

# *in*Motion

A magazine dedicated to living well with limb loss

A Publication  
of the



amputee  
coalition™

## A Virtual Room of One's Own

*Can Virtual Technology  
Advance Amputee Support?*

Mirror Therapy:  
Seeking Relief  
Through the  
Looking Glass

Savvy Surfing for  
Health Information

The Thin Line  
Between  
Devoted Friend  
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# Reach out and Touch

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Interaction and communication are vital to your emotional well-being. But for people with limb loss, living with a disability can make some feel like an alien on their own planet, especially in the case of new amputees. The temptation to close up emotionally can be very strong, at the time when communication and support are needed most.

Family and friends can make all the difference. But not everyone has that vital support. And not everyone is equipped to provide the kind of support that an amputee needs.

For others, they may not have a support group in their area or they may be physically or emotionally unable to attend one. They may consider reaching out as a sign of weakness, or they may fear rejection. But a conversation with another amputee can not only ease these fears, it can lead to a wealth of information about living well with limb loss.

Although peer support is especially critical for new amputees, this is actually only the beginning of a lifelong process, and the Amputee Coalition is there for you every step of the way. The Coalition has trained and certified nearly 1,100 volunteers to provide personalized peer support. With a database of over 260 support groups, we can also help you find a local support group, start one, or find other avenues of support.

This issue explores some of these alternative options, such as online and virtual therapy (see page 24, *A Virtual Room of One's Own*) and social networking. They offer a way to re-engage with society, with people who truly understand what they are going through.

The community of people with disabilities is as diverse as the larger family of humanity. As a result, there are many kinds of adapted media for people with disabilities to use to communicate within their own communities and with non-disabled people (see page 16, *Advancements in Assistive Technology*).

This issue covers a variety of options to help you reach out and break through the feelings of isolation. It helps to know that these feelings have been experienced by many others, that understanding and constructive help are available, and that you are not alone.

*Bill Dupes, Senior Editor*

*"No man is an island."*

—John Donne



## BE AN INFORMED READER

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

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

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**Cindy Charlton** is a professional speaker and published author, sharing her story of survival, inspiration and hope to people of all ages.



Cindy became a triple amputee after surviving a life-threatening illness.

**Peggy Chenoweth** is a left below-knee amputee. She coordinates *inMotion* advertising sales and maintains Facebook pages for the Amputee Coalition and the Orthotic Prosthetic Center.



**Roberta Cone**, PsyD, is a research psychologist and a below-elbow amputee.

**Amy Di Leo** is the founder of Aim Hi Public Relations (AimHiPR.com) and has been a television and print journalist for more than 20 years.



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**Denise D. Keenan**, OTR, CHT, practices as a hand therapist in an Intermountain Healthcare, Inc., outpatient clinic in Salt Lake City, Utah.



She is adjunct faculty in the Occupational Therapy Program at the University of Utah.

**Debra Kerper** has visited more than 30 countries and has been on over 75 cruises in her career in travel for people with disabilities.



**Phantom Fashionista**

**Robert Thompson** CPed, BOC pedorthist, is executive director of the Institute for Preventive Foot Health.



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**Sierra Younger** is an active high school sophomore with proximal femoral focal deficiency (PFFD), which requires a prosthetic leg.



A Publication of the Amputee Coalition

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

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**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.

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## HOW SOCIAL MEDIA CAN IMPACT *Grassroots Lobbying*

by Dan Ignaszewski

### A Step-by-Step Approach to Grassroots Activation

Grassroots lobbying focuses on raising awareness of issues at the local level to influence elected officials in the decision-making process. Here's a model of how, together with the Amputee Coalition using social media, we can provide an even greater impact for the limb loss community.

**Step 1:** The Amputee Coalition develops policy perspectives and drafts model legislation to ensure adequate and affordable insurance coverage for prosthetic devices, and provides information to help support this legislation. The Insurance Fairness for Amputees Act is born.

**Step 2:** An alert is sent out to 1,000 of the Amputee Coalition's members through email, Facebook, Twitter and other social media sites, asking to

urge legislators to pass the Insurance Fairness for Amputees Act.


**Step 3:** All 1,000 people use the alert to contact their legislators.

**Step 4:** Those who use social media to spread the word have an even greater impact! If only 10 percent post or share the alert on their Facebook or Twitter account to help the cause, all of their friends or followers see the alert too. As a result, many feel they should also contact their legislators to ask for support, which can exponentially increase the number of people contacting their legislator!

**Step 5:** By using social media as a tool to let others know about the importance of this issue, legislators receive more than 10,000 calls and messages instead of the original 1,000 because more people were made aware of the issue.

**Step 6:** Because of the huge volume of contacts, the legislator is compelled to look into the issue, and with all of the urging from local constituents, signs on as a cosponsor, or even holds a hearing because, not only is it the right thing to do, they know that a large number of their constituents find this issue to be of the utmost importance.

**Step 7:** With the outpouring of support from amputees, their families, caregivers and friends on social media, legislators can pass Insurance Fairness for Amputees and ensure that arms and legs are not a luxury, making adequate and affordable coverage for prosthetic care a reality.

*Join the Amputee Coalition on Facebook and Twitter, and make your voice heard on important issues affecting the limb loss community.* 





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**NOVEMBER 14**  
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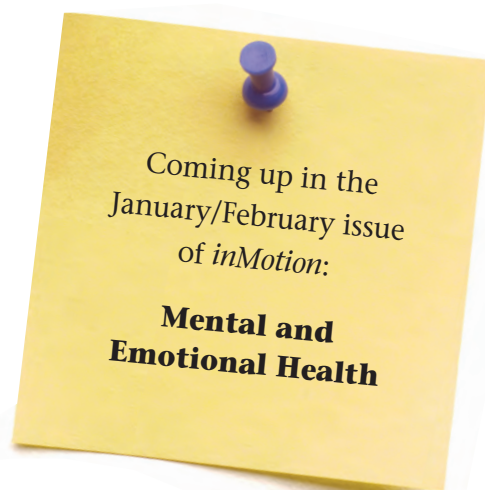
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un.org/disabilities

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**DECEMBER 15**  
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# Telemedicine



by Fabio C. Figueiredo, MD

The ability to exchange information with professionals in real time.

## *Modern technology at the service of amputee rehabilitation*

Technology is advancing at an exponential rate in all fields of human knowledge. Advances in high-speed data transmission have resulted in remarkable new methods of communication. The rapid transmission of images and sound has made it possible for all of us to communicate efficiently, even with people located on the other side of the planet.

Through this technology, it is now possible to simulate, with significant realism, a person's physical presence (at a meeting, for example) located thousands of miles away. When applied to medicine, the concept of "telemedicine" opens the door to previously unimagined possibilities. The scenario of a patient consulting – or even having surgery performed by – a professional located on another continent is no longer considered science fiction.

*continued on page 14*

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Can anyone imagine the limits to where science will take us in this field?

Lower-limb amputations are, unfortunately, commonly performed in all geographic areas, so that, even in less-populated locations, rehabilitation professionals are familiar with prosthetic fitting and patient training following such procedures. However, this is not always the case for upper-extremity amputations (excluding simpler ones, such as distal fingers).

The technology of modern prosthetic/bionic hands, elbows and fingers is evolving very quickly; therefore, the fitting of these devices is becoming an increasingly specialized process. That fact, in conjunction with their lower frequency of occurrence, creates a difficult problem in more remote areas; while there is a need for an upper-limb prosthetics specialist in those situations, it is simply impractical for prosthetic facilities to maintain one at each location. Also, having such specialists travel constantly from location to location to cover extensive geographical areas can be exhausting for the professional and not cost-effective for the healthcare system.

