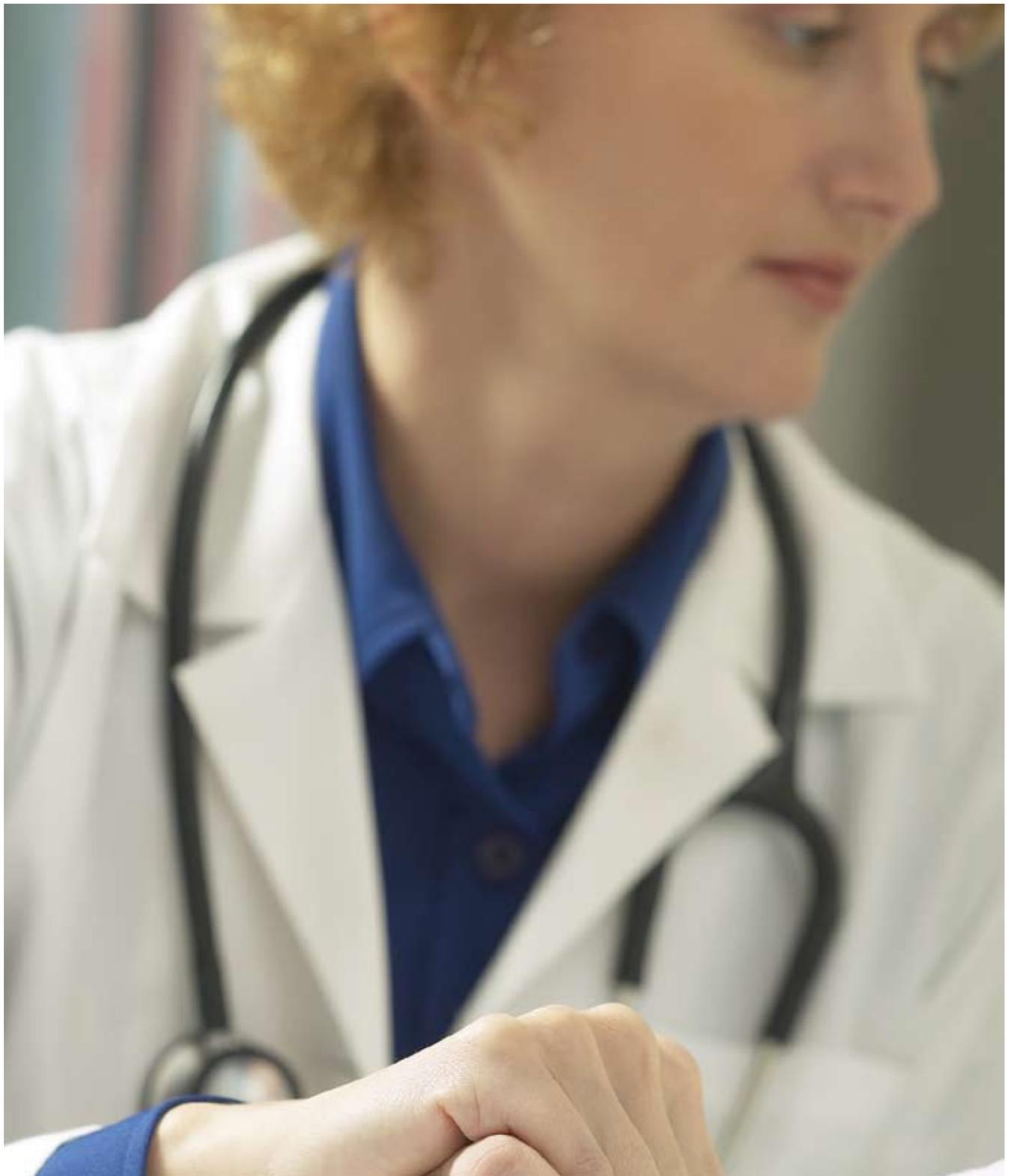


THE NEW EXPERIENCE OF LIMB LOSS



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Life Without a Limb May Be Different, But It Doesn't Have to Be Worse

by Paddy Rossbach, RN, ACA President & CEO

When I was asked to write about what it is like to live without a limb, I replied, "I'm not sure that I know the difference. What is it like living with all of your limbs?"



Paddy Rossbach

You see, I lost part of my leg when I was 6, and I honestly don't remember having two. In fact, it took the question of a patient who had recently had an amputation to make me realize that I had a lot to learn about the differences between people

who are born with a limb difference or who lost a limb at an early age and those who lose a limb later in life.

She asked, "When you go home at night, get undressed, and take off your prosthesis, don't you think you look awful?"

I was a little taken aback at her question. No one had ever asked me such a thing so I just answered quite truthfully, "I don't know; I'll go home and look."

So I solemnly went home and looked. As I was sitting on the floor looking at my one and a half

legs, I thought, "Do I look awful?" Then I thought, "No, I've always ..." and, with a flash of understanding, I thought, "I've always looked like this. If I suddenly sprouted a leg, foot and toes, that would look peculiar to me!"

I went back and thanked her for teaching me a very valuable lesson.

Of course, living with the loss or absence of a limb is different, but I

am a firm believer that the effect it has on our lives depends less on the severity of the loss than on how we deal with it.

Children born with a limb difference don't miss what they never had, but they probably wonder what it would be like to be the same as their friends. Unfortunately, they may also have to deal with cruel teasing from other children at times.

Losing a limb is particularly difficult for teenagers. While they are in the midst of discovering who and what they are, they are suddenly "different" – and not in a way they would choose to be.

Adults who lose a limb have their own set of problems and are more likely to spend time in the anger, denial and guilt phases of grief. The fact is that some people are survivors by nature, while others find it more difficult to cope with adversity. All of us are, however, likely to benefit from some kind of support.

The things people worry about fall into two main categories: physical and emotional. Will I be able to



wear a prosthesis if I decide to? Will I be in a lot of pain? How long will it last? Will I have to depend on others for the rest of my life? Will I be able to function like I did? Will I be able to keep my job, support and care for my family, travel, go to school, play sports? How will my children, life partner, friends, and the general public react to this different me? How will I feel when I look at myself? Will I ever wear shorts or short-sleeve shirts again?

