

LIVING WITH LIMB DIFFERENCES

Limb amputation interferes with getting on with life, a situation that can be compounded by the false conceptions of people who have never experienced amputation or been closely associated with someone who has. Most people tend to believe that a person loses a limb, gets a prosthesis, and everything is fine. The first task of new amputees, their families, and friends may be to learn that it is not so easy.



BUILDING SELF-ESTEEM

Getting by with a little help from your friends, family, and other amputees

by Gail M. Williamson, PhD

One way to expedite this process is to talk to other amputees, preferably, those who are similar to you before undergoing the surgery. Knowing what to expect significantly decreases both physical and psychological distress. Unfortunately, few amputees (only about 10 percent) are offered this opportunity. But those who do talk to another amputee before surgery are much better adjusted after their surgery than those who do not.

A second option is to talk to another amputee shortly after surgery but only about 25 percent report having been given this opportunity. It is hard to explain why so many people undergo amputation without being more aware of the challenges that lie ahead. Although some amputations are unexpected (as in traumatic injury), limb removal usually is not unexpected but, rather, the result of prolonged attempts to save the limb. Moreover, a large number of amputees are more than willing to visit with patients both pre- and post-surgery. Thus, it appears that you may have to take control of the situation yourself. If you are facing, or have recently experienced, amputation, ask (demand, if you must) that your healthcare and service providers refer you to other amputees in your area. The information they can provide, most likely gleaned from their own trial-and-error endeavors, may well be invaluable to you and those around you.

Despite their lack of forewarning, many amputees adapt quite well, but substantial percentages do not. In collaboration with colleagues at the University of Pittsburgh, Carnegie Mellon University, and Hobart and William Smith Colleges, research at the University of Georgia has been focused on identifying differences between these two groups. The result is that we can offer some additional clues about factors that reliably predict adjustment. Among these are: (1) extent of surgery (2) patient age, (3) financial resources, (4) individual differences in personality, and (5) support available from close others. A person who adjusts most readily is one who has the best-case scenario in all areas. This does not mean, however, that all are necessary. Indeed, they are closely intertwined, and some can offset deficiencies in other areas.

Preservation of the knee (or elbow) joint enhances use of a prosthesis. This has to do with the actual physics involved, but it also relates to overall physical condition, the presence of complicating illnesses, and psychological factors such as personal motivation. For these (and probably other) reasons, many older adults are



never able to use a prosthesis. Does this mean that older adults are less likely to successfully adapt to amputation? Not at all.

In fact, research strongly suggests that elderly people adapt better to all forms of chronic illness and disability than do those who are younger. This may be because illness and disability are more expected in old age and, therefore, of less concern. Our research shows, however, that it is experience rather than actual age that makes the difference. Older children (adolescents), who have had more experience with chronic disabilities, are less distressed than are younger children who have, by necessity, had less experience. The same is true for older versus younger adults. Thus, time appears to be an important factor. The longer people deal with a health problem, the better adjusted most become.

Research by Dr. Richard Schulz and his colleagues at the University of Pittsburgh indicates that this is the case for even severely disabling conditions such as spinal cord injury. Over time, most evaluate their quality of life as being as good as (or even better than) people who have no disability. But time is not the only factor that influences both short- and long-term adaptation.

As crass as it may seem, financial resources help a great deal. Our own research clearly shows that adequate income facilitates the ability to conduct normal activities, and this ability then leads to less depression. Additional information provided by participants in our research helps explain why. For example, a retired dentist, who had never married, reported feeling fortunate that he was financially able to hire a companion. He stated, "Money can make it easier to deal with almost any of life's difficulties."

Another man, a 48-year-old victim of a job-related accident, had lost both legs at the hips. However, the large financial settlement he received allowed him to travel extensively with the wheelchair Olympics program. He reported having "a nice girlfriend" and viewed his life as better than before his accident. Both of these men were extremely well adjusted.

Now, let's assume the optimal situation: An amputee has retained the critical joint, is older, and has ample financial resources. Is he or she necessarily well adjusted? The answer is no, because other factors also play a role. Among these are aspects of the individual's personality. For example, people whose dispositions are more neurotic (e.g., they more easily become discouraged, feel like giving up when things go wrong, feel helpless, and want someone else to solve their problems) and less optimistic (e.g., they frequently feel that if something can go wrong for them, it will, and rarely count on good things happening to them) are less likely to adapt to any form of life stress. In addition, we have repeatedly found that, when faced with a disfiguring medical condition, people who are more self-conscious are more likely to avoid activities conducted in public and to experience more depression as a result of restricting their valued activities.

The support that other people provide can make a critical difference. But social support is not a one-way street — success depends on both the supporter and the recipient. New amputees often find accepting help difficult. This is understandable. It threatens one's sense of independence and, perhaps, the most basic sense of self-worth. But people who are willing to provide help, despite the fact that it takes away from other aspects of their lives, are also those who care the most about your well being. They



A group of young amputees at the 2000 ACA Conference in Orlando, Florida.

may falter in their efforts; they may want to help too much or they may be afraid of helping too much and, thus, help too little. Knowing exactly what to do is complicated by the dynamic recovery process that influences the amount of care an amputee needs.

Communication is of the utmost importance during this period. Do not be afraid to ask for help you need but also do not be afraid to refuse help that you do not need. People who are close to you will appreciate your guidance because they are likely to have no clear concept of what you actually need. Working "in the dark" is extremely stressful in any situation. Above and beyond everything else, try not to take out your frustration on them. Demonstrate that you appreciate their efforts and that you do recognize that they are motivated (perhaps erroneously) by their concern for your welfare. Communicate! Talk about your feelings and encourage your close others to express their feelings as well. Chances are that they are as scared and uncertain as you are. Sharing these fears and uncertainties will strengthen, rather than weaken, your relationship.

Of all the factors known to influence adaptation to amputation, interpersonal relationships with others may be the most critical. They can overcome more severe physical disability age-related adjustment problems, less-than-optimal financial resources, and potentially hampering personality traits. It

can be hard to focus on a significant other's feelings when you are going through a major life transition of your own, but the effort is more than worthwhile. You need to make every effort to understand the other person's perspective, and it is of extreme importance that you continue to provide some relationship rewards that supersede your medical condition. Compliment your partner. Indicate that you appreciate his or her efforts. Spend quality time together, even if it is no more than relaxing, watching a movie, and eating popcorn. Taking the initiative will not only make your partner feel that you recognize his or her feelings and concerns but also will give you the personal satisfaction of being able to influence this, perhaps most important, aspect of your life.

About the Author:



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SKIN AND SOCKET CARE

Basic tips on caring for your skin (Always consult your physician or prosthetist if sores or blisters erupt, which can lead to ulcers and serious infections.)

by Paddy Rossbach, RN

For your prosthesis to work at maximum efficiency, your socket needs to fit your residual limb intimately. This is called a “total contact” socket, and fabricating this socket requires the skills of a prosthetist. Though sockets are usually made of flexible materials, often they are limited in their ability to flex and change shape while maintaining support. However, if you have a major change in the shape of your residual limb, the socket has to have one, too, to avoid the complications of friction and pressure that can cause sores, blisters and even serious ulcers and infections.