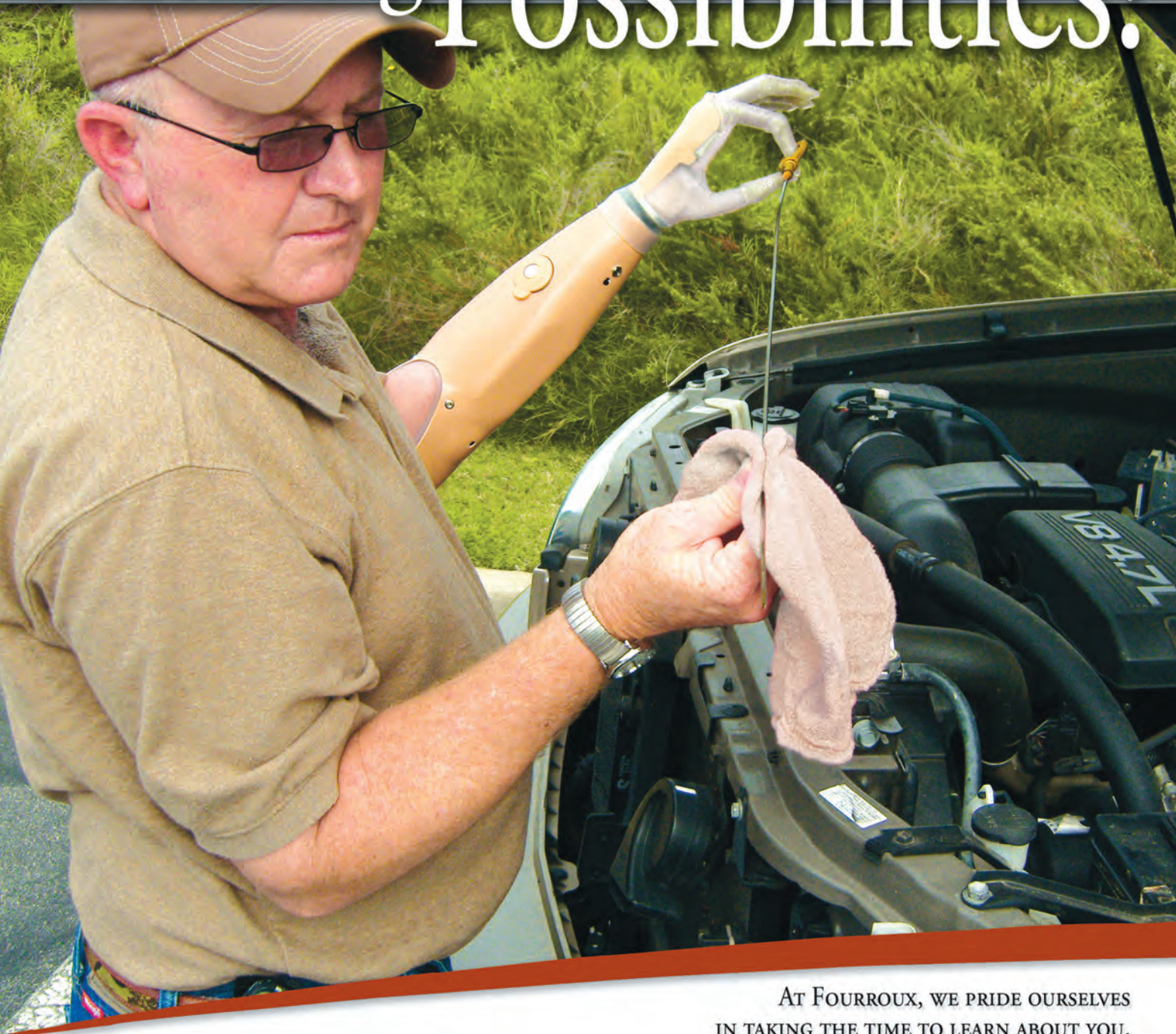
I consider the rehabilitation of amputees one of the areas of medical practice in which patients benefit the most from continuous and ethically correct interaction and collaboration between their surgeons and the healthcare industry. In my practice, through the use of telemedicine, by simply having a laptop computer in the room, we are now able to have a prosthetics subspecialist “telepresent” every time we find it necessary during a clinical encounter. The ability to exchange information with such professionals in real time and to have the patient ask questions and have them immediately answered by his/her entire rehabilitation team has proved to be a valuable tool. Moreover, we are currently planning to connect, using such technology, patients to other, already rehabilitated amputees through Hanger’s Amputee Empowerment Partners program, which I believe will enhance and accelerate the rehabilitation of our patients even more through exchange of their experiences. 

*continued from page 12*

There is probably no question in most people’s minds that certain aspects of medical practice are probably best delivered through the physical presence of a healthcare provider. I believe there is some unquestionable value in the provider’s “touch” among the mechanisms that favor successful recovery and/or rehabilitation. However, many stages of a long rehabilitation can likely be provided to patients appropriately without such presence, or at least without the physical presence of every single specialist and subspecialist who takes part in the process.

As a reconstructive hand and orthopaedic surgeon, I am frequently responsible for the surgical care of patients with complex extremity injuries. Advanced surgical and microsurgical techniques can often be successfully employed for limb salvage; unfortunately, complications (such as infections) sometimes do occur in the course of long treatments. Also, the reality is there are circumstances where traumatic damage to the extremity is so severe that surgical salvage is likely to result in a nonfunctional and/or chronically painful appendage. In such cases, amputation and prosthetic fitting often constitute the best treatment option I can offer my patients.

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# Advancements in Assistive Technology

by Denise Keenan, OTR, CHT

For some individuals, a device may be a convenience; for others, it is an assistive technology.

Although there is no uniform legal definition of assistive technology, it can be described as any device that replaces or supports a user's impaired function without being expected to change the individual's native functioning. Enabling technology can be categorized by its application rather than by its device. For some individuals, a device may be a convenience; for others, it is an assistive technology. The mini-food processor, TV remote control, iPad or trackball mouse are examples.

Electronic assistive technologies can be categorized in three areas: electronic daily living aids, alternative communications and general computer applications. As technology continues to advance, it is likely that other mass market devices are the most beneficial to an individual seeking out the use of technology to enable the highest level of independence and that adaptive devices are not necessary. The philosophy of universal design is that all products and environments should be as usable as possible by as many people as possible, regardless of age, ability or situation. Therefore, communication and computing devices will be more usable for all, with and without disabilities,





if this philosophy is supported by manufacturers.

Electronic Aids to Daily Living (EADLs) control electrical devices in one's home via use of power switching, wall current control, telephone electronics and infrared. An example of system types and baseline costs are:

- Software package for PCs \$200
- X-10 adapter control \$150
- Wifi/IR (infrared) control \$350
- Switch interface with control unit \$250
- Scanning infrared \$700
- Voice-activated \$1,800
- Touch Screen \$2,700

## General Computer Applications

Computers have a dual role in relation to assistive technology as computing or surfing the Web may be the actual activity desired or it may enable one to access activities that would not be possible without it. If an amputee uses a computer/PDA (personal digital assistant) to maintain schedules, record

information, communicate with others because writing or computing is illegible or slow and managing calendars and paperwork is unwieldy, the computer then becomes the assistive device/technology. Electronic control can be divided into three broad categories: input, performance and output.

Input can occur via physical (keyboard), speech or scanning methods. Keyboard input can be adapted by use of alternative keyboard patterns (Dvorak Two-Handed, Dvorak One-Handed, Chubon vs. QWERTY), delayed acceptance (pause between key press and effect), and enlarged or minimized keyboard scale (mini-keyboard, notebook). The Toshiba Libretto W105 (\$1100) and the iPad (\$400-\$750) are examples of notepads that have eliminated the traditional keyboard and built one into the device with the option to hide the keyboard and use a touchscreen only.

If an amputee operates the traditional keyboard with a significant rate delay or lacks the motor control to use the keyboard because of dominance change, prosthesis design or loss of digital motion of the residual hand, pointing systems via head or mouth control are available. Cost of

pointers ranges from \$80 to \$300. The optimum pointing system is eye-tracking input. Cost for current systems is quite high, ranging from \$7,000 to \$9,000. There is a brief set-up process to read one's eyes and eye position before use. Although control input for EADLs does not need to be rapid, control of the system for computing does require a rapid rate to be effective. Rate enhancement options include automatically completing words or phrases and compression/expansion (storing abbreviations of common phrases that can be expanded when the abbreviation is typed).

