he doesn't see disability as a hindrance and is a kind, caring and empathetic person. Worries and anxiety about how my amputation would impact him have faded as I see a happy, well-adjusted little boy who can deal with the realities of the world.

"… I awoke with an epiphany: I couldn't do anything about my little boy having a mom with one leg, but I could be the best mother possible by demonstrating that one can flourish and thrive with limb loss."

Breaking News

September-October 2011

Dateline: Dallas, Texas

$1.00

SCOTT SABOLICH OPENS A NEW PLACE OF HEALING!

Dallas, TX World renowned Scott Sabolich Prosthetics and Research is proud to announce their expansion to North Dallas, opening in January 2012! Combined with the latest technological advancements, our new 11,500 sq. ft., state-of-the-art facility will offer restoration and healing to the thousands facing limb loss in North Texas. Call today to schedule your free evaluation for our grand opening, and experience the Sabolich difference!

"I am able to wear my prosthesis all day, everyday. Most people don't realize I'm an amputee."

Holley Howard
Above-knee amputee Tyler, TX

"I leave my medical practice in Virginia to go to Oklahoma for my prosthetic care because I know they will take good care of me."

Dr. Fred Duckworth
Above-knee amputee Richmond, VA

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Limb Loss Awareness Month

April 2012

We're leading the fight to empower people affected by limb loss and to reduce amputations. This year, we're focusing on reducing diabetes amputations, the #1 cause of limb loss in America.

"The Amputee Coalition was there when I needed them; now it's time for me to *'pay it forward.'*"
– Charlie Steele, National Spokesperson

This April, we'll need volunteers to:

- Distribute educational materials
- Organize a foot screening
- Join our exclusive 507 Club
- Share your personal story!

Even if you have just one hour to give, you can make a difference. Please join us in our effort. The life you improve just might be your own.

Call 888/267-5669 to sign up!

Save the Date - April 21, 2012

Amputee Coalition Limb Loss Education Day
Atlanta, GA at the Gwinnett County Fairgrounds
For more information, see page 49 in this issue of *inMotion*
or visit our Web site at amputee-coalition.org