Comfort in a prosthetic socket depends on:

- Maintaining a good fit
- Correct alignment
- Skin care

Fit and alignment are the responsibility of your prosthetist; however, he or she cannot help you unless you tell him or her when something is wrong. The first rule, therefore, is “Communication.”

Skin care is the responsibility of the individual. There are a few basic rules, the first of which is cleanliness. Remember that your residual limb is encased in a completely - or partially - airtight socket, which does not breathe or allow sweat to evaporate. Sweat is acidic and salty and, when allowed to dry, forms tiny crystals (like sandpaper) on your skin. If this sweat is left on the skin and socket, bacteria can grow, and if the skin is broken, infections may occur, which can become severe if left untreated.

To avoid skin problems, follow these steps:

- Every day, or more often if necessary, wash the residual limb with a mild or antibacterial soap and rinse well.
- Every day, wash everything in contact with your skin with a mild or antibacterial soap and rinse well. This includes socks, nylon sheaths, silicone suction sockets, gel inserts and flexible or hard sockets. Note the manufacturer’s instructions for cleaning and follow closely.
- Do not shave your residual limb. Shaving

can cause ingrown hairs, and often leads to infected hair follicles.

- Only use softening creams when your skin is at risk of cracking or peeling.
- Do not use alcohol-based products on your residual limb; they dry out the skin, can cause cracking or peeling, and create a potential site for infection.
- If you must cover an abrasion, use the thinnest dressing possible. If the abrasion was caused by pressure, adding a bulky dressing will increase the pressure.
- Do not add soft materials such as wool to “pad” a sore spot. This will only add more pressure.
- Be aware of how your socket fits. Adjust sock ply if appropriate. If you cannot maintain a good fit, visit your prosthetist.
- Try to maintain the same body weight. A gain or loss of five pounds should be manageable; more than that will probably require a prosthetic adjustment.



If a problem does occur, it usually falls into one of the following categories:

- Rash
- Blister
- Ulcer
- Infection, local or disseminated
- Verrucous (wartlike) hyperplasia

First, visit your prosthetist. The problem can usually be solved with a prosthetic adjustment. If you have an ulcer or infection – or if you have diabetes or circulatory disease and have anything more than a mild rash – consult your physician immediately. The following treatments are short-term. Problems that persist require help from both your physician and prosthetist.



Rashes

A rash can be caused by either an allergic reaction, often to your own sweat, or a fungus, similar to athlete's foot. It occurs more frequently in people who perspire heavily and use heavy suction liners.

To avoid rashes:

- Wash and rinse limb and liner every day.
- Lightly dust the residual limb with a medicated talc powder such as Gold Bond at night, and, if this is not contraindicated by the manufacturer, before donning your liner. (Ammens is preferred by some because it does not contain talc.) Suction will not be affected as long as the dusting is light.
- Or
- Use a light film of diaper rash cream such as Balmex at night and under the liner if not contraindicated by the manufacturer. (This has been found to be very effective for small children.)

To treat rashes:

- Use an antihistamine lotion, such as Benadryl, which will usually take care of the rash if it is an allergic reaction.
- If you do not catch the rash quickly enough, you may have to resort to an over-the-counter-strength cortisone cream.
- Use a commercially available athlete's foot treatment such as Tinactin.

Remember, if the rash does not respond within 24-hours, seek medical help. Sometimes, it is necessary to wear a thin sheath under the liner during treatment to allow for a little air flow.

Blisters

A blister can be caused by abnormal pressure or by shearing of the skin against "tacky" silicone or plastic.

To avoid blisters:

- Maintain a good fit; if necessary add or remove a sock during the day.



- Unless contraindicated by the manufacturer, lightly powder the inside of silicone liners or flexible plastic sockets until they lose the "tacky" feeling.
- Blisters can be avoided by using a commercially available "paint-on" film dressing, such as MedLogic's LiquiShield, designed to help prevent skin breakdown.

To treat blisters: (individuals with diabetes or circulatory disease should see their physician)

- A surface blister should be left intact if possible. If it opens, keep it clean and covered with a thin layer of antibiotic ointment. Soak a small piece of tissue (such as Kleenex) in mineral or baby oil with vitamin E; place the tissue over the blister and then don the silicone liner as usual. The tissue is used because it does not add bulk. Until the blister heals, you may find watery fluid in your liner. Wash and dry the limb and liner frequently throughout the day, reapplying the antibiotic ointment and oil.
- A line of itchy blisters sometimes appears around the edge of, or inside of, silicone liners, especially in hot weather. A little

mineral or baby oil around and under the edge of the liner prevents this. Treat the blisters as above.

- Blisters that occur with above-knee sockets can sometimes be covered with very thin see-through dressings such as LiquiShield.

Ulcers and local and disseminated infections should all be treated by your physician; however, the fit of your prosthesis should also be checked. If the cause of the pressure is removed, the problem will often be resolved without the need for aggressive measures.

Verrucous hyperplasia

This is an itchy, red, raised, circular area on the distal end of a residual limb, caused by suction being applied to the end of the limb. This condition frequently occurs when the socket is too tight and the limb does not make total contact with the bottom of the socket.

To prevent verrucous hyperplasia:

- Maintain a good "total contact" socket fit.

To treat verrucous hyperplasia:

- Remove the cause.

Miscellaneous tips:

Excessive sweating can be reduced by using a strong antiperspirant gel on the residual limb. Apply every night until sweating is reduced, then as often as necessary to control sweating. Do not use this if there are any breaks in skin integrity. A stronger preparation, Dri-sol, is available by prescription.

About the Author:



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KEEP MOVING...

Exercises for Lower-Extremity Amputees

by Melissa Wolff-Burke, EdD, PT, ATC,
and Elizabeth Cole, PT

Getting back to your previous activities may be your objective following amputation. Even if you decide not to use a prosthesis (or are unable to use one), the following exercises are designed to help you reach your goals. Many of these activities can be done with or without a prosthesis while lying on a firm surface, sitting in a straight back chair or on the edge of your bed, or standing at a counter. Very little equipment is needed to keep you and your residual limb in good working order. Exercises are an essential part of maintaining your health and function, and getting back to your hobbies and activities is possible in the near future, if you keep moving!

Please be sure to check with your doctor or physical therapist before beginning these exercises or any other exercise program. Your current level of fitness, your general health, and the condition of your residual limb are all factors that will play a role in how rigorously you can exercise. A qualified health professional can teach you how to take your pulse and stay within your target heart rate.

Range of motion

Following your amputation, you will need to decrease the amount of time your leg is bent. Because you will initially spend more time sitting, the remaining joints of your leg, and even your back, will spend more time bent or flexed. Too much of this can cause problems for your muscles and joints because they get used to being in a shortened position and you may develop a contracture. A contracture is when your joints cannot go through the full range of motion. This can cause problems whether you are ready for a prosthesis or not. Often a contracture can be avoided by simply paying attention to the following simple exercises.