Other low-tech options for computer input include the use of a joystick, foot mouse, a trackball, or use of a trackball on the floor to serve as a foot mouse. With sensor pad usage, the unilateral amputee usually computes with the residual hand; for the bilateral amputee, a stylus is needed to interact with the touch device. These are relatively inexpensive (\$10). A stylus "mount" could be fabricated at the end of a prosthesis to stabilize it during use or the stylus may be directly held by the prosthesis.

Dragon Systems introduced speech input in 1990 and now has premium (\$200) and professional (\$500)




Photograph provided by Denise Keenan

editions for the Mac and PC. The systems are reportedly quite accurate and user-friendly. Windows 7 (\$200) and 8 includes free speech recognition software, which has good reviews related to casual use. The user can operate these software programs with a standard keyboard. iPad has an application for the Dragon Dictate program. The downside to these programs is that they are inaccurate in loud environments.

Digital pens, such as the Echo Smartpen, Pulse Smartpen and Capturx for OneNote, require special paper and contain a camera within the pen itself (average cost, \$150). For others, such as the Mobile Digital Scribe, the recording/

sensor technology is housed in an accompanying docking device that must be placed on or near the paper on which you are writing. All the pens allow you to upload handwritten words, tables and illustrations to a computer. Most convert the data to text, which can then be imported into a Word document or an email.

Many options exist for computing with the current state of electronic technology, and the device and control decisions are unique to each amputee. Some will benefit from assistive technology and others will perform successfully with mass marketed products. One thing is certain, however – even more options will exist in the future. 

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# The Pros and Cons of Group Travel

by Debra Kerper

*There is a wide choice  
of groups available  
to meet every  
demographic and need.*

There are many reasons why people choose groups over independent travel, but it's important to understand why traveling with a group works better in certain situations, while independent travel works better in others.

Group travel is beneficial for inexperienced travelers and people going to foreign countries, where English is not the primary language.

People are, by nature, social beings; when you travel with a group, you have the advantage of traveling with people with similar interests. You'll always have someone to dine with, sightsee with and converse with.

A major advantage of group travel is **the luxury of having your itinerary fully planned** out for you, with the exception of some built-in free time for exploring on your own. How nice it is to just wake up, eat breakfast and then get on the bus and be taken around to see the sights! It's been said that people always do well in a structured environment, and traveling with a group is the epitome of structure. The downside of this is the loss of control. You may not want to spend two hours at a museum and only have 30 minutes to shop or vice versa.

Another advantage is **the safe environment that a group of people and a guide provides**. Your guide will give you safety tips along the way and will ensure that you stay out of questionable areas. You'll have the security of being with a tour guide who knows what to do in case of an emergency. You'll never be left to fend for yourself.

**You'll often find that the cost of your trip is significantly reduced**

by joining a group tour. Groups can take advantage of rates offered only to them based upon the volume of business that they bring to the various vendors. There are a lot of "value-added" features when you travel with a group, such as being assured you will gain admittance into crowded venues, not having to stand in long lines and reserved tables in restaurants, to name a few. And you'll be sure to see all the highlights the area you're traveling to is famous for. In fact, when I travel independently, I often consult various tour Web sites to check out where they go, so I don't miss anything!

As I alluded to before, the best thing about traveling in a group is **the people you meet**. So, what's the worst thing about group travel?

It's the people you meet! There's one in every crowd – the person who's perpetually late for the bus in the morning and when it's time to board the bus after an excursion. This person is also great at disappearing! Then there's the person who knows more than everyone, including the tour guide, and just has to be the center of attention. Hopefully, you'll have a tour guide who can tactfully keep this person in line.

There is a wide choice of groups available to meet every demographic and need. Perhaps you want to travel at a slower pace and desire extra free time. Study the brochures and Web sites and learn to understand the jargon that is used in the travel industry. For example, when you see the phrase "On Your Own," it means


that this activity is not included and you may need to pay admission costs, etc. You will truly be on your own. If you see the word "View" in a tour description, this means that you're merely driving by and not stopping or getting off the bus to get a close look.

There's a tour for everyone out there, and by becoming educated you'll learn to make the proper choices. After a few group trips, you'll be ready to explore the world on your own! 🌍



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## *Social Media's Effect on Relationships*

by Sierra Younger

Social media sites such as Facebook, Twitter and MySpace have changed the world forever. These Web tools have revolutionized a generation; however, as with anything, this can be both good and bad.

For instance, with the invention of social media, dating in high school has become more complicated – as if it needed any help. Sadly, our society is obsessed with beauty, so it should be of no surprise that most high school students rate each other on some scale of physical beauty similar to the whole reason Facebook was started.

Through social media, people can create an online profile of themselves, sharing photos and interesting status updates that they think their friends would like to see. This type of activity is beneficial to your friends and relatives living in other cities or states as they get to stay abreast of what's "new with you." This profile is built daily by you through finding friends, checking your friends' status updates and commenting on other people's stories and photos, all the while painting a pretty good picture of

who you really are, as if to tell the world: "Here I am, and I am looking to attract friends and soulmates through this online profile."

Conveniently, once you find someone to date, with the click of a mouse you can tell the whole Web that you are in a relationship with so-and-so. Easy? Yes. All good? Not so fast. Social media is unfortunately an easy place to bully people as well. Keyboard cowards are waiting to pounce on their supposed friends and rip them to shreds or worse, spread



trying to be nice by saying “your hair looks great” in that photo. A lot of trouble starts because we no longer pick up the phone or talk face-to-face to friends; instead, we just sit back and wait for another comment to be posted.

Please keep in mind that anything you say or do will stay online forever. In the case of cyberbullying, that can be a good thing if you are the victim; you can simply print out the material and submit it to your school resource officer or principal. You do not have to be a victim. This doesn’t necessarily mean that the bully will magically go away, but you can always “unfriend” those people or increase your security settings on your profile, which is highly recommended anyway. The less personal information that outsiders have access to, the better. As studies show, sexual predators or criminals love to surf the Web in the hopes of finding new victims to exploit. Stay safe and protect your personal information, keep your conversations friendly and join the trend of complimenting your friends to encourage and build them up instead of the nonstop petty drama.

false rumors, post unflattering photos or send private messages to your boyfriend or girlfriend. Many a fight between friends and their sweetheart start just by an innocent “liking” of someone’s status or photo; the green jealousy monster arrives, and a full-on cage fight ensues. If this happens to you, before you shoot back a nasty reply, remember that you are simply staring at a computer screen or smart phone and you cannot judge the tone of someone’s voice in that comment or the real intention of another friend just

With new drama always around the corner, social media sites almost seem to encourage people to say things that they would never have the courage to say in person. My advice? Don’t talk the talk, if you can’t walk the walk. Be the best you that you can be. 🌀

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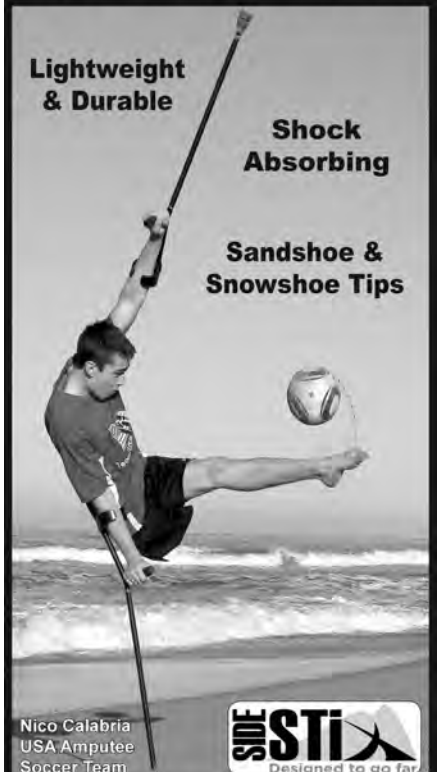