These and many other thoughts go through every new amputee's mind. Some answers will depend on the quality of care and support you receive. We all do better when our surgical and prosthetic care and emotional and physical rehabilitation are performed or supported by trained professionals who work together as a team. But much depends on our own determination to simply "get back and get on."

No matter how good our healthcare providers are, nothing can take the place of talking with an ACA-certified peer visitor (PV). This is someone who has recovered from a similar experience and can, therefore, truly understand your challenges and fears. This is someone who has been trained to listen and who can provide appropriate educational materials and resource information to help you through the recovery process. Spouses can be peer visitors to other spouses, and parents of children with limb differences can be peer visitors to other parents. Peer visitors can also serve as wonderful role models.

Another way to benefit from interacting with others living with limb loss is to join a local support group. (See pages 32-38.)

Being a knowledgeable patient will relieve much of your anxiety about the future, and being less anxious will promote faster recovery. If you are going to use a prosthesis, learn about different components and the fitting process, and discuss things with your prosthetist. Learn how to choose a prosthetist, what questions to ask your healthcare providers, how to find a peer visitor or support group, and



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On October 17, 2005, Sarah Reinertsen, an Amputee Coalition of America Board member, became the first female amputee to complete the legendary Hawaiian Ironman course, which is widely considered the toughest endurance competition in the world.

what your rights and responsibilities as a patient are. Be knowledgeable about your insurance coverage and what can be done if it is inadequate. If you are not going to wear a prosthesis, learn about what other assistive devices can help you maintain an independent, active lifestyle. The answers to all of these questions can be found at the ACA, and many of them can be found in this publication.

Set small, achievable goals so that you feel good about yourself when you reach them. Try not to compare what you can do now with what you could do before. This is a new beginning. Just compare where you are today with where you were when you started this journey, and feel good about your progress. This is not easy. Recovery can take some time so it is important to realize how far you have come. You know what your ultimate goal is, but you cannot just leap from the

bottom of a high flight of stairs to the top. Reaching your goals is the same; you do it one step at a time. (See pages 14-16.)

Although you may not believe it now, many people who live with the loss or absence of a limb believe that their lives have been enriched by the experience. Since losing a limb, many have gone on to achieve things they would never have thought of doing. Young people, in particular, become superb athletes, even competing against other athletes without a disability. (See photo and caption above.) Others find that just facing the challenge and succeeding has strengthened them and given them a whole new set of skills. Whatever your circumstances, please know that the ACA is here for you to "empower you through education, support and advocacy." Just reach out to us, and we will help you in any way we can.

Amputation Surgery and Afterward

What Should I Expect?

First Step asked several highly qualified professionals and amputees to answer a number of questions about amputation surgery and pain to give prospective and new amputees a better idea of what to expect during their surgery and afterward. Following is a list of the contributors and their qualifications.

Contributors



Douglas G. Smith, MD, is ACA's medical director, an orthopedic surgeon, the director of the Prosthetic Research Study (PRS), and an associate professor at the University of Washington, School of Medicine, Department of Orthopaedics, Harborview Medical Center.



Christina Skoski, MD, is a retired clinical anesthesiologist with 30 years experience and a member of the ACA's Medical Advisory Committee. She has been a hemipelvectomy amputee since she was a teen-ager.



Terrence P. Sheehan, MD, is the medical director for Adventist Rehabilitation Hospital of Maryland and the director of its Amputee Rehabilitation Program. He is also a member of the ACA's Medical Advisory Committee.



Mary Williams Clark, MD, is a pediatric orthopedic surgeon and a member of the ACA's Executive Publications Committee.



Becky Bruce is a former ACA information specialist and a bilateral lower-limb amputee.

"I've just been told I need an amputation, and I am really afraid."

This is a typical reaction to such life-altering news. The unknown is frightening, and you may know little, if anything, about surgery or amputation. You may have never even met a person with limb loss. Just knowing the answers to a few basic questions should help alleviate much of the fear you have.

Can I speak to someone else who has had the same type of amputation?

If you are having emergency surgery, this may be impossible. "Fortunately, true emergencies are rare," says Douglas G. Smith, MD, ACA medical director. If there is time, you should contact the ACA toll-free at 888/267-5669 to see if the organization can arrange for you to be visited or called by an amputee who is of the same gender and age group as you with a similar type of limb loss.

How long will the surgery take?

Douglas G. Smith, MD: The time required for different types of amputation surgery can vary tremendously. A forefoot amputation involving the toes may take less than one hour, while a complex hip- or pelvis-level amputation can take four to six hours. In addition to the different times required for different amputation levels, the time required varies according to the quality and involvement of the tissues. Amputations above the zone of injury, infection or disease have more normal anatomy and usually proceed in a more predictable and straightforward fashion. Amputations done in the zone of injury, infection or disease can be quite



complex, which can add several hours to the surgical procedure. In general, amputations below or above the knee performed for diabetes or vascular disease take the surgeon between two and two and one-half hours. An additional 20 to 30 minutes before and after the surgery may be required by the anesthesiologist and nursing team. *(For more information about the various levels of amputation, go to the resources section on pages 125-128 and look under Amputation Levels.)*

Isn't it dangerous to be anesthetized for surgery?

Christina Skoski, MD: There has never been a safer time to have an anesthetic. In the last 25 years, deaths due to anesthesia have decreased significantly to one death per 250,000 to 300,000 cases, according to recent statistics compiled by the Institute of Medicine, a leading scientific advisory body.

Over the last few decades, anesthesiologists have been in the forefront of patient safety issues. They have advocated the use of sophisticated monitoring equipment that alerts doctors to potentially fatal problems in the operating room. Machines that alert doctors when there are abnormal levels of gases, such as oxygen and carbon dioxide, and when breathing circuits are inadvertently disconnected are now the norm. In addition, computerized mannequins that simulate real-life medical crises and other educational tools are routinely used in training programs and continuing education courses for physicians.

Today, more surgical procedures can be safely done on premature infants and

the very elderly who may suffer from a multitude of serious medical conditions. Still, no medical procedure is completely without risk. The risks involved are directly related to the health of the patient and the procedure. If you are elderly, obese, and have uncontrolled diabetes with severe heart disease, uncontrolled hypertension and asthma, you are more likely to have complications than someone in better health.