- Perform flexibility/range of motion slowly, holding each position for 30 seconds.
- Do not bounce.
- Count aloud slowly (try counting in another language) or use a timer.
- Stretching is a mild sensation of tension - not painful agony. Use your good judgment to find the right amount of stretch.
- Be sure to stretch your knee and hip many times every day.

- Do not hold your breath.

Knee flexibility exercises and positions

To keep the motion in your knee, let your knee



Picture 1

rest on a cushioned board or on the leg rest of the wheelchair in its fully extended position. If you don't have a wheelchair leg rest, position your leg on a couch or chair. See if you can devise other ways throughout the day to avoid sitting in the same position. Perhaps you have a cane or stick handy and can do the rotation stretch shown in Picture 2. Lying on your stomach is a great way to stretch out many joints. See Picture 1.



Picture 2

Hip and back flexibility exercises and positions

By resting flat on your stomach or on your elbows, as shown in the picture, you can maintain or improve the flexibility (extension) of your knees, hips and lower back. It is recommended that you lie on your stomach twice a day for 10-20 minutes. If your breathing is impeded or it's uncomfortable for you, use pillows under your chest for support or ask the advice of a physical therapist.

Strength

Now that you are on the way to being more flexible let's look at some ways to make you stronger. You will need to rely on your nonamputated limb heavily now. Therefore, strengthening exercises will involve both your amputated limb and your nonamputated limb. Any of the exercises shown below can be performed with either leg.

■ If you are adding weights as shown in Picture 3 the nonamputated leg may be able to manage heavier weights.



Picture 3

■ You can begin with no weights on your limb and try to move it in all directions as many times as possible. As you add weights, keep the repetitions to a maximum 25 and then move on to a heavier weight or a more challenging exercise (Picture 4).



Picture 4

■ Don't forget your stomach muscles and your arms as you will need a lot of help from them to get moving (Picture 5 and Picture 6).



Picture 5



Picture 6

■ Try playing "tug of war" with an elastic band tied to a sturdy object or held by your foot or a friend (Picture 7). Pull the band in all directions. Begin in a sitting position, and then try it kneeling and standing.

Strengthening does not need to be done every day. It is best if you do it every other day and alternate it with a different activity. On your days off from strengthening you can work on balance and agility skills.



Picture 7

Balance

Whether you are sitting up, lying down, standing or walking, your balance will be different following your amputation. You will need to retrain your brain and that takes practice. Many people with amputations have risen in the night, tried to take a step and found themselves on the floor. Their brain forgot to remind them that the limb was no longer there and the balance center did not figure it out soon enough.

■ Help your brain by practicing very simple activities such as sitting and reaching for objects (Picture 8), kneeling (Picture 9) and standing on one leg.



Picture 8



Picture 9

■ Stand up and turn from side to side, with or without a prosthesis. Hold on to a counter and reach forward, sideways, and back to exercise the balance center in your brain. (Picture 10, Picture 11)



Picture 10



Picture 11

If you are going to use a prosthesis, you will need to work on basic balance activities before you become an accomplished walker. Being able to balance on your prosthetic leg with full weight is necessary for a smooth walk. With every step, there is a moment when you have only one leg on the ground. That leg, whether prosthetic or natural, will have to be able to hold all your weight. Practice accepting weight on your prosthesis by leaning over the prosthetic leg (Picture 12). Then kick a ball to someone using



Picture 12



Picture 13

your nonprosthetic leg to do the kicking (Picture 13). Hold on to a rail and lift your nonprosthetic leg up to the step and then bring it back to the floor (Pictures 14 & 15). If both of your legs have been amputated, step up with either leg.



Picture 14 & 15

Agility

In addition to good balance, you will want to practice your agility. Agility is what lets you move confidently from place to place and gets you out of the way of a fast-moving object.

■ Sit or stand and play catch (Picture 16). Begin by having your partner throw the ball directly to you, then make this more challenging by having the ball tossed out to the side. This should be done in a place where you cannot fall into anything that can injure you.



Picture 16

■ Sit in a chair and throw or kick a ball against a wall.

■ Dancing with or without a partner is a great way to work on your balance and agility. Even if you just stand in one spot and rock back and forth, you are working on your strength, balance, agility and togetherness! (Picture 17)



Picture 17

Conclusion

Range of motion, strength, balance and agility all play a part in your plans to get back to what you like to do. By following these exercises or those prescribed by your health professional, you will reap the rewards when you are ready to get moving!

A special "thank you" to the members of the Winchester Amputee Support group for being models and reviewers of this article.

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(formerly Austin Prosthetics Center) in Austin, Texas.

VETERANS HEALTH ADMINISTRATION

Dedicated to Veterans' Causes

by David Whatley

The Veterans Health Administration provides comprehensive prosthetic and orthotic services to eligible veterans in a timely, customer-friendly, cost-effective manner. These services are provided in the Prosthetics Treatment Center (PTC) by a team of well-trained professionals who are dedicated to veterans' causes.

Services provided by the PTC staff include, but are not limited to, evaluation, prescription, measurement, fabrication, fitting and follow-up of orthotic and prosthetic devices. Other services include the ordering, instruction, delivery, pickup and repair of medical equipment and supplies. The PTC also provides hearing and communication aids, environmental controls and adaptive equipment for motorized vehicles for eligible beneficiaries, as well as critical care equipment such as food pumps, in-home oxygen equipment, respirators and air filtration systems.

The Orthotic Laboratory staff provides clinical and consultative services to the physician staff regarding patient evaluation and prescriptions for orthotic and prosthetic devices. When necessary, the staff also provides technical support by fabricating, fitting and adjusting prescribed devices.

Orthotic services are provided upon receipt of a physician's prescription. For patients requiring clinical evaluation or custom devices, appointments are scheduled to ensure the clinician takes the time necessary to provide services that meet patients' needs.

When possible, noncustom, off-the-shelf devices will be provided on a walk-in basis.

The Veterans Health Administration offers specialized services in some of its comprehensive medical centers. These specialized services include:

- **Regional prosthetic clinic**

This clinic is available for the evaluation and treatment of amputee veterans.

- **Specialized wheelchair and custom seating**

This clinic prescribes and develops custom wheelchairs and electrically powered mobility aids.

- **Regional orthotic and custom footwear clinic**

This clinic evaluates patients and prescribes custom shoes and orthoses for lower-extremity conditions.

- **Home improvement and structural alterations**

These grants to eligible veterans are intended to ensure the continuation of treatment or to provide access to the home or essential lavatory and sanitary facilities.

Home oxygen therapy

The PTC is responsible for issuing in-home respiratory and oxygen equipment and supplies through an accredited contractor. Prescription and prescription changes must be coordinated with the local VA Medical Center's pulmonary and critical care staffs.

Home health care equipment

An accredited contractor provides equipment for home care. The contractor provides delivery, set up, and patient/caregiver education.