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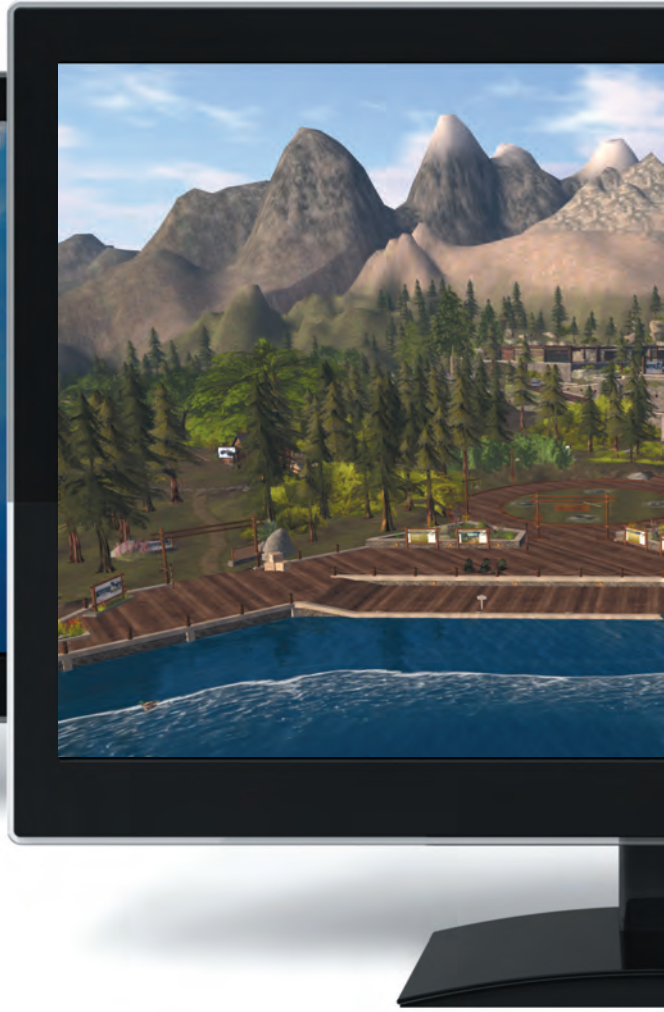


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## *A Virtual Room*

# Can Virtual Technology Adv

**A**s anyone who has recovered from a traumatic amputation knows, recovery requires more than just physical rehabilitation. The benefits of social support among people who have been through similar traumatic events are supported by research and scores of personal testimony. Support groups, combined with the support from friends, family, and the community,

are necessary to help individuals regain physical and emotional strength and rebuild their lives. The concept is not new: peer support programs for war veterans existed as early as World War I.

What *is* new is that the nature of peer support has in the last decade also taken the form





# *of One's Own* nce Amputee Peer Support?

by Élan Young

of online discussions forums, chat rooms and social media groups. Connecting with others for peer support can be challenging because of real-world hurdles – schedules, distance and even the disability itself can make it difficult or impossible to get the people who need it most in the same room with others. Research indicates that the advent of Internet communication

technologies has increased the quality of life for people with disabilities.

Online communities are not a replacement for human contact, but advocates of technology that engages users in a simulated world as a recovery and support tool are motivated by the knowledge that, in

>> **Online communities are not a replacement for human contact, but advocates for technology that engages users in a simulated world as a recovery and support tool.**



these virtual worlds, people can find support, feel empowered and gain real-world resources to improve their lives. More support groups are finding homes in virtual space to bring geographically diverse groups of people with common traumas together in the same virtual room, where users can log in from anywhere, at any time of day, and can remain anonymous if they choose. Nevertheless, there remains a gap in understanding how people with disabilities might benefit from these virtual world technologies. Studies show that the benefits are real, but in terms of peer support – especially peer support for amputees – there is no empirical evidence that virtual world peer support is a trusted match to real-world peer support. Researchers at the Telemedicine and Advanced Technology Research Center (TATRC), a facility in Ft. Detrick, Maryland established to address gaps in Department of Defense medical research programs, are seeking the answer to this and other questions, specifically as it applies to military amputees. Even as the research is underway, more and more individuals with disabilities are experiencing virtual world technologies and reporting positive results.

In 2009, Ashley Fisher and Troy Turner, both portfolio managers at TATRC, and Adam Kisielewski, a double amputee Marine who also worked at TATRC, discussed ways they could use more forward-looking Internet technologies to help service members. “Conversation led to the problems and challenges that folks have when they stay in a hospital for a long time,” explains Turner. “In our case, we were thinking of the men and women who spend a year or more at places like Walter Reed or Brooke Army Medical Center, and who have family members stay with them; it’s usually not economically viable for a person to stay extremely long-term. We wanted to find a way for the service members to maintain regular and fairly easy contact with their families and members of their unit, using tools other than Facebook and Twitter.”

With a grant from the Army Medical Department’s Advanced Medical Technology Initiative (AAMTI), their conversation turned into a funded research project: the Amputee Virtual Environment Support Space (AVESS). The project sets out to create a safe virtual environment for amputee peer support groups, regardless of one’s physical or geographic constraints. The vision is to create a virtual environment that will serve as a platform for veteran amputees to exchange stories, information and tips, as well as provide

the peer support framework that amputees might lose when they leave military treatment facilities after rehabilitation. “A core premise of AVESS is that while the initial environment will be sufficient to engage users, provide the tools for educational and social activities, and allow for private sessions to facilitate future counseling,” says Fisher, “it will also change over time based on the contributions of the community, and significant space has been assigned to areas that users or user groups can customize.”

To understand what the project seeks to accomplish, it’s important to understand how a virtual world is different from that of social

The most popular virtual-world platform is Second Life, established in 2003, which hosts nearly 13 million users globally. People come into Second Life for a myriad of reasons: to take a college class, to express themselves creatively, to socialize, to listen to live music, to tour the world or museums, to engage in role-play, to learn a new language – the possibilities are endless. As the field has grown, other companies have stepped in to offer similar platforms for a variety of uses. One of the differences between Second Life and some of the other platforms is that anyone over age 16 can join Second Life, making it widely accessible with no charge to open an account. Many

argue that virtual reality platforms are tools that are applicable to real life, not simply as a game for escaping reality.

While there’s a wide range of possibility for different types of support groups – for people with disabilities or otherwise – the AVESS team began focusing on amputees because their work already put them on the forefront of amputee and advanced prosthetic research. But it wasn’t just that amputees were a common thread through their jobs; they also recognized that there was a lot of opportunity with the amputee population. In terms of self-identity, amputees can easily display the avatar as missing the

*“...in a virtual world, each individual determines for his or her self what will be accomplished.”*

media and chat rooms. To exist in a virtual world, users first create a human-like avatar, three-dimensional self-representations that computer users can use to interact with others. Avatars move through the environment, manipulate objects and participate in day-to-day activities that most people take for granted, but they can also do things that can’t be done in real life, like fly and teleport. The avatars can reflect a person’s own physical traits or the user can claim any set of imagined traits. People with disabilities can choose to self-identify as a way to connect with others with the same disability, or they can create a different version of themselves free of their disability. In a virtual world, people can project themselves however they choose. The only limitation is imagination.

organizations have embraced Second Life for a variety of applications, including circulating information and hosting discussion forums and educational lectures. Since Second Life has no stipulated goals, winning and losing are not applicable terms to describe the users’ activity and experience. Alice Krueger, president of Virtual Ability, Inc., a nonprofit company that partnered with TATRC at the beginning of the AVESS project, emphasizes that using a virtual world like Second Life is much different than playing video games. “Unlike an online game, where the goal or objective is set by the game designer,” says Krueger, “in a virtual world, each individual determines for his or her own self what will be accomplished.” Although the topic is still debated, advocates strongly

same limb that they are missing, which might help when walking around in AVESS and trading stories or connecting with amputees of a similar kind. Alternatively, if users want to try out a new self-perception and project themselves as having all of their limbs, then that is possible, too. In terms of research, there are ample possibilities for studying the effectiveness of a virtual environment for amputees in a manner similar to mirror therapy, where amputees can see the limbs in the virtual world, which can often mitigate phantom pain.