How will I be anesthetized, and is the method painful?

Christina Skoski, MD: There are several ways of providing anesthesia for amputation surgery. The most common is general anesthesia during which a patient is rendered totally unconscious. Usually a drug is given intravenously (through an IV) to "knock you out," and this state is maintained by a variety of other medications, such as narcotics, muscle relaxants and inhaled gases. The exact combination depends on the specific health and medical conditions of the patient.

Other methods are also available. Regional anesthesia is where only a part, or region, of the body is anesthetized through the use of local anesthetics. An example of this is spinal or epidural anesthesia, in which an anesthetic is injected into the spinal area to anesthetize the lower extremities and the abdominal area.

Blocks of specific larger nerves may also be done, such as a block of the femoral nerve of the leg or the axillary nerve of the arm. These methods are usually done in combination with heavy sedation, also given intravenously so that the patient won't hear or remember the surgery.

Another alternative is to place tiny catheters directly into the nerve sheaths around the area of amputation. Local anesthetics can then be administered slowly and continuously directly to the site by the use of pumps, both during and after surgery.

More recently, the concept of pre-emptive analgesia has been widely adopted by many anesthesiologists and surgeons. Even under general anesthesia,

pain impulses are still generated and sent through the spinal cord to the brain where pain is actually "felt," even though the patient is not aware of the feeling. It is well-known that we can decrease post-operative pain by blocking these painful sensations at the site of the surgery. Preoperative blocks may also prevent the formation of long-term phantom pains, although this is still being studied. As a result, it is becoming very common to use a combination of anesthetic techniques to achieve optimal pain control. Using preoperative nerve blocks, placing an epidural catheter preoperatively, and the use of continuous pain pumps in combination with general anesthesia is becoming the norm.

Of course, not all methods are applicable to all patients, and individual medical histories must be taken into consideration. In addition, not all anesthesiologists are comfortable with and skilled in all of the newer techniques.

Ideally, pain control should begin before surgery. Discuss your pain control and anesthetic options, what methods and drugs have worked well for you, and any concerns you may have about any procedures with your anesthesiologist. Qualified medical professionals welcome and encourage questions about surgical procedures. Moreover, studies have shown that well-informed patients heal faster and report a better overall surgical experience. Be sure that all of your questions are answered clearly and completely.

Additional Information

American Society of Anesthesiologists

www.asahq.org

www.asahq.org/patientEducation.htm

Anesthesia Patient Safety Foundation

www.apsf.org



If a child is having surgery, may a parent or guardian stay with him or her when he or she is being put to sleep?

Mary Williams Clark, MD: This usually depends on the anesthesiologist who will be taking care of your child and the age of the child, but it is a relatively common practice for a parent to be there. In addition, your child can usually bring a favorite toy or blanket along to hold while going to sleep and waking up.

Is the surgery painful? What about the period afterward?

Douglas G. Smith, MD: Amputation surgery divides all of the tissues present in our body, skin, muscle, blood vessels, nerves and bone. There is, unfortunately, pain associated with this major type of surgery. The amount of pain a given individual feels in response to amputation surgery can vary over the entire 0 to 10 scale that the healthcare team commonly uses to rate a person's pain, with 0 as no pain and 10 as the worst pain. Unfortunately, why people have different amounts of pain and why people perceive pain more or less intensely than others is not well-understood.

The perception of pain following surgery can also depend on the amount of pain that was present before the surgery. In general, the worse people's pain is before their amputation, the lower they typically rate their postoperative pain. I have had some individuals with very severe vascular disease-related pain even tell me that their pain was much less right after the amputation. I have also had the opposite occur, where people told me that their pain was much worse the first few days after their amputation.

On average, most people rate the pain in the 7 to 10 range for the first 24 to 48 hours and then tell me the pain lessens to the 4 to 8 range for the next few days. Within four to 10 days, most people are on all-oral medication, and many individuals can taper that medication down over four to eight weeks.

It is important to let your healthcare

team know if you experience pain; they will do everything they can to make you more comfortable.

Becky Bruce, former ACA Information Specialist:

My actual surgeries were not painful for me. I was under general anesthesia for most of them. I have also had local anesthesia for a couple of toe amputations, and none of them caused me any pain either. I was either sleeping or so "jacked up" on Valium that I never felt a thing.

In addition, the pain I experienced following my amputation surgeries was minimal. I experienced some muscle spasms that were a tad unnerving but not painful. There are many different options for managing postsurgical pain. I've tried many, and the one I liked best was the postsurgical epidural. They placed a small catheter in my spine that slowly dripped

morphine, Demerol, or something else and numbed me from the waist down. I was able to move, but nothing hurt. The only drawback to this method for me was that it was sometimes difficult to urinate, and I needed to be catheterized to do so.

About how long will I have to stay in the hospital after the surgery?

Douglas G. Smith, MD: Hospital stays can also vary tremendously depending on the complexity of the surgery and how soon individuals regain appetite, strength, balance and the ability to transfer on and off the toilet. The time will also vary depending on whether the person will be going from a regular hospital to a skilled nursing facility, to home, or to a rehabilitation center. For most people, the hospital stay will be somewhere between three and 10 days.





Will I always have pain in my residual limb?

Terrence P. Sheehan, MD: During the first several months after amputation, all people have pain in their residual limb. This pain can be separated into musculoskeletal pain and neuropathic pain and is intensified initially with touch and pressure. Fortunately, this type of pain generally diminishes over time, usually within the first two months.

This pain can often be effectively treated with medications that block inflammation, bone/muscle pain, and nerve pain. Usually, these medications are decreased after a couple of months to the point that they are just taken on an as-needed basis. Residual-limb pain can also be effectively relieved by repeated touch and massage, wearing a shrinker, and using a prosthesis that fits properly rather than an ill-fitting one. (See pages 48-53, 56-57.)

Residual-limb pain should not increase in frequency or intensity.

What might cause or increase pain in my residual limb?

Terrence P. Sheehan, MD: Pain in the residual limb is usually caused by a few common culprits. If the limb loss is new, your residual-limb pain might be caused by an infection, either deep or superficial, at the surgery site. An infection can also occur at any time on the surface of the

skin if hygiene has been marginal.