To contact the VA for a site location in your area go to the Web site: www.va.gov/about_VA



About the Author:

David Whatley is a retired director of the Houston VA Medical Center, one of the most complex VA medical centers in the country with over 2,800 employees. Caring for more than 50,000 southeast Texas veterans, the Houston VA Medical Center also serves as a regional and national referral center for services including cardiac surgery, radiation therapy and spinal cord injury care.

A MAN OF HONOR

One man's refusal to give up and let his dreams be stolen

by Rick Bowers

"It's not a sin to get knocked down. It's a sin to stay down."

These words define the life of Navy diver Carl Brashear, whose life is the subject of the Fox 2000 Pictures movie, *Men of Honor*.

Despite starting out in poverty, a lack of education, being black in a white world, and an accident that left him an amputee, Brashear rose to become the Navy's first black master diver — the highest position possible for a Navy diver.

When he began his Navy career at age 17 in 1948, Brashear, like most blacks, was sent to the steward branch where he cooked and served white officers — a long way from what he had dreamed of before leaving his happy Kentucky home for the Navy.

Brashear might have remained there for the duration of his military career if he hadn't stubbornly set his sights on becoming a diver — a seemingly impossible goal for a black man at the time.

When he wrote letters requesting admittance to diving school, he was either told that the letters were lost or that the Navy didn't have black divers. But he didn't give up. After persistently writing more than 100 letters, he was finally accepted in 1954. It was clear that he was not wanted. The only black man in the program, he found notes on his bunk, saying, "We're going to drown you today, nigger!"

Though he laughs about it today, in 1954 it was unwise to ignore such threats, and Brashear was about to quit until a staff member at the school talked him out of it. "Show them you're a better man than they are," the man advised.

Enduring threats and discrimination, Brashear struggled on to integrate the Navy diving school and open doors of opportunities for blacks in the future.

Though he believed he was a natural-born diver, diving school was a different matter for the young man who had dropped out of school after the eighth grade to help his father on the farm. After earning his high school equivalency diploma in 1960 when he was 29, he failed diving school

and was devastated. This time, however, he didn't even consider giving up. "It just gave me more ambition and determination to go out in the fleet and study the requirements to pass," he says.

After a lot of hard work, he graduated as a first-class deep-sea salvage diver in 1964 — a decade after he started in the program.

For the next few years, he recovered numerous items from the ocean, including crashed planes,



Photo courtesy of the Fontana Family

U.S. Navy Salvage School Class #56 training picture, Bayonne, N.J., 1954. (Carl Brashear is in the back row, second from right).

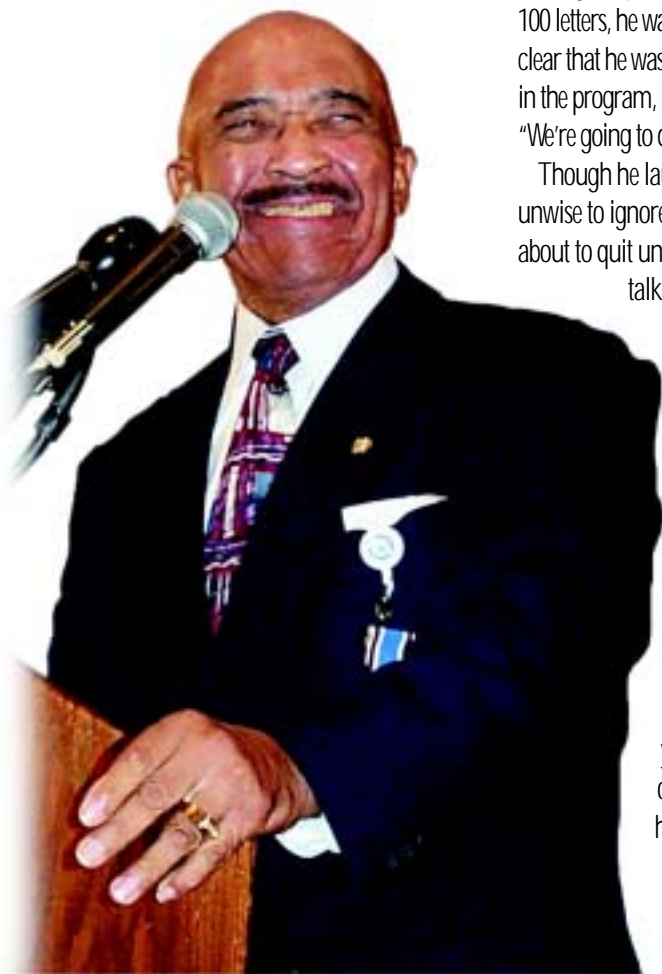
sunken ships, and old World War II ammunition. "Every so often, we would find a torpedo that wasn't detonated, and then we would have to detonate it," Brashear says. It was dangerous work, but Brashear was living his dreams.

Then, in 1966, while helping to recover a nuclear weapon that had fallen into the Mediterranean Sea after a plane crash, Brashear was knocked down again.

After the crew brought the nuclear device to the surface, Brashear saw a line break. Though he was able to move quickly enough to knock another sailor out of the way, he didn't see the pipe that was hurled across the boat and struck his leg with tremendous force. "They said I was way up in the air just turning flips," Brashear says. After he landed, he jumped up and tried to run. "That's when I knew how bad my leg was," he recalls. It was hanging by tendons.

Brashear later went into shock and was almost pronounced dead, but after checking him one last time, the doctor found a "very, very faint heartbeat."

A surgeon wanted to try to fix Brashear's leg but said it would take three or four years, Brashear explains. "I said, 'Go ahead and amputate. . . . I



can't stay here three years. . . . I've got to go back to diving.' They just laughed. 'The fool's crazy! He doesn't have the chance of a snowball in hell of staying in the Navy. And a diver? No way! Impossible!'"

This knockdown in Brashear's life — the amputation of his left leg — threatened to end his career and put a stop to his dreams. The Navy planned his retirement, but he had other ideas. "I had set my goal to be a master diver. When I lost my leg, I was a first-class diver. I had set my goal to be a master chief petty officer. When I lost my leg, I was just a chief petty officer. I had to reach my goals. I wanted to be the first black master diver in the United States Navy."

Disobeying hospital and Navy rules, he began diving and taking pictures to prove that he was still able to do his job. With this evidence, he was officially accepted into diving school. Because he was required to walk 12 steps in a 290-pound diving suit in front of a Navy court to be restored to active duty, he needed to exercise to strengthen his remaining leg and residual limb. "Sometimes I would come back from a run, and my artificial leg would have a puddle of blood from my stump," Brashear says. "I wouldn't go to sick bay. In that year, if I had gone to sick bay, they would have written me up. . . . I'd go somewhere and hide and soak my leg in a bucket of hot water with salt in it — an old remedy. Then I'd get up in the morning and run."

After successfully completing his training and proving himself before a Navy court in 1968, Brashear became the first amputee in the history of the Navy to be restored to his position as a diver and returned to full active duty. Two years later, he became the Navy's first master diver who was either black or an amputee.

"My father was the only role model I've ever had, and he had a can-do spirit and a good positive attitude, and that's what kept me going," Brashear says. "And, of course, the trust in the good Lord."