The AVESS environment is intended not only for peer support, but also for patient education and telerehabilitation provided by professionals, including physical and occupational therapists, prosthetists

## A Virtual Room of One's Own



Photograph provided by Ashley Fisher

*Marine Sgt. (Ret) Adam Kisielewski was one of the original members of the AVESS concept development team.*

**>>> People come into Second Life for a myriad of reasons: to take a college class, to express themselves creatively, to socialize, to listen to live music, to tour the world or museums, to engage in role-play, to learn a new language – the possibilities are endless.**

and physicians. The AVESS model of service delivery to people with disabilities reaches far beyond military amputees, who are the first trial audience. It has the potential to apply to people with any chronic illness or ongoing disability who could benefit from ongoing interaction both with medical professionals and peers.

Currently, Virtual Ability, Inc., has identified over 120 peer support groups in Second Life established for various chronic illnesses and disabilities, almost all of which are peer-led and independent of external organizations. However, some large groups, such as the American Cancer Society, the Autism Society of America, the Boomer Esiason Foundation and the Michael J. Fox Foundation have an official presence in Second Life. The AVESS concept is platform-independent as well, and can be implemented in any virtual world setting. The AVESS research is focused on the technical capability of a peer support experience and proving the benefit to users. When and if it becomes available, the developers agree

A Second Life user with multiple sclerosis identified simply as “Amy” states on the Virtual Ability Web site how the virtual world has enhanced her real life: “There are so many ways that Second Life has helped me in real life. Second Life gives me a chance to communicate with others, to socialize and gain valuable knowledge. Second Life helps me to remember things because it’s so visual.”

Although the experience is a visual one for most users, there are even force feedback applications for people without sight, making it a truly unique space for just about anyone to connect. The long-term implications for the disability community are huge, but it still remains a frontier with many opportunities for exploration.


Multiple studies have already shown the benefits of virtual technologies in different medical situations, such as pain relief. For example, burn patients have

*“Second Life gives me a chance to communicate with others, to socialize and gain valuable knowledge.”*

that service members would have access to the service free of charge. As for how it would be made available to the general public, it’s still too early to tell.

As the project enters different phases, it has had to evolve with the funding. The first phase of the project was a working mockup of an environment where soldiers, support personnel and family members could interact casually. The second phase of the project leveraged the lessons learned in the first phase to create a more visually appealing environment and further explored issues of privacy and security. The third phase has branched into two concurrent projects. One focus will be to develop technologies that enable mapping of facial expressions and limb gestures and in-world physical therapy to increase immersion in the environment. In another focus, Fisher and Turner are exploring other virtual world platforms for hosting the final AVESS environment. Once the environment is up and running, the next step would be to conduct research to evaluate the environment’s performance. Turner explains: “We have always intended to come back and pursue validation studies with real users and consumers to prove efficacy. Right now, we’re just trying to keep all the balls in the air while we’re pursuing funding.”

experienced less pain when interacting in a virtual realm that simulates a cold environment. So far, the main researched benefits to people with disabilities is that they can engage in a range of activities relatively free from the limitations imposed by their disability, and that they can do so in a safe place. Perhaps ironically, this includes success in developing social skills, specifically as a way to escape prejudice and experience inclusion by their peers.

The findings from the AVESS study are still a few years away, but the researchers remain hopeful that the platform will prove its benefit and be available to the amputee population. In the meantime, readers of *inMotion* are invited to submit ideas and questions for further research to [editor@amputee-coalition.org](mailto:editor@amputee-coalition.org), which may be used in later phases of research. Perhaps there will eventually be an Amputee Coalition support group in virtual space for amputees to join and share in peer support. For now at least, amputees and their caregivers, family and friends are always invited to connect with each other and join the dynamic conversation on the Amputee Coalition’s Facebook page. 



# Reaching Out... through blogging

by Cindy Charlton

Becoming an amputee wasn't on my bucket list. It wasn't something I envisioned or planned for myself. I have thought about estate planning and investment planning. I have planned for my future. But not limb loss. Writing a blog – a series of writings posted on the Internet – about the tools I've used to survive wasn't on my bucket list either, but I find that it connects me to those who want to know how I have survived extraordinary loss, including three limbs, over the past 15 years.

## Popular Blog Sites



Blogger.com



Simple-Press.com



Tumblr.com



Weeblr.com



WordPress

WordPress.com



Xanga.com



## Blogging Tips

After I lost my limbs, I found myself in a whirlwind of unknowns. I desperately needed information. I wanted to know how other amputees coped with amputation. My prosthetist provided me with information – but she had all of her limbs. It was difficult for me to hear from her that “things would get better.” Fortunately for me, her technician was an above-knee amputee; I found his information and experiences valuable. What made the biggest impression on me, however, was that I didn’t realize he was an amputee until he told me. I was equally surprised and inspired.

“Communication” became my battle cry. I started an amputee support group, and facilitated it for many years, but as my life became busier I found it necessary to leave the group. I still wanted to stay connected to the amputee community – I just needed to do it in way that fit my lifestyle. The freedom of giving (and receiving) support on my own time, from the comfort of my own home, was very appealing.

After looking at my options, I felt that blogging was a good choice. It intimidated me at first, as I’m not a natural “techie,” so I needed something easy to use. I perused many blog sites until I decided on the site I wanted to use. The blogs I most closely connected with offered useful information and made me feel something. My blog is written to be useful and to deliver hope and inspiration.

With my blog site chosen and my purpose established, I was ready

to look at the design – the visual component for my blog. I wanted my blog’s design to evoke emotions of optimism and joy. It was important for the background to align with the content. I found that I didn’t need a class in graphic design to accomplish my goal. Blog sites provide many templates from which to choose.

After setting up my blog ([thesurvivorshandbook.blogspot.com](http://thesurvivorshandbook.blogspot.com)), I was ready to “roll it out.” I began marketing it by sending emails to everyone in my address book. I have established Facebook and LinkedIn pages, so when I post a new blog, I send an email and put the link to my blog on those pages. Social media is a great way to promote blogs. However, I’ve learned the hard way to check my posts before publishing them. In my very first blog post, I used the term “cruising altitude” but wrote it as “cursing altitude.” One of my friends asked how high she needed to be before she could start cursing. I quickly learned how to edit a post online.

Blogging has provided a wonderful vehicle for me to continue helping people. I’m connected to the amputee community by virtue of my membership in our exclusive club – the one I never planned on joining. I hope that, through my blog, I can reach other amputees to let them know that it really does get better and to provide the information and inspiration that I so desperately needed 15 years ago. After all, what are we, if we are not here to help one another? 🌀

### 1. *Find Meaningful Content – What’s Your Passion?*

The best way to decide what to blog about is to ask yourself: “Would I do this for free?” If the answer is yes, then you’ve found your topic.

### 2. *Update Often*

This is where your passion comes in. Blogs that aren’t updated at least every two weeks are perceived as static Web pages.

### 3. *Get to Know Your Readers*

Your blog’s design and content should reflect your readers’ expectations. Blogging is a two-way street; it’s about forming relationships.

### 4. *Make an Impression With Your Design*

It’s important to choose the appropriate design; it should relate to your content.

### 5. *Be Grammatically Correct*

This sounds like a no-brainer, but it’s important if you want to be taken seriously.

# *The Thin Line Between* Devoted Friend & Devotee

by Peggy Chenoweth

**I**f you mention the term “devotee” to people outside the amputee community, chances are they won’t know what you’re talking about. For those unfamiliar with the term, a devotee is someone who is attracted to a person with limb loss. The attraction can range from simple admiration of the amputee to the full sexualization of the residual limb.



A little vigilance  
and detective work  
can help make social  
media a positive  
experience!



Within the amputee community, devotees have a negative connotation because of the actions of a small group. The radical extreme devotee demonstrates an obsession versus the admiration shown by the benign admirer.

Facebook and Internet forums have become a virtual minefield for amputees. As they use the Internet to network and to share experiences, those with less respectable intentions are often lurking in the shadows. However, a little detective work can help you protect your corner of the Web.