If you use a prosthesis, you can develop pain in your residual limb as a result of a poor fit, which can cause abnormal pressure or rubbing against your skin. This pain is an alarm that tells you that the skin is being traumatized and that you should not wear your prosthesis until it has been fitted properly and your skin has been evaluated for damage.

Tips for Preventing or Dealing With Residual-Limb Pain

Terrence P. Sheehan, MD: Pain is a symptom and can have one or more causes. You may, therefore, need multiple healthcare professionals to help you sort through the causes of the pain and the solutions for it. These professionals should include your physiatrist, your surgeon, and your prosthetist, who should all work together and communicate as a team in your best interest. This is best done in an amputee clinic setting.

Because a poorly fitting prosthesis can quickly cause a sore and infection if not addressed, early communication with your doctors and prosthetist about the onset of your pain and changes in it is very important. It is also important to understand that pain is often affected by the patient's emotional, spiritual and psychological states as well as his or her physical problems. To effectively deal with

your pain, therefore, these issues also need to be addressed, possibly through individual counseling, peer visitation or support groups.

You should not accept pain as chronic until you have exhausted the many treatment options available. This may mean that you have to seek the counsel of multiple pain clinicians rather than settle for insufficient relief of your pain.

Over the long term, your pain may come and go just like my grandmother's "achy" days did with the cold or damp weather. Still, you need to have a plan for these painful days, including knowing how to comfort yourself during them.

I am privileged to care for many people with limb loss, and although most have moments of pain, I can't think of any that have such unresolved pain that they are not living their lives. One person has even chosen not to use a prosthesis because she has not been able to achieve a comfortable fit. Fortunately, she is pain-free most of the time and is enthusiastically living her life. That's what it's all about, right?





Will I have phantom pain? If so, how intense will it be?

Terrence P. Sheehan, MD: Phantom pain is common after amputation, and some have reported that it occurs in 80 percent of amputee patients. It often accompanies phantom sensation, and both are perceived as being in the missing limb.

The pain is often described as cramping, aching, burning or lancinating. Though it can be quite severe in a small percentage of amputees, it is also quite responsive to medications and rehabilitation techniques.

The longer a person has had pain in his or her limb before surgery, the more likely he or she is to have phantom pain afterward. Fortunately, this pain usually diminishes with time, and chronic phantom pain is rare.

What might cause phantom pain to increase?

Terrence P. Sheehan, MD: To understand what might increase, or exacerbate, phantom pain, you need to understand that this pain is nerve-cell hyper-excitability. Thus, things that would ordinarily excite the nerves in the limb would also hyper-excite this group of nerves that are behaving poorly to begin with. So, the things that

may increase the phantom pain are usually things that feel fine with good nerves but feel bad to these misbehaving nerves, such as heat, cold, extremes in weather, applied pressure, light and normal touch, certain positions, changes in position, caffeine, stressful daily situations, monthly cycles, your son-in-law (just kidding), etc. It is an individual experience. What is common, though, is the fact that when you're lying in bed late at night with the lights out, the TV off, and the dog asleep, this pain usually rages. This is because all of the other distracting sensations have been diminished, which just pronounces the hyper-excitability of these misbehaving nerves.

I've seen advertisements that claim that certain products or treatments can prevent, alleviate or cure phantom pain? Are these claims true?

Terrence P. Sheehan, MD: I have not come across any product or technique that claims to prevent phantom pain, but there are many things, such as medication and rehabilitation techniques, that can alleviate it either partially or totally. To avoid being taken advantage of by scams, however, you need to be under the care of a credentialed professional, and you need to use a systematic approach to find which of these particular agents or techniques gives you relief.

Tips for Dealing With Phantom Pain

Terrence P. Sheehan, MD:

- **Find an amputee specialist, such as a physiatrist or chronic pain specialist, who knows about phantom pain through education and experience with patients.**
- **Use a systematic approach to trying the different approaches and medications.**
- **Speak up!** Ask why you should try a specific medication or technique, what the side-effects are, and what science supports the treatment. There are plenty of nontraditional approaches to pain out

there. You need to use something that is safe and that has been proven effective. If a product or technique sounds bizarre, shaky and unreasonable, it is probably ineffective. You need to believe in your treatment; if trust is established, the treatment will probably be more successful because of the placebo effect.

- **Write the When, Where, How, Why, and To What Extent details about your phantom pain in a journal.** This will help your doctor better understand your pain and will give you an objective tool to see how your pain changes over time and whether it has been affected by treatment. Use a scale of 0 (no pain) to 10 (severe/worst pain) to help define your pain.

- **Know that it's OK to get second and third opinions from pain specialists.**

Unfortunately, we are better-educated consumers of household products, such as washers and dryers, than we are of the products and techniques that might benefit our bodies.

- **Realize that narcotics are short-term friends; they are not usually effective against phantom pain, they are addictive, and their effect wears off, making you need more to get the same marginal relief. Perhaps even worse, they are constipating.**

- **Find a way to talk about your pain.** A constant, intermittent pain is disruptive to the moments and relationships in one's life. You need to talk about these disruptions and develop healthy strategies to deal with them. Remember: It's not the quantity of life but the quality that's important. This "talk" can occur with psychologists, with peers in a group or individually, and/or with spiritual advisors. Be open; your mind is very powerful in controlling your body. Picture the man walking on hot coals.

For more information about pain, go to the resource section on pages 125-128 and look under Pain.

Milestones

The Positive Signs on the Road to Recovery

by Robert Gailey, PhD, PT

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Nothing is quite as bewildering or scary as the unknown. That's why one of the most frustrating aspects of limb loss is trying to understand what lies ahead on the road to recovery.

Some of the most common questions include: When will I receive my first prosthesis? How long must I wrap my residual limb? When will I walk again? How long does phantom pain last?

The usual "one-size-fits-all" response is something like, "Well, that depends," or, "Everybody is a little different." But in today's world, where our lives are measured by calendars, clocks and coffee spoons, we want something more. We want a date, the number of days, weeks or months.

Are We There Yet?