Men of Honor dramatically portrays the obstacles Brashear overcame to reach the pinnacle of success. "It's very, very close to my life," the 69-year-old Brashear says, although he readily admits that some artistic license was taken. "This isn't a connect-the-dots biography,"

screenwriter Scott Marshall Smith says. "My goal was to be true to his spirit, not his shirt size."

That, he accomplishes, according to Brashear, though the excellent movie and the great acting by Cuba Gooding Jr. as Brashear threaten to skew the lines between the man and the myth.

Brashear denies that he was a hero, but his tenacity and indomitable spirit in the face of adversity belie his humility.

Today, Brashear — who retired from the Navy in 1979 as a master chief petty officer — travels around the country promoting the movie and speaking at schools and universities. He's come a long way for a man who entered the Navy in 1948 with only an eighth-grade education. But, then, for Brashear, it's never been about where he started, but rather where he finished. And he finished at the top. "If you dream big and work towards those dreams with all your might, you'll be successful," he says.

Some of the quotes in this article are from the U.S. Naval Institute's oral history, "The Reminiscences of Master Chief Boatswain's Mate Carl M. Brashear." He is one of only seven enlisted people whose oral histories have been recorded by the Institute — a great honor for a Navy man. A copy of the entire history can be obtained from the Institute's Web site at www.usni.org/hrp/oralhist.html



Photo by Staff Sgt. Scott Ash, USAF

The Navy's diving community presented actor Cuba Gooding Jr. (left) with a framed Navy diving certificate and named him an honorary diver. Master Chief Petty Officer John Schnoering (right) presented the certificate.

LANDMINE SURVIVORS NETWORK



Roughly every 22 minutes someone is killed or maimed by a landmine. That amounts to more than 20,000 men, women and children each year injured

through no fault of their own. The number of victims has been portrayed in terms of shocking ratios, i.e., one in every 230 Cambodians is an amputee from a landmine injury, one in every 330 Angolans, etc. In truth, no one knows the exact numbers. Most mine victims die without anyone documenting the tragedy.

Today, there are hundreds of thousands of landmine survivors worldwide, including thousands of children, with no access to proper and affordable medical care and rehabilitation. Moreover, the number of victims is on the rise with assistance programs unable to keep up with the demand.

Created by landmine survivors for landmine survivors, Landmine Survivors Network (LSN) works directly with those whose lives have been devastated by these cheap instruments of destruction. LSN helps landmine survivors find the assistance they need so that they can lead fuller, more productive lives.

The LSN does more than just help survivors. It is also a fierce advocate for the immediate removal of these barbaric tools of mutilation and horror. Today LSN provides a strong world voice for those who never before had a voice, tenaciously petitioning governments and the public alike to stop the use of landmines.

The LSN works to help mine victims and their families recover through an integrated program of peer counseling, sports, and social and economic integration into their communities.

For more information on the LSN, write 1420 K Street, NW, #650, Washington, D.C. 20005. Call 202/464-0007 or visit the LSN Web site: www.landminesurvivors.org

WHO CARES FOR CAREGIVERS?

by Nancy Carroll

A "As each day goes by dealing with the disease, I reach down into my bag of tricks and find the magic to get him through another day. However, when it comes to dealing with me, my emotions, my time off, there are no magic tricks, just fortitude to get another day over with."

A Family Caregiver

It was 1974 when doctors diagnosed Suzanne Mintz's husband, Steven, with multiple sclerosis, a chronic, often disabling disease of the central nervous system. "We were devastated," Suzanne recalls. "Steven was only 31. We had been married seven years and had a 5-year-old daughter." Today, he is 57, in a wheelchair, and needs help in virtually every activity of daily living.

Though years later in 1993 Suzanne would found the National Family Caregivers Association (NFCA) - a nonprofit membership organization dedicated to improving the quality of life of America's family caregivers - in 1974 Suzanne admits that neither she nor Steven knew how to cope with the physical or emotional impact of his illness.

"Back then we didn't know where to turn. Steve may have had the clinical diagnosis, but I was just as impacted by the disease. I know now that illness and disability is a family affair. Today, we don't say Steven has MS. We say 'we' have MS."

Steven and Suzanne reacted to their private pain and grief in very different ways, which created a barrier between them. Frequent bouts with depression, frustration, anger, and poor communications took its toll on the marriage. They separated twice, reconciling both times, all the while trying to figure out how to deal with the debilitating disease that had changed the course of their lives.

Coping with anger

Expressing your feelings is critical to maintain mental and physical well-being, Suzanne admits; however, it's important to translate your anger into positive action. "I kept my anger bottled up and eventually it spilled over into major depression. I wasn't angry at my husband; I was angry at his illness, at our circumstances."

Through regular exercise and writing about her feelings in a journal, Suzanne learned to channel her anger constructively. "Ranting and raving will get your feelings out but the idea is to vent all that energy into something positive," she stresses.

Citing an example, Suzanne referred to a friend in Washington State whose wife has Pick's disease, a rare form of presenile dementia that occurs mostly in women ages 40-60 and involves progressive, irreversible loss of memory.

"He was so frustrated because there is no known cure, and because it's such a rare disease, there's not much research going on," Suzanne explains. "So to vent his anger and frustration, he's become an activist for NFCA and is channeling his energy to do something positive for caregivers."

Positive expression

How do you tell your loved one how you feel without being hurtful? Suzanne suggests choosing your words carefully so you can get the anger out without verbally attacking the person. Example: "I'm not angry at you, I'm angry at your illness. I am so frustrated and tired and angry that I don't have enough time for myself and I am so angry at your disease. I want it to go away and I know it won't and it's affecting you and it's affecting me, too. I feel so upset and lonely"

Identify sources of your frustration other than the person, i.e., "I'm frustrated because the home care person didn't show up; I'm frustrated because someone parked in the handicapped parking spot at the grocery store, and I'm frustrated because this illness has caused it to take an hour to get you dressed in the morning. I know it's not your fault and I know it's caused by the disease, so I'm angry at the disease."

Getting help

How do you get a break? Perhaps you have siblings or other family members who live



Suzanne and Steven Mintz

nearby and still most of the burden falls on you. How do you get your family to share in the responsibilities of caregiving?

Suzanne recommends calling a family meeting with a third party present, perhaps a therapist, a social worker or a minister – to serve as an arbitrator. The caregiver should then bring family members up to date on the loved one's condition and share his or her concerns and frustrations. Everyone present should have an equal opportunity to express thoughts and feelings about the situation.

Optimally, the meeting will yield a better understanding among family members of what the primary caregiver is going through and the importance of lending their support in the caregiving process. Whether family members offer to contribute financially, to conduct research for adaptive products and services, or to be physically present to give the primary caregiver a respite break, all contributions and offers should be explored.

"The idea of the family meeting is to get everything out on the table, to understand where each person is coming from, and to underscore the fact that the primary caregiver cannot continue to do everything alone, that they need help from the rest of the family," Suzanne says.