Upon receiving a friend request, always investigate the individual. Being a member of the same themed group doesn't guarantee that the person's profile is genuine. Look at their list of friends: Having only disabled friends or friends of one gender can be indicators of a devotee mentality.

Investigate the groups and interests that the individual "likes." Devotees seldom stalk alone – they tend to join tell-tale groups such as "amputee devotee" or similar themed associations. Look at the Web sites that are listed, and, if possible, the posts and photos on their Facebook wall.

Friend requests from an individual without a profile picture, someone who has just joined Facebook, or a person who is friends with a known devotee are warning signs. When in doubt, send the individual a message, asking them their intentions. You'd be amazed how many will confirm that they are indeed a devotee.

Beware of individuals who are fixated on seeing photos of your residual limb. Highly personal questions centering around the limb loss, especially early in a cyber relationship, are often markers of devotee intentions.

A quick search on several forums reveals a troubling trend. Many of these sites exploit new amputees to obtain pictures of residual limbs and their heartbreaking stories. They create a facade of support to solicit personal pictures, which are often distributed for sexual gratification.

Use caution when posting a photo of your residual limb. Assume that any picture of a residual limb posted on the Internet may eventually find its way onto an amputee pornography site. Know the risks, because some individuals scour the Internet for photos such as these for profit as well as to satisfy their fixation.

Because of the Internet and social media, amputees are connecting more than ever before, facilitating the sharing of experiences, ideas and information. New amputees need only to log onto the Internet to realize that they are not alone on the journey and that help is always a post away.

Unfortunately, this ability to connect does not come without risks. Never forget that it is impossible to control the dissemination of photographs and personal information once it has been posted online. But a little vigilance and detective work can help to make social media a positive experience! 🌐

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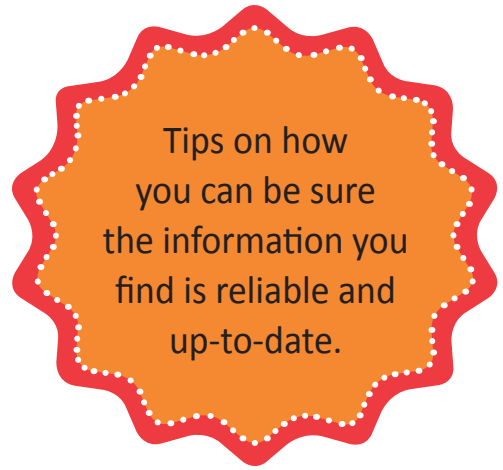
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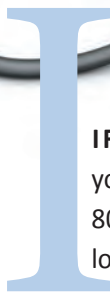


Tips on how you can be sure the information you find is reliable and up-to-date.

# Surfing for Health Information...

## *Is that Web Site reliable?*

by Amy Di Leo



**IF YOU SEEK OUT HEALTH AND MEDICAL INFORMATION ONLINE,** you're not alone. According to a 2011 report by the Pew Research Center, 80 percent of all Internet users, or nearly 60 percent of American adults, look for answers to their health questions on the Internet.

But when your Internet search yields hundreds, if not thousands of Web sites, how can you be sure the information you find is reliable and up-to-date?

First, it's important to consider the source. For example, any site that ends in .gov is sponsored by the federal government, and the information should be legitimate. Additionally, .edu sites are run by universities or medical schools and should provide good information as well. Most .org sites are maintained by nonprofit groups. Their sites should clearly include

information about the organization's mission, board and funding.

However, *anyone* can get a .org Web address. If you're unfamiliar with the site or it's unclear who owns it, check the "About Us" section. You should be able to identify what entity (company, agency, institution, individual) is financially supporting the site. A reliable health site will also have contact information easily accessible.

You should be most cautious with commercial (.com) sites. Information found

on these sites may be legitimate but if there are ads on the site, it could reflect a potential bias in the content. It should be clear whether the site is for educational and informational purposes, if it's selling a product or service (a physician's site would fit into this category as well), or whether its primary goal is fundraising or a news site. Ask yourself what gives this organization the authority to provide this information. It's advisable to check at least a second source to compare information.

Most health sites have a goal of educating and supporting consumers by offering quality health information. Health-related

Web sites should give information about the medical credentials of the people who prepare or review the site content. Also, pay close attention to where the information on the site comes from; original sources should be clearly identified. It's particularly important that medical information be current, so always look for dates to ensure that the information is the latest available.

Be careful not to provide personal information on Web sites unless you know why you're asked to provide it. Many commercial sites sell aggregate data about their visitors to other companies. That information could include race,

age and other demographic details about you. It could also be used to sell sponsorships or ads on the site. Be sure to read privacy policies, and don't sign up for anything you don't fully understand and embrace.

Last but not least, pay attention to claims of "cures," "breakthroughs" or a "secret" being promised on a Web site. Chances are, if it's the only site offering this information, it's probably too good to be true.

The Internet has changed people's relationships with information, but it is a remarkable tool. By paying attention to certain details, you can be a smart, safe surfer. 🌐

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# Holiday Season

## Preventive Foot Healthcare Tips

by Robert P. (Bob) Thompson, CPed

Shopping trips, parties and family gatherings can take their toll on your feet during the holiday season, but you can avoid the stress if you practice these simple tips from the Institute for Preventive Foot Health (IPFH) throughout the year.



### 10 Top Tips During the Season

1. **Check your feet every day** – twice daily if you have diabetes: once in the morning and again before bedtime. If you can't see the bottom of your feet, use a mirror on an extended handle or have someone else perform the examination for you. Look for cuts, scrapes or redness and feel for lumps and bumps that shouldn't be there. A numb diabetic foot is especially susceptible to unrecognized, repetitive trauma that could result in the formation of lesions/ulcers. Consult your doctor or foot health specialist if *any* lesions are found.
2. **Wear socks with padding under the toes**, the balls of the feet and the heels, made of acrylic-blend fibers. They'll absorb and wick moisture away from your feet. Avoid socks made of 100 percent natural fibers like cotton, wool and silk, as they absorb and retain moisture.
3. **Use an integrated approach to selecting comfortable, properly fitted and supportive shoes.** Know the proper shoe length and width you should be wearing. Don't rely on the size you've "always worn." The toe box should be tall and follow the shape of your feet (oblique or square-toe shoes are probably best) and footwear with both an arch support and a strong heel counter is recommended. You should be able to wiggle your toes in your shoes, which should be one-third to one-half inch longer than the longest toe on your longest foot when you're standing. Select shoes with softer



soles, such as thermoplastic rubber or ethylene vinyl acetate instead of leather; for better winter protection, select shoes with solid uppers instead of mesh fabrics.

4. **Use an arch support** (over-the-counter or custom-designed if needed) particularly if you have high arches or flat feet or require some biomechanical correction. Even a simple gel insert can help when you're out power shopping!
5. **Wash your feet in warm – not hot – soapy water daily.** If you have no feeling in your feet, use your elbow to test the temperature first. (Soaking your feet in Epsom salt may bring temporary relief if they're tired and achy). Dry them thoroughly before donning socks. Seek professional assistance if your toenails are discolored or separating from the skin. Such discoloration may be a sign of fungal infection or injury.
6. **Apply moisturizing lotion to your feet after bathing to alleviate dry skin.** If you have diabetes, *do not* apply lotion between your toes, as the resulting moist environment could favor fungal development and the friction created where the bony prominences of the joints meet between your toes could cause lesions/ulcers.
7. **Trim your toe nails.** Cut them straight across. If your toenails are thick or you can't reach them easily, *do not* attempt to trim them yourself. Seek professional assistance.
8. **Limit the time you go barefoot around the house.** Avoid temperature extremes (especially in winter!). If you have diabetes, *never* go barefooted! At a minimum, wear houseshoes.
9. **If possible, don't wear the same pair of shoes two days in a row.** The moisture that builds up inside your shoes needs time to evaporate, and the shoes need to dry out if they get wet on the outside.
10. **Avoid crossing your legs – doing so may inhibit your circulation.** The breakdown of nerve function combined with restricted blood flow is virtually a guaranteed prescription for amputation. 🌀

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## Fashionable Illusions

Can I just say how excited I am to hear from you fabulous fashionistas? Since this column began two issues ago, I have heard from you with your own prosthetically induced fashion situations (PIFS), and more are waiting in the queue. And because the Phantom Fashionista is about all of us fashionably coming together and sharing things we've learned along the way, please keep them coming....