The hard truth is that we all march to a different drummer; not everyone progresses at the same pace. A date is nothing more than a goal, a target that everyone likes to have so that we can measure our progress. Most folks are content to accept whatever time frame is offered by their physician, physical therapist and prosthetist. The trouble with such goals is that if we fall short, we all feel a small sense of failure, whether real or imagined. We wonder what we did wrong. Unfortunately, recovery time after limb loss can be unpredictable because there are so many variables unique to each person, and rehabilitation doesn't come with a crystal ball.

So what are the common signs or milestones that tell us we're on the road to recovery? There are several, and though the time frame for reaching each may vary, almost everyone will reach their goals and eventually get to the place they want to be. Like any journey, the anticipation of getting to where we want to go always makes the trip seem longer than it actually is.

Making the decision. One of the hardest decisions a person will ever face is the one to have

a limb amputated. Few people actually have the decision made for them because most people are required to give their consent. Though it's difficult to weigh the concerns and agree to adopt a life with an uncertain future, many people have said that once they made their decision, there was a great sense of relief. Once the decision was made, they could begin to look to the future.

Getting out of bed. The day after your surgery is one of the most difficult to get through. It's painful. It's sad. And it's scary. The "simple act" of getting out of bed and starting the process of rehabilitation takes a tremendous amount of courage. Typically, just sitting on the edge of the bed and moving over to the chair is a painful but very important beginning.

Walking with an assistive device. As the old saying goes, the journey of a thousand miles begins with a single step. Even if you have upper-limb loss, getting out of bed and walking is an important first step. Learning to walk while in the hospital is not an easy task, but it will help improve your mobility around the house and will make getting back to your way of life much easier. However, many people are not ready to walk just after surgery because of weakened muscles or other medical conditions; in their case, it is not practical. If this is the case for you, don't worry; your time will come.

Meeting family and friends for the first time. Once you get home, you may have difficulty with having your family and friends around. Most people are not themselves during this time. You may feel uncomfortable because your body has



changed, the residual limb is painful, and you may require considerable assistance. Family and friends may also feel uncomfortable. They may find it hard to strike a balance between being helpful and being bothersome. Also, choosing the right words in conversation can be awkward. It's up to you to set the tone. Be yourself; don't be afraid to ask for what you need, and let them know what you can do for yourself. If someone says something awkward, laugh it off and realize that no harm was intended. Accept their support *and* establish your independence.

Accepting a peer visitor or joining an amputee support group. Asking others for help can be very difficult for some people. However, accepting a visit from a peer visitor or another amputee can not only be comforting but can help you find the answers to many questions you may have. If knowledge is power, then getting in touch with an ACA-certified peer visitor or support group can be a critical milestone. (See pages 32-38.)

Restoring physical conditioning. From the first day after surgery, you should be striving to increase your cardiovascular endurance, strength, balance and flexibility. Even if exercise was not a significant part of your life before, it must be now. The sooner you can rise from a chair on your own, walk moderate distances with an assistive device, and maintain your standing balance, the sooner you will be ready for prosthetic fitting. Moreover, you will begin to notice that everyday activities, such as moving around the house, getting in and out of the car, and going places in the community, will be much less demanding.

Reducing residual-limb swelling. Using compression dressings will help reduce the swelling and create a "stable limb." (See pages 48-53.) In other words, the swelling will not increase and decrease as much throughout the day. This is a key milestone; once the residual limb is stable, the pain will typically decrease enough to



begin the fitting process for the prosthesis. For some people, however, their residual limb may always fluctuate in volume or swell because they tend to retain fluids or have a secondary condition that causes swelling. If this is a problem for you, it just means that you will have to continue using a compression wrap when you're not wearing your prosthesis.

Meeting your prosthetist. For many people, finding the right prosthetist is a process that takes some time. Because your prosthetist could potentially be a lifelong caregiver, it is important that you take the time to explore your options and interview several prosthetists. (See pages 19-20.) You need to discuss what your prosthetic needs and options are and make several decisions about components,

socket design, and other issues that you are probably not very familiar with. Taking the time to ask questions, talk to other amputees, and do a little research on your own can really help with the decision-making process.

Receiving your first prosthesis. There is something unique about receiving your first prosthesis. Many folks will tell you that there is a sense of turning the corner. There is a quiet excitement because you feel that once you receive the prosthetic limb, your life will be whole again. You'll be able to go on walks with your spouse, dance or use both arms. Sometime during the fitting process, however, it will strike you just how difficult it is to use a prosthesis in the beginning. Though it's easy to let yourself become disappointed, you



have to understand that with time and practice, you will become increasingly skilled at using your new prosthesis.

Learning to use your prosthesis.

Regardless of whether it is an upper- or lower-limb prosthesis, prosthetic training takes time. Unfortunately, many people only learn the basics, just enough to do simple tasks with their prosthetic arm or to walk a little. Seeking a physical or occupational therapist that specializes in prosthetic training is just as important as finding a qualified prosthetist. Far too many people fall short of their prosthetic potential simply because they don't receive proper training. Learning how to use a prosthesis correctly can reduce the amount of effort required and increase your functional ability. Once you have mastered the use of your prosthesis, everything else will tend to become just a little bit easier.

Getting back to work. For many people, retirement seems to be a logical option after the loss of a limb. But this must be a considered decision, not one made simply because of limb loss. Several studies have shown that most people with limb loss can and do return to work, regardless of the level of amputation or number of limbs amputated. If you are a leg amputee, the main difference may be the amount of standing and walking that you can do compared to before. Work is a positive experience, and for many of us, it provides a sense of worth and contribution to the community. Getting back to work should be a goal. You may have to make some adaptations, but, for most people, the minor accommodations are well worth being able to get back to the job. (See pages 69-71 and 78-84.)

Getting back to leisure activities.

Returning to activities that you once enjoyed is one of the most significant

milestones. Again, some accommodations may have to be made, but they will be worth it. Sharing your leisure interests with other people with limb loss is a great way to overcome any obstacles and to make a few friends with common interests.

Accepting your new body. One of the most difficult milestones to overcome is the overall acceptance of limb loss. A gentleman with multiple amputations once said that for him to return to work, sports and life, he had to let go of the notion that he would still be able to do things the way he once did. Only after he stopped trying to do things as a "two-legged" person and learned how to do them with the body he now had was he able to move on and embrace life. The key for many people with limb loss is to stop focusing on the part of their body that they have lost and to focus on the whole of the person that they are. In short, be comfortable with who you are and continue to live life to the fullest.