Of course, if family members still don't respond, you can't force them, Suzanne adds. "Our daughter recently moved near us so she helps out. Sometimes I call on my friends and neighbors for help," she says. "I don't need continuous help but I know that if Steven falls out of his wheelchair, they would come over in a minute. It's important to have that kind of support system and assistance."

Combating isolation

"Isolation creeps up on you," Suzanne says. "Sometimes you're not even conscious of it happening. Other times it's a rude awakening when people just stop being your friend."

But reaching out to others can be difficult, especially when you've been isolated for a while and are out of sync with the outside world. It requires an active push – a firm resolve that you're going to find friends that you can rely on, whether they are phone pals, female friends, neighbors, or people at church. "It's really

important to maintain some kind of network because not only can friends keep you from being isolated, they can also be there for you when you need support and help," Suzanne says.

Self-advocacy for caregivers

Suzanne confesses that she "talks the talk" very well – but doesn't always follow her own advice. "When I'm starting to feel overwhelmed, and life is topsy-turvy, I remember the four rules of self-advocacy and try to slow down and prioritize my own health. People need to realize that self-preservation is not selfish."

The four rules of self-advocacy

1. Take charge of your life.
2. Love, honor and value yourself.
3. Seek and at times demand help.
4. Stand up and be counted.

Looking to the future, Suzanne says, "We're all going to be in this boat eventually so we need to help each other. I think caregivers should be seen as part of the healthcare team. We need training and support, healthcare benefits, changes in Medicare, more community-based support, volunteer groups and help networks.

"I think Care Advisors should be available to help people figure out the options and resources they need during difficult times," she continues. "When you're going through crisis and transition it's so hard to go it on your own. Having a Care Advisor to consult with caregiving families would be an enormous benefit."

When it's time for a nursing home

"This is definitely one of the toughest decisions you'll ever have to make," Suzanne says, adding that she recently faced this with her 86-year-old father. "My mom, 82, couldn't take care of him any longer, and there's no point in having two very ill people. The caregiver is the steward of this person and we have a moral responsibility to monitor their health as well. And, it's important to remember that just because a person is in a nursing home doesn't mean that you're not taking care of them."

Support for caregivers

People may say they are interested in caregiver support groups, but statistics show that not many people utilize them, Suzanne notes. Some

people are reluctant to share their feelings, some consider attending support group meetings inconvenient, others enjoy "chat rooms" on the Internet; everyone has to find his or her own medium.

Membership in the NFCA is one solution. Founded in 1993, the organization has over 7,000 members. Membership for family caregivers is free. You will receive information about practical aspects of caregiving as well as emotional ones, all written from a caregiver's perspective.

"There's no doubt that Steven inspired me to form the NFCA," Suzanne says. "He has the slow, progressive type of MS; in 25 years he has had no remissions. Still, he works as an economist for the U.S. Department of Energy. He drives to the office three days a week in a special van that he can drive in his wheelchair. Two days a week he works at home, so he puts in a full week. He's a strong person."

For more information on NFCA membership, call 1-800/896-3650; write NFCA, 10400 Connecticut Avenue, Kensington, MD 20895, or visit the NFCA Web site: www.nfcacares.org

Other resources:

Interfaith Caregivers Alliance

1-816/931-5442

They provide respite support through local congregations and supply information about volunteer services.

Easter Seal Society 1-800/221-6827

They offer respite services (varies from location to location), give referrals to over 400 locations nationwide, support direct rehabilitation services to disabled people, and provide family support groups.

Friends Health Connection

1-800/483-7436

They match people with health problems with others in similar situations, bring together family/friends/caregivers of people with health problems with others in similar situations via the Family Network, and publish a newsletter.

FamilyCareAmerica

1004 North Thompson St., Suite 205
Richmond, VA 23230

Web site: www.familycareamerica.com

Phone: 804/342-2200 • Fax: 804/342-2338

E-mail: info@familycareamerica.com

PROSTHETIC COSTS

by Jon B. Holmes, PT, CP

It always amazes me when new patients come into my office and say, "I want the best leg there is and I do not care how much it costs." They seem to have the idea that the most expensive prosthesis will be the best one for them. I guess that is some sort of "American logic." In this age of so many prosthetic choices, it is hard to figure out what is best for each individual - but it certainly is not necessarily the most expensive prosthesis.

I have seen invoices in our company's archives for complete below-knee prostheses for \$150. There were no prosthetic choices given to the consumers; they paid cash for their leg and would often tell me all the wonderful things they were able to do with it. This is no longer the case. Patients now come into our office with all this literature they have printed from the Internet and want a prosthesis just like the one they saw on television. Then they present us with their insurance card, telling us it will pay for whatever they want. This also is not usually the case. So how do we figure out what is best for each individual?

The cost of a new prosthesis can be a staggering amount and is often a factor in the kind of prosthesis the consumer will get. Your doctor or surgeon, a comprehensive amputee clinic, your therapist, your social worker, and a certified prosthetist are best suited to help you with the choice and to show you how to maximize your investment and realize your ultimate potential with your new prosthesis. At this point, you should conduct a preliminary check of how you are going to pay for your prosthesis. If you have insurance, verify that there is prosthetic coverage and what the coverage is. It is important to have a professional help with this. A rehabilitation nurse, a social worker, or an insurance expert at a prosthetic company would be good choices. Insurance wording can be confusing and it is easy to make assumptions based on generalities in your policy. Often the insurance company has prosthetic coverage, but will only pay for a

prosthesis once, has specific exclusions, or will only pay a certain amount. Without checking the specifics, it is easy to make poor choices. How your policy reads can help determine what is the best prosthesis for you.

If you do not have insurance, it is just as important to think about how you will pay for your prosthesis. There are state agencies that can be helpful, but lots of paperwork is involved, so get started early. Local charities are often a source of funding, but there is usually no organized process to obtain this money. It will require a lot of work to identify these groups, make the appropriate contacts, and get the



assistance. In addition, some prosthetic firms will be willing to work out payment arrangements for limbs. The Barr Foundation in Boca Raton, Florida, helps people pay for prostheses when they are unable to get funding any other way (call 561/394-6514).

Start by considering your needs from your body and work from there. The most important part of the prosthesis is "the motor" (the amputee). Spend your time and energy getting your body in the best condition possible before moving on. To use a prosthesis effectively, your body must be well-healed, have a good range of motion, be strong, and have good balance. Investing in a prosthesis before you are physically and mentally ready is not the most economical way. The prosthesis is a tool to help you with your rehabilitation not a cure-all. Engage a good physical therapist to help you with this.

When determining your prosthetic needs you may have to choose between a temporary

prosthesis and a definitive one. Knowing how much your insurance will cover can be helpful in this situation. If your insurance is going to pay for only one prosthesis, this might be a factor in making your decision. If you still expect many body changes, a temporary prosthesis may be in order. It will allow you to get more prepared for the definitive prosthesis and even help you figure out which components might be best. A definitive prosthesis, anticipating socket changes, can be a good choice for someone who is ready to be fitted. Then, when you get your training with your new prosthesis, you are learning to use the components best suited for your needs. This can save going back later for more training when you move on from a temporary to a definitive prosthesis. Once again, which is more cost-effective is an individual decision. The amputee clinic team will be the best people to assist you with this difficult choice.