So, without further delay, let me begin with the first PIFS from Fashionista Susan, who writes:

"Is there ANYTHING that can be done to camouflage the bulk that the [AK] socket adds to my middle section? Good grief! Looks like you could set a table on my \_\_\_!"

The "\_\_\_" replaces a word referring to her posterior "aspect" (and the editors kindly requested that I take some poetic license here).

My dear Fashionista Susan, as a fellow above-knee (AK) amputee, I know *exactly* what you mean. While prosthetic solutions may fix this particular PIFS (and are better left to discussions with

your prosthetist), let's talk about fashionable ways to cover it up instead.

My socket is an ischial containment design, which means that my left gluteal aspect almost "sits" on the posterior part of the socket ledge, making it a challenge to maintain an otherwise "normal" look (if you know what I mean). Because of this, I have discovered the magic of shirred clothing. Quite frankly, I am smitten with all things shirred. Shirred skirts. Shirred dresses. If pants could be shirred, I'm certain I'd love them too.



### *Belly Bands*



For those who don't know what I'm talking about, shirring is a gathering technique done with elastic thread, which creates a stretchy garment. The stretchy thread causes the fabric to gather, or bunch up, when stitched. Shirring is commonly done with stretchy fabrics such as knit jersey or cotton knits to give the side panels a softer, more flattering look than a straight seam.

What's great about clothing with shirring is that it creates an optical illusion of things being fuller, but in a flattering way. And it definitely helps hide the "bulk" that AK sockets tend to create. Also, if you wear a Silesian belt or other type of suspension belt, shirring tends to hide the hardware of the belts.

Send your questions and success stories to [fashionista@amputee-coalition.org](mailto:fashionista@amputee-coalition.org)

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Belly bands are another great accessory that can help to camouflage this posterior socket bulk. Originally designed for pregnant bellies, these little pieces of material magic work wonders for those of use with *any* mid-riff bulk, prosthetically induced or not. What I love about them is that they also hide the extra “lateral” play that sometimes comes from AK sockets. For me, especially when my residual limb decreases in volume, the top part of my socket is looser and tends to move laterally when I take steps.

### Tip:

What’s great about clothing with shirring is that it creates an optical illusion of things being fuller, but in a flattering way.



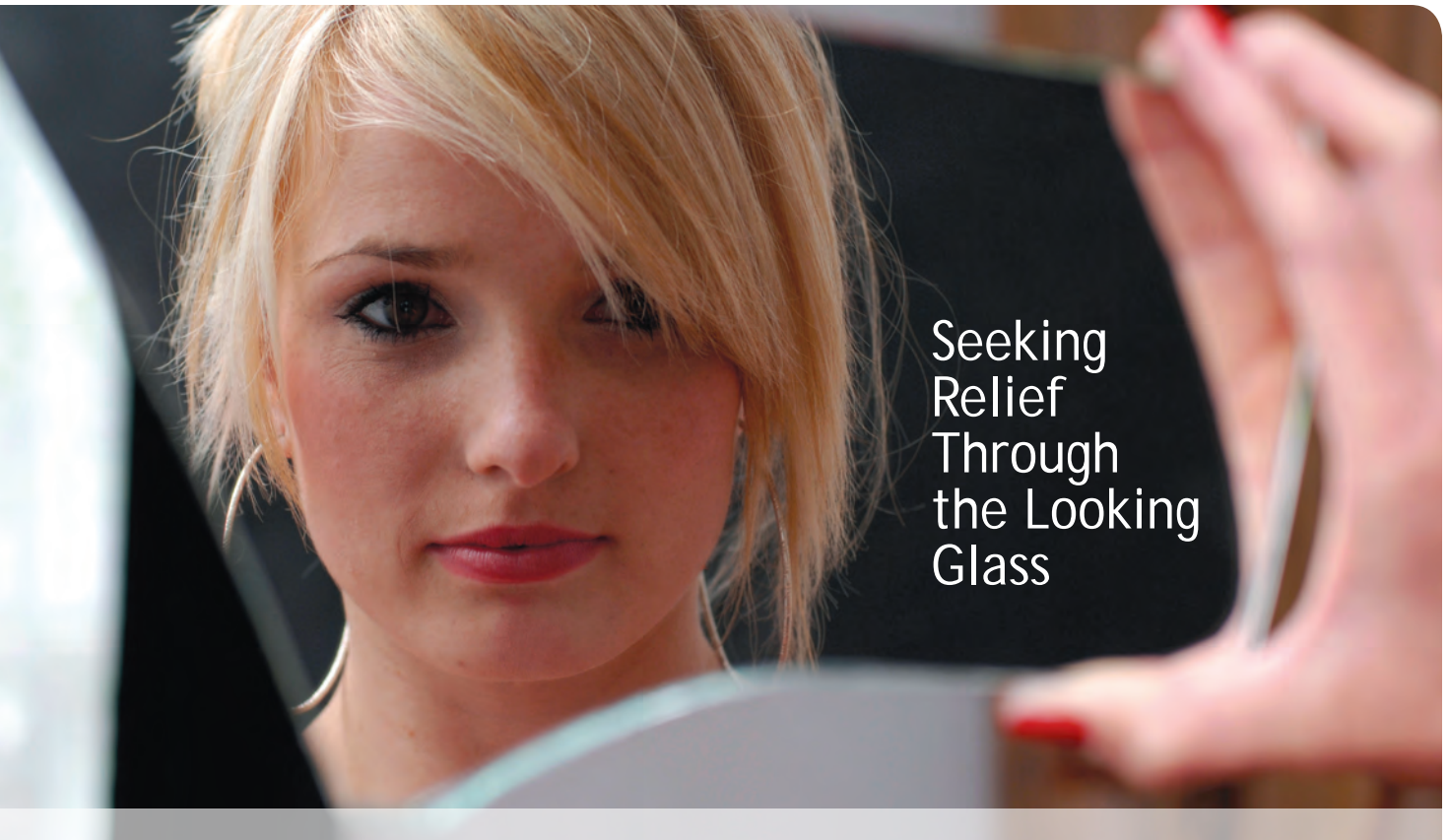
Not only do belly bands hide that movement, they also help to hold my socket closer to my body when my limb loses volume.

While these are only a few of my fashionable tips, I have an entire closet of others that will make their respective debuts with the new seasons. Please keep sending your questions and success stories to [Fashionista@amputee-coalition.org](mailto:Fashionista@amputee-coalition.org)!

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## Seeking Relief Through the Looking Glass

by Roberta Cone, PsyD

Participants reported that the visual image of the missing limb created a sensation of motion in the phantom limb.



Photograph provided by Dr. Beth D. Darnall

Phantom limb pain (PLP) and phantom limb sensation (PLS) have long intrigued physicians and clinical psychologists. PLP is commonly seen in people who have lost a limb due to disease or trauma. Although it no longer exists, the phantom limb becomes the location of severe pain, characterized as cramping, shooting, squeezing, stabbing, throbbing or burning. In addition, phantom limbs are often perceived as paralyzed in an unnatural position or shape.

Following amputation, virtually all patients experience PLS, painful or not. Essentially, the brain remembers the missing part of the limb and is still reporting its feelings. A person with PLS may feel numbness, tingling, heaviness, temperature change, pressure, constriction, reduced or changing limb length and a sense of voluntary movement in the phantom limb.

V.S. Ramachandran, MD, is the developer of the mirror box treatment for PLP. The theory proposes that when a patient gets visual feedback (i.e., using a mirror) that the phantom limb is obeying the brain's command, the learned paralysis or pain is sometimes "unlearned." His original mirror box treatment evolved into the use of a single mirror.