Remember, there are no time frames for reaching each milestone because everyone is different. Set short-term goals that you can reach within a reasonable time while keeping your eye on your long-term goals. Don't become impatient and so focused on the milestones along the road of recovery that you miss all of the other things that life has to offer. Think of each step as an event in itself. Then, after some time, look back and see which ones you've completed. You might find that you are farther along than you thought.

About the Author



Robert Gailey, PhD, PT, is an associate professor at the University of Miami School of Medicine, Department of Physical Therapy, and health science researcher, Miami

Veterans Affairs Medical Center.

Being a Proactive Patient What Does It Take?

by Kevin Carroll, MS, CP, FAAOP

Many situations require us to decide what we want and then figure out how to get it. This process is sometimes called “information gathering” or “problem-solving.” I simply call it “being proactive.”

Being proactive as an amputee means that you take the leading role in your prosthetic care and rehabilitation. Though doctors, prosthetists, therapists and friends can all provide good advice and support, only one person will be there through every phase of your care and rehabilitation, pressing through each challenge and celebrating each achievement. That one person is you. In spite of the fear, depression, pain, frustration, exhaustion, and physical and emotional limitations you may be experiencing, you must be your own best advocate. Asking questions, doing your own research, standing up for what you believe you deserve, expecting a lot from your care team; these are the hallmarks of being proactive.

Getting Started

If the word proactive doesn't exactly describe you, keep in mind that even “nice” people can learn to be proactive. You can be direct *and* nice. You can have high expectations *and* be nice.

Clearly, being rude and difficult to deal with are usually not effective ways to get what you want. But being proactive is another matter entirely. Being proactive often increases your sense of confidence and can help you feel more optimistic about the future. The more you present yourself in a proactive manner, the easier it gets. When you've “done your homework” on a subject, asking for what you need is not so difficult because you know what you're talking about. And when being proactive leads directly to the result you

were after, you'll be willing to use this approach again when the situation calls for it. Remember the truth in that old saying, “The squeaky wheel gets the grease.” Being withdrawn or undemanding will not get you closer to what you want. I have repeatedly seen that people who expect more and ask for more tend to get more.

The Youngest and the Oldest

The importance of being a proactive patient and consumer is heightened when the person is at either end of the age spectrum. People older than 60 and parents of infants or young children with prosthetic needs may find that they are not encouraged by their healthcare providers in the same way as young, active adults. Unfortunately, recovery expectations are sometimes lower for older adults because of their age and/or other health-related issues. Yet I have worked with hundreds of people in their 70s, 80s and 90s who have been very successful prosthesis users. Still, older adults and their healthcare providers may have to stand up and argue to get insurance companies to pay for the components they believe will help them the most. Regarding children, some physicians and prosthetists believe that it is not necessary to rush babies and younger children into prosthetic care; however, there are still several reasons to begin consulting with a prosthetist as soon as possible, even if you ultimately decide that you will not pursue prosthetic care for your child. Being proactive means believing that



Photo courtesy of Hanger Prosthetics & Orthotics, Inc.

whether the person is very young or very old, he or she deserves every opportunity to be successful.

Proactive Relationships

A good place to start being proactive is in your interactions with healthcare providers, beginning with your doctors. People who are facing amputation need to know every available option before undergoing surgery. Ask your doctors to explain various surgical options, what you can expect after surgery, and what their recommendations are for prosthetic care, including the use of Immediate Post-Operative Prostheses (IPOP). Ask for information resources, and then follow up with your own research on the Internet and in medical and prosthetic journals. Always seek a second medical opinion before undergoing surgery. And if your physician does not refer you to a prosthetist for a preoperative consultation, take the initiative to schedule one on your own. Remember: Once you have recovered from surgery, you will have little or no contact with the surgeon, but you will require the services of a prosthetist for the rest of your life. The sooner you begin building this relationship, the better. You have every right to request a preoperative consultation that includes you, the surgeon and the prosthetist. If you have had an emergency amputation without the benefit of a preoperative consultation, you are entitled to a detailed postoperative discussion with



Photo courtesy of Hanger Prosthetics & Orthotics, Inc.

- Seeking at least two medical opinions
- Seeking at least two prosthetic opinions
- Requesting to meet with one or more people who have had similar revision surgeries
- Doing some independent research on revision surgery procedures/options and subsequent prosthetic options.

the surgeon, and you should also request a meeting with a prosthetist as soon as possible. In addition, you might benefit from talking to an ACA-certified peer visitor who has experienced the same or similar surgery and recovery. Don't wait for the doctor, prosthetist or anyone else to suggest this; be proactive. Contact the Amputee Coalition of America at 888/267-5669 to help you locate a certified peer visitor in your area.

As you move into the rehabilitation phase of your recovery, you will be working closely with a prosthetist, a physical therapist, and possibly an occupational therapist. All of these professionals will provide you with information and options to consider. Again, be proactive; be prepared to tell them your rehabilitation goals, and ask plenty of questions about techniques and products. Supplement this by using the search engine on your computer to tap into an array of information to help guide you through the process of selecting and fitting a prosthesis and to help you learn how to get the most from your rehabilitation. If at any point you feel you are not being heard by your prosthetist or therapist, it is your right to seek a consultation with a different provider and decide if he or she can better meet your needs. (See pages 19-20.)

Unfortunately, some prosthesis users need revision surgery to achieve better prosthetic fit and function. If you are ever advised to have revision surgery, be proactive by:

Educating Yourself

Everyone with a limb difference can benefit from the wealth of information available through the ACA. ACA publications and the ACA Web site (www.amputee-coalition.org) are some of the best resources for educating yourself about amputation, prosthetics, rehabilitation and lifestyle recovery. The Web site also offers an online support group, an online library catalog of amputation-related materials, and links to other key sites, publications and journals.