The interface between the body and the prosthesis, known as the socket, should be the next thing to consider. This intimate part of the prosthesis will need to be customized for your individual needs. A well-fitting socket will provide comfort, suspension, and control of the prosthesis. Special needs because of scars, unique body proportions, muscle function, and other physical characteristics must all be considered when deciding which type of socket is best for you. Choices will not be the same for everyone. The certified prosthetist will be able to give you direction. Rarely will insurance companies dictate your socket choices, as they also recognize that without a well-fitting socket interface the prosthesis will not be used to its fullest potential.

Using the HCFA (Medicare) classification system is a good way to begin considering your choices for knees and feet. Being placed into a specific K-level classification will begin narrowing your options (See K-Level Classifications on page 86). Certain components are appropriate for each individual level; however, these guidelines will only be generalities and will not help you select specific brands. This will be your most difficult choice. Hundreds of different feet and knees are on the market, and advertising will lead you to believe each one is the best. You must rely on professionals and your peers



for advice, remembering that even these people will have their own biases. Often after you have made your general choices, various components can be tried to see which one is best for you. Many manufacturers will allow a “free trial period” allowing amputees to compare components before deciding which ones they prefer. The correct knee and foot will allow greater prosthetic efficiency for each individual. Specialty devices like shock absorbers, rotators, torque absorbers, swimming ankles, quick-change devices, and numerous other components can make the prosthesis function better. Though these devices may not be covered by insurance, they could be worth the additional expense. These devices have their drawbacks, too, since they take up a lot of room, add weight, require more maintenance, and increase costs.

After an exact prescription has been made for a new prosthesis, insurance preapproval must be obtained. It is not enough that you verified your coverage in the beginning. The insurance company must now authorize the new prosthesis with every detail accounted for. Only the prosthetic firm where the prosthesis is made should do this. Be prepared to make appeals and justify the exact components selected. Often the insurance company will deny specific components as not enhancing the “fit or function” of the prosthesis. Be prepared to get letters of medical necessity from your doctor and make phone calls to the appropriate people to get what you need. Payment is the patient’s

responsibility and you will have to work to maximize your benefits.

Obtaining the best possible prosthesis (especially a first one) is not a simple matter. It will require lots of energy. This will include putting together a good support team, getting your mind and body prepared, and obtaining funding. The amputee is forced to deal with these challenges. But if this process is undertaken with care and understanding, you will be an informed prosthetic consumer who is pleased with your prosthetic choices.

For more information on funding sources, call the Amputee Coalition of America (ACA) toll-free at 1-888/AMP-KNOW (267-5669).

About the Author:



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Muilenburg’s, adjunct faculty at Texas Woman’s University, and associate professor at Baylor College of Medicine in Houston, Texas.

FINANCIAL ASSISTANCE FOR PROSTHESES AND OTHER ASSISTIVE DEVICES

compiled by Mary Jo Walker,
NLLIC information specialist

Some of the questions most frequently asked by amputees relate to the purchase of prosthetic devices, wheelchairs, ramps, and other adaptive equipment. Given the exorbitant costs of many of these devices, most amputees will require some financial assistance to obtain the equipment needed to maintain their independence.

Starting the process

Before attempting to find a funding source amputees should determine the specific assistive device they need and where to purchase it. For new amputees or those who need a new prosthesis, consulting with medical and rehabilitation professionals is an essential first step. Good record keeping is important so that you have accurate information on hand when it is requested.

Some funding sources require applicants to prepare a justification statement before funds are appropriated. They may require that applicants demonstrate that the service or technology will enhance their ability to prepare for, get, or keep a job, or that it will enhance their independence. Success in securing funding frequently depends on the applicant's ability to address the specific agency's unique requirements.

MEDICARE

In the U.S., Medicare is the largest financial resource for prosthetic care. In addition to prostheses, Medicare commonly covers wheelchairs, walkers, and crutches. Ramps, adaptive driving devices, and other nonmedical devices are not covered.

Obtaining Social Security Disability (SSD) Medicare coverage

For those under age 65, the first major obstacle to obtaining Medicare coverage for assistive devices may be getting approval for SSD benefits. Approximately 70 to 75 percent of SSD applicants are denied initially. Persistence, detailed documentation of your medical history, and the help of an attorney are often the keys to getting approval.

L-Codes and Level II Modifiers

The "L-Code" system is the current method of billing Medicare for orthotic and prosthetic services. Historically Medicare had no qualifying standards that related which components and procedures were appropriate for each amputation level. The recent introduction of Level II or

"K-Modifiers" helped organize components and amputees' access to them based on the patient's rehabilitation potential as determined by the prosthetist and ordering physician. Criteria considered for assessing the functional level include the patient's past history and current condition including the status of the residual limb, the nature of other medical problems, and the patient's desire to ambulate.

Classification levels are:

- K0 (Level 0)** - Does not have the ability or potential to ambulate or transfer safely with or without assistance and a prosthesis does not enhance their quality of life or mobility
- K1 (Level 1)** - Has the ability or potential to use a prosthesis for transfers or ambulation on level surfaces at fixed cadence. Typical of the limited and unlimited household ambulator.
- K2 (Level 2)** - Has the ability or potential for ambulation with the ability to traverse low-level environmental barriers such as curbs, stairs or uneven surfaces. Typical of the limited community ambulator.
- K3 (Level 3)** - Has the ability or potential for ambulation with variable cadence. Typical of the community ambulator who has the ability to traverse most environmental barriers and may have vocational, therapeutic, or exercise activity that demands prosthetic use beyond simple locomotion.
- K4 (Level 4)** - Has the ability or potential for prosthetic ambulation that exceeds basic ambulation skills, exhibiting high impact, stress, or energy levels. Typical of the prosthetic demands of the child, active adult, or athlete.

Because of their greater rehabilitation potential, amputees in higher levels are generally allowed better choices of prosthetic components, while prostheses are denied as not medically necessary if the patient's potential functional level is "O." Exceptions are considered in individual cases if additional documentation is included that justifies the medical necessity.

If your claim is denied

If your Medicare claim is denied, it is important to understand why, and to find out what options you have left. Reasons for denial of claims for Durable Medical Equipment and prosthetic devices usually fall into five categories:

1. Lack of Medical Necessity

2. Noncovered Services – Medicare has excluded these items from its list of covered services.

3. Incomplete Information

4. Duplicate Submission – Claims denied for this reason should be investigated immediately

5. Not Separately Payable – These claims were denied because the service was considered to be included in another code.

In some cases, appeals can be made; in others, they cannot. Your primary source of assistance with appeals and resubmission of denied claims will be your provider's administrative staff.

If you have questions about your eligibility for Medicare or want to apply for it, you should contact the Social Security Administration (1-800/772-1213).