## mirror box treatment



To explore the phantom limb phenomena, Ramachandran conducted a study of 10 arm amputees using the mirror box to generate an illusion of a missing limb. Patients were instructed to place their amputated limb behind the mirror and to place their surviving limb in front of the mirror while freely moving the intact arm and hand. When the patients looked into the mirror they saw the illusion (image) of their missing limb as being intact and moving freely. Six participants experienced phantom limb movement; four experienced relief of spasms when the mirror was used to facilitate the unclenching of the phantom hand. Another participant's pain disappeared with repeated use of the mirror over a three-week period. Participants reported that the visual image of the missing limb created a sensation of motion in the phantom limb. Three participants reported a relief of pain using the mirror image to "move" the phantom.

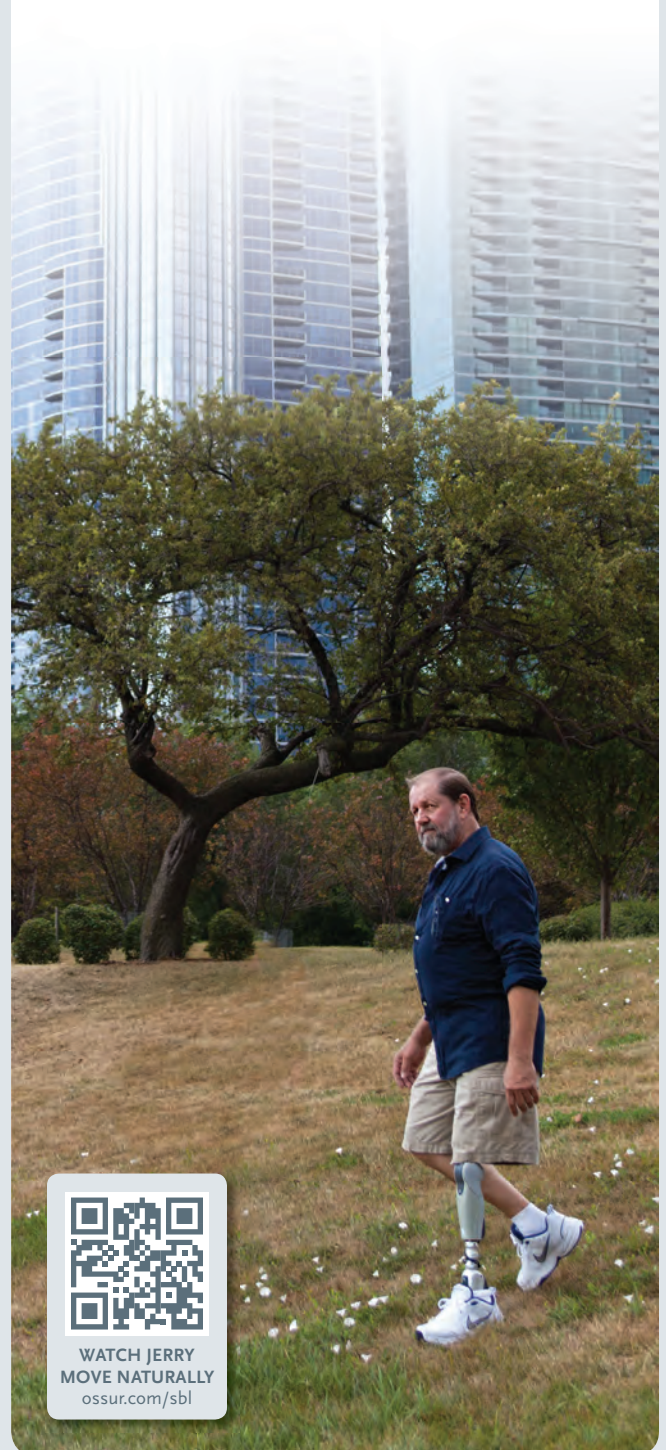
Despite the published success of treatment with single mirrors, many amputees experience no relief using a single mirror. At this time, the rates of response are unknown, and the individual differences influencing mirror therapy are not well-understood. In addition, there is some evidence that PLP is more common in lower-limb amputations. This may either be due to it initially being more likely to occur, or that PLP is more likely to resolve naturally in upper-limb amputations.

I have created a new mirror apparatus that has generated phantom sensations in nine pilot patients with limb loss. The new device uses three vertical mirrors, with panes oriented at angles. The tripartite mirror apparatus (TMA) enables viewers to see unusual multiple images of themselves from the side with the illusion of the missing limb intact. Two pilot patients (missing left arms) who reported

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their phantom hand in a painful, cramped, frozen position, felt movement, relaxation (unclenching of the phantom hand) and temporary relief of pain using the mirror image to “move” the phantom. One participant says, “When I am experiencing throbbing and stabbing feelings in my missing arm and leg, I use the mirror. It alleviates the pain and relaxes my phantom hand. I can then get on with what I am doing.” Another participant with a missing left arm experienced movement in his phantom limb for the first time in 18 years. He reports feeling amazed at the sensation of his phantom hand moving and at seeing the illusion of his limb intact. A participant with a missing leg who reported perceptual telescoping (retraction of the phantom limb into the residual limb) experienced the lengthening of his phantom leg and a reduction



The tripartite mirror apparatus (TMA) enables viewers to see unusual multiple images of themselves from the side with the illusion of the missing limb intact.

Photograph provided by Roberta Cone

All participants in the TMA study experienced phantom limb movement.



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in discomfort. This patient was emotionally overwhelmed by the sensation.

A common theme that emerges in response to mirror use is reports of phantom limb movement, relaxation (to a lesser degree) and pain relief. As a result of TMA use, all participants experienced phantom limb movement. A clinical trial has recently been completed with a cognitive behavioral intervention integrated with the TMA to treat phantom limb pain and psychosocial disability at the Veterans Administration Healthcare System. This data will provide further explanation of the TMA pilot study results.

The implications of the single mirror and TMA findings are that visual input (using the mirror) can reduce PLP. While most reports have used upper-limb loss patients, several case reports with lower-limb loss have also shown success in increasing perceived control over phantom limbs and reducing PLP.

Although at least 80 interventions exist to treat phantom limb pain, it is rarely treated successfully. For many sufferers, the ensuing chronic pain results in a decreased quality of life and an increased dependence upon costly medicines and medical resources. The potential efficacy of treating PLP with a single or tripartite mirror offers hope for finding a viable pain intervention. 🌀

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## *Blogging:* One Step at a Time

I used to bike to work, skate with friends, chase after my nieces and race to catch subway trains. Now I don't move so quickly.

In November 2010, I was hit by a garbage truck while riding my bike to work. I am now an above-knee amputee. In some ways, I'm lucky. I have insurance to pay for my high-tech prosthesis. My therapists, prosthetists, doctors and nurses are excellent.

Family and friends surround me with support. Still, I am often the clumsiest, slowest one in the group. At times, their pace feels frenzied to me. I end up feeling tired and lonely.

I have always loved to write. I knew I had a story to tell through this experience, but the memories were too big, traumatic and disorganized to line up neatly on paper. Shortly after the accident, my aunt and uncle sent me a necklace with the Confucius quote: "The journey of a thousand miles begins with a single step." As I learned to use my prosthesis, I decided to set a goal: I would walk a thousand miles. And I would tell my story, step-by-step, in an online journal – a blog.

Blogging has opened up a new community. Every few miles, I post photos, videos and anecdotes to convey events and feelings. I've discovered that most people don't understand the ins and outs of life as an amputee, but my "blog followers" are interested in the adventures and frustrations, the pain and the joy. They can leave comments, ask questions, show support and share their own stories. They can even join me on a group walk!

More recently, I've expanded to a Facebook page that's linked to helpful and inspiring organizations such as the Amputee Coalition. I've also developed friendships with other amputees.

Blogging has not made my gait smoother or faster. But it has enabled me to track my progress as the miles stack up. And it has allowed others to share in the journey.

High-speed Internet isn't a substitute for the speed of life, but blogging has given me a reason to keep moving, one step at a time. 🌀

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by Rebecca Levenberg



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