In recent years, the market for prosthetic components has exploded with choices. There are hundreds of socket designs, feet, hands, knees, and accessories to select from. It can be overwhelming to try to determine what is best for your specific situation so educate yourself as much as you can and allow your prosthetist to help guide the decision-making process. Learn about the components you are interested in, and, whenever possible, talk directly with others who are using them. Remember, however, that just because a certain item works great for someone else, it does not mean that the item will be exactly right for you. Fortunately, some manufacturers allow a trial period for their components so be sure to ask if this is an option. Look at what is important in your life and what activities you wish to pursue, and use this to guide your questions, research efforts, and

choice of components. Also keep in mind that product marketing and advertising are methods for increasing the sales of specific items. Balance the fabulous claims you may read about in ads with the input of your prosthetist, the experiences of other users of the products, and the more objective information you are able to gather on your own.

Ultimately, your choice of components may be dictated by your managed-care organization or Medicare. If you disagree about the components your plan will cover, you will have to be prepared to stand up and argue your case. Your doctor and prosthetist can be very helpful. If you cannot get authorization on certain items, these healthcare providers can help you get authorization or determine the next best choice. If nothing else works, you have the option of paying for the item out-of-pocket. Still, that's something you'd probably like to avoid.

Be Proactive!

Remember: Being proactive is your choice. Make it happen by asking questions, doing research, standing up for what you deserve, and setting high expectations for your healthcare team.

For more information, go to the resources section on pages 125-128 and look under the following headings: Advocacy, Seniors and Youths.

About the Author



Kevin Carroll, MS, CP, FAAOP, has been a practicing prosthetist for 28 years. He is the vice-president of prosthetics for Hanger Prosthetics & Orthotics in Bethesda, Maryland.

He presents scientific symposiums to healthcare professionals both nationally and internationally and manages one-day prosthetic clinics for patients with complex cases.

How to Choose Healthcare Professionals and When to Change Them

by Sherry Marchi, RN, BSN, CWOCN

In the current era of managed care, ever-changing healthcare plans provided by employers, Medicare and Medicaid, choosing a healthcare provider and maintaining a relationship with him or her is often difficult.



For amputees, the need to find or keep a healthcare provider who is willing to participate in a team approach to care and who has experience with issues related to amputation adds an entirely different dimension to the decision.

The Basics

Some aspects of your choice may be out of your control, such as the location of providers and whether they accept your health insurance. When considering those aspects that are in your control, however, it might help to identify some of your needs and preferences in advance. Following are some of the questions you might ask yourself:

- Do I want to see an MD (medical doctor) or a nurse practitioner?
- Do I want a male or female practitioner?
- Do I want a large clinic with more availability to see practitioners (but not always the same one) or a small clinic where I will see the same one or

two practitioners?

- Do I want a practitioner with a hospital affiliation?

Questions you may want to have answered by the practitioner when you interview him or her could include the following:

- What are your qualifications (both education and work experience)?
- Do you have experience with people with limb differences?
- Will you allow enough time for me to ask questions?
- Will you try to answer my questions to my satisfaction?
- How do you maintain patient confidentiality?
- What type of options do you offer for patients to pay fees not covered by insurance?
- Are you aware of the team approach to dealing with people with limb differences? This is

especially important for people with limb differences who may need to work with a prosthetist, physical and occupational therapists, a physiatrist, the staff of a wound care clinic, and other assorted healthcare professionals. The primary healthcare provider's ability to work effectively within such a team will be a tremendous asset to your overall care.

- Can you provide references?

Many of these same questions and considerations apply to choosing a prosthetist. Though many amputees stay with the prosthetist they meet during their hospitalization or rehabilitation stay, this is not always possible, necessary or desirable, especially if he or she does not meet your needs. Whether you are an avid rock climber, a dancer, a swimmer, a sailor, or a self-proclaimed couch potato, your prosthetist should be able to work with your lifestyle and understand your goals and expectations.

You'll want to ask how much experience the prosthetist has both in years of practice and with your specific type of limb difference, if he or she is available after hours and on weekends if your prosthesis is damaged or breaks, and if he or she is certified by the American Board for Certification in Orthotics and Prosthetics (ABC) or the Board for Orthotist/Prosthetist

Certification (BOC). These certification boards demonstrate through testing that a prosthetist has met established standards for orthotics and prosthetics. The certification is voluntary and is renewed every five years with requirements for ongoing training and education.

Ongoing Care

Care of your prosthesis and your affected limb extends far beyond the immediate postsurgical stay and rehabilitation. It is important to know what commitment your prosthetist, your insurance company, and your healthcare providers are willing to make. Questions to consider include the following:

- How often does your insurance provide for a new limb or modifications to an existing limb?
- How successful is your prosthetist and provider when they recommend a new prosthesis outside of an insurance-designated time frame? Do they get the job done for you? They may need to write a letter of medical necessity, use photo documentation of residual-limb complications or socket degeneration, and communicate with other members of the healthcare team.
- Is your prosthetist proactive as an advocate for optimizing your potential?
- Does your prosthetist use check or test

sockets before assembling your permanent prosthesis or when modifying an existing prosthesis?

- How willing is your healthcare provider to refer you to specialists for specific problems, such as pain and skin problems on the residual limb?
- How do these healthcare professionals respond when you have questions or problems?

Never underestimate the value of other people's experiences. Attend a local amputee support group if one is available in your area. Talk to other amputees there or even hang out in the waiting room of the prosthetist's office you are considering to talk to his or her patients. Talk with local orthopedic surgeons and physiatrists for recommendations if you are new to the area.

Remember: It's OK to interview any healthcare professionals you are considering using. You are the customer and an important part of the team. They should value your questions and be interested in your ideas about your care or the care of your loved one. You should feel comfortable with their experience and abilities. By asking questions, identifying your expectations, and knowing your rights as a consumer (see page 2), you will be confident that you have chosen and still have the team that is right for you.

TIPS FOR DEALING WITH HEALTHCARE PROFESSIONALS

- If you have a question or concern about your residual limb or prosthesis, it's OK to call your prosthetist. He or she can often tell you what is normal or abnormal and allay your concerns.
- Your primary healthcare provider and your prosthetist should deal with any wound on your limb promptly.
- Only you know how you feel. You are your own best advocate. If your limb feels uncomfortable, it's OK to push your prosthetist to check and re-check your socket until you get a comfortable fit.
- Write down your questions so you will not forget to cover them in your doctor's or prosthetist's office.
- If an explanation or advice doesn't make sense, get a second opinion.