MEDICAID

Medicaid is a jointly funded cooperative venture between the federal and state governments to assist states in the provision of adequate medical care to eligible, needy people. Within broad national guidelines that the federal government provides, each of the states:

1. Establishes its own eligibility standards
2. Determines the type, amount, duration, and scope of services
3. Sets the rate of payment for services
4. Administers its own program

Medicaid eligibility and covered services vary considerably from state to state, as well as within each state. Unfortunately, coverage for prosthetic care is not mandated; therefore, it ranges from reasonably good to nonexistent.

To be eligible for federal funds, states must provide Medicaid coverage for most individuals who receive federally assisted income-maintenance payments, as well as for related groups not receiving cash payments. Some examples of the mandatory Medicaid eligibility groups are low-income families with children, Supplemental Security Income (SSI) recipients, and infants born to Medicaid-eligible pregnant women.

For people with too much income to meet the mandatory eligibility requirements and/or those adopted by their state, many states have a "medically needy" program. This option allows them to "spend down" to Medicaid eligibility by

incurring medical and/or remedial care expenses to offset their excess income or by paying monthly premiums to the state equal to the difference between family income and the eligibility standard.

For information about your state's version of the Medicaid program, contact its administering agency, usually the Department of Health and Human Services, or Department of Medical Assistance. Most of your healthcare costs are covered if you have Medicare and you qualify for Medicaid. States also have programs that pay some or all of Medicare's premiums and may also pay Medicare deductibles and coinsurance for certain low-income people.

Prescription drug assistance programs are also available. These programs offer discounts or free medications to individuals in need. For more information on these programs, call your nearest medical assistance office listed in the telephone book under Medicaid, Social Services, Medical Assistance, Human Services or Community Service.

VETERANS ADMINISTRATION

The Veterans Health Administration (VHA) provides a broad spectrum of rehabilitative care to its beneficiaries, including a wide array of prostheses, mobility devices such as wheelchairs, and adaptive driving equipment. In addition to coverage for veterans, the VA provides needed healthcare benefits, including prosthetics, medical equipment, and supplies, to certain children of Vietnam veterans. Veterans may also receive VA healthcare benefits, including prosthetics and medical equipment through participation in the VAs vocational rehabilitation program.

VA healthcare enrollment is a new system providing access to a comprehensive package of services. To be eligible for healthcare enrollment, you must have:

- Been discharged from active military service under honorable conditions
- Served a minimum of two years if discharged after September 7, 1980 (prior to this date there is no time limit)
- If a National Guardsman or Reservist, served the entire period for which you were called to active duty other than for training purposes only

Artificial limbs must be prescribed by a

designated physician/podiatrist of the VAs Amputee Clinic Team or the Prosthetic Representative. Devices may then be fabricated and fitted by VA hospitals or clinics, private prosthetic facilities on contract with the VA or, under certain circumstances, by noncontract prosthetists. While the VA prefers that patients use either VA facilities or private facilities under contract with the VA, veterans who have previously received artificial limbs from commercial sources may continue to receive services from their noncontract prosthetist, providing the prosthetist will accept the VA preferred provider rate for the geographic area. Veterans may also receive services from noncontract vendors when a prescribed limb or component is not available through VA or contract facilities.

For more information you can visit the VHA Web site at www.va.gov/About_VA/Orgs/VHA/index.htm or call the VA Health Benefits Service Center toll-free at 1-877/222-VETS.

CHAMPUS/TRICARE

CHAMPUS (Civilian Health and Medical Programs of the Uniformed Services), now called TRICARE Standard, has evolved into a key component of the new TRICARE health benefits program of the Department of Defense. Any of the TRICARE programs are available to dependents of active-duty service members and retirees and their families and survivors. Eligible family members include spouses, unmarried children under age 21, unmarried children who are full-time students under age 23, and stepchildren adopted by the sponsor.

For more information regarding any of the TRICARE programs, contact your TRICARE Service Center or visit the military's TRICARE Web site at www.tricare.osd.mil/ or Palmetto Government Benefits Administrators' TRICARE Web site at www.mytricare.com/

VOCATIONAL REHABILITATION

Most states have vocational rehabilitation programs to help people with limb loss obtain and keep employment. These programs vary widely from state to state as to the eligibility requirements and services provided. Some may fund prosthetic care and other assistive devices if they are deemed necessary for employment or job performance. Assistive devices, such as wheelchairs, lifts, and

adaptive driving equipment are often furnished to enable a person to get to the job site.

Visit www.pueblo.gsa.gov/crh/vocational.htm for contact information and links to your state vocational rehabilitation agency's Web site.



STATE TECHNOLOGY ASSISTANCE PROGRAMS

These programs support statewide, comprehensive, technology-related assistance for individuals of all ages with disabilities. State projects typically provide assistance in choosing and acquiring off-the-shelf, modified, or customized items and equipment used to increase, maintain, or improve functional capabilities of individuals with disabilities.

A few state programs provide direct financial assistance to individuals in need of various types of adaptive equipment, including prostheses. Some have loan programs. Others provide no funding at all to individuals. Most do have information and referral services and may be able to direct you to local sources of financial assistance.

The telephone number for your state's program may be found in the "blue pages" of your local directory. A listing of state assistive technology projects, complete with contact information and links to Web sites, may be found on the Rehabilitation Engineering and Assistive Technology Society

of North America (RESNA) Web site at www.resna.org/taproject/at/statecontacts.html

PRIVATE INSURANCE

Coverage for prosthetic care and durable medical equipment varies widely from one insurance company to another and may also differ with various policies offered by a given company. Coverage can range from all medically necessary devices for life to no coverage at all. While it is impossible to provide specific information about every health insurance company, there are some basic things to consider when selecting an insurance policy:

- Eligibility requirements
- Pre-existing condition clauses
- Devices covered (Get something in writing to assure that artificial limbs are covered.)
- Coverage limits
- Limits on number of items per year or per lifetime
- Rate of payment (Should be at least comparable to Medicare rates.)
- Preferred Provider Network (Is your current prosthetist included?)
- Must you go through a "gatekeeper" to obtain care?

Many health insurance companies have Web sites through which you may be able to obtain information about their policies. In addition, there are several Web sites that inform consumers and help them compare health insurance companies and policies. They include: www.insure.com/health/; www.insweb.com/; www.netquote.com/; and www.quotesmith.com/#medical/

Insurance problems

If you have problems getting the coverage to which you are entitled from your insurance company, the most valuable source of assistance is your state department of insurance. This office is located in the capital city of each state and the telephone number should be in the "blue pages" of your local directory. Insurance commissioners can take action against insurance companies, agents, and brokers. They are empowered to conduct investigations, acquire records of relevance to your case, issue orders, hold hearings, and suspend and revoke licenses. Contact information may also be found on insure.com's state gateway page at www.insure.com/states/index.html/

MEDICAL DISCOUNT PROGRAMS

Relatively new on the healthcare scene are medical discount programs. These companies negotiate with PPO providers for their members to receive discounts on medical goods and services ranging from prescription drugs to office visits to nursing home care. While durable medical equipment is often included in the benefits packages provided in the programs, prosthetic care is not usually specifically mentioned