About the Author

Sherry Marchi, BSN, RN, CWOCN, is a board-certified wound ostomy continence nurse and runs the Providence Wound Ostomy Clinic in Everett, Washington. She is currently finishing her Master's Degree in Nursing at the University of Washington as a clinical nurse specialist with a focus in wound and ostomy care.



The National Limb Loss Information Center

Help Is Just an E-Mail or Phone Call Away

The Amputee Coalition of America's National Limb Loss Information Center (NLLIC) provides free information about limb loss to amputees, their family members and caregivers, medical professionals, and other interested parties in the United States. Whether you would like to communicate with us by phone or e-mail, the NLLIC's trained information specialists are ready to assist you with any questions you might have.



In addition, a librarian is on staff to ensure that the NLLIC's information is current and easily accessible via our Web site and online library catalog.

The NLLIC Call Center

At the NLLIC's call center, our information specialists are continually researching, producing and analyzing vital information that can make a difference in your quality of life.

You can reach us by phone Monday through Friday, 8am-5pm (EST), through our toll-free number – 888/AMP-KNOW (888/267-5669). Or you can reach us by e-mail day or night through our *Ask the NLLIC* Web page (www.amputee-coalition.org/forms/nllicask/index.html). Remember, no question is too big or too small. We'll do our best to ensure that your requests are answered in a detailed and timely manner.

Why should I contact the NLLIC?

- You or someone you know is a new amputee.
- You need information about your healthcare and future.
- You would like to schedule a visit from an ACA-certified peer visitor.
- You would like to find an amputee support group

in your state.

- You would like to locate certified prosthetists and prosthetic facilities in your state.

What are some of the NLLIC's most frequent requests?

• **New Amputee Information** – Most new amputees have a serious need for general, introductory information concerning the specifics of their situation and their level of amputation. Therefore, the NLLIC created the *New Amputee Information (NAI)* packet, which includes state-specific lists of support groups, prosthetists, and facilities, as well as introductory articles and fact sheets related to your individual situation. This packet helps the NLLIC fulfill its mission of educating amputees so that they can make informed decisions about their healthcare and future.

• **Funding Information** – As a nonprofit organization, the ACA does not provide funding; however, we recognize the need for quality information about funding sources and have created a funding packet to address this need. The packet provides contact information and links for organizations that help with funding and is intended to help you



locate and obtain financial assistance for prostheses, motorized wheelchairs, home and auto modifications, education, and much more. This packet also describes the benefits of vocational rehabilitation and includes numerous articles that shed light on various avenues for locating and securing funding.

• **Pain Information** – The NLLIC offers a pain packet that addresses the various types of pain associated with limb loss, especially phantom pain. This packet, which includes a detailed fact sheet that describes the many types of pain, various methods of treatment, the various roles that healthcare professionals can play in its treatment, and links and contact information for numerous organizations that specialize in this field, can help you learn to minimize, or at least lessen, your pain.

• **Diabetes Information** – Each year, more than half of all amputations performed in the United States are caused by diabetes and its complications and secondary conditions. As a result, we have written several articles and fact sheets that look at the relationship between diabetes and amputations. These articles discuss the importance of foot care, diet and regular exercise, all of which are vital to maintaining a healthful lifestyle for people with diabetes.

• **Advocacy Information** – The ACA has assumed the challenge to address and improve the health and care of people living with the absence of a limb and those at risk for primary amputations or secondary conditions, including additional amputations. The ACA's Action Plan for People with Limb Loss (APLL) focuses on two main areas:

1. Identifying ways to resolve access and coverage issues for prosthetics and adequate healthcare for all amputees in the U.S. (One way to address insurance coverage issues is by promoting insurance parity at the state level.)
2. Promoting a healthful lifestyle, which can prevent primary amputations and secondary conditions that can result in additional amputations.

For more information on APPL, visit the advocacy area of the ACA Web site (www.amputee-coalition.org/aca_advocacy_stateparity.html) or call the ACA. Many articles are available on the Web site for download. In addition, the site contains a Web log (blog) dedicated to the state parity effort (www.acaparity.blogspot.com).

Note: *No funding from the Centers for Disease Control & Prevention (CDC) is used to support ACA advocacy efforts.*

What are some of the resources the NLLIC offers?

• **Because We Care Packets** – One of the NLLIC's main goals is to provide information to new amputees and to let them know that they can rely on us during this difficult time.

• **ACA Web Site** – The ACA Web site offers a wide variety of educational resources to assist patients and professionals in their search for specific information.

• **Ask the NLLIC** – You may complete our online information request form at www.amputee-coalition.org/forms/nllicask/index.html and send it to us by e-mail. An information specialist will then research the topic and provide you with a packet related to your specific inquiry.

• **Information Phone Line** – If you do not have Internet access, you may simply call the ACA's information line (888/AMP-KNOW) to speak directly with an ACA information specialist.

• **Library Catalog** – You may begin your research by searching our comprehensive online library catalog to access articles, books, fact sheets, PubMed® abstracts, and Web sites related to your interests.

• **NLLIC Fact Sheets** – Our fact sheets cover a wide variety of topics. A few of the more popular titles are *Financial Assistance for Prostheses and Other Assistive Devices*, *Amputation Statistics by Cause: Limb Loss in the United States*, *Pain Management and the Amputee*, and *Prosthetic Limb Donations*.

• **Topic of the Month** – This publication is a bibliographical resource list of articles,

books, Web sites and other resources available on a particular subject.

• **APLL Core: Your Health** – Each month, this publication highlights a new health promotion topic.

• **ACA NewsFlash** – On the *ACA NewsFlash* section (www.amputee-coalition.org) of the ACA Web site, you can stay abreast of relevant news from or about amputees, professionals and industry leaders; read the latest ACA press releases; and keep current on hot topics related to limb loss.

• **Links of Interest** – You may view ACA's Links of Interest page to locate informative Web sites relevant to your specific question or topic of interest. Sites are listed according to subject area.

• **ACA Marketplace** – You may visit the *ACA Marketplace* to order ACA resources, make advocacy contributions, and join the ACA or renew an existing membership.

Your healthcare and future are important to us. Contact us today so that we can help you locate the information you need.

National Limb Loss Information Center

888/AMP-KNOW

Ask the NLLIC Web Page
(www.amputee-coalition.org/forms/nllicask/index.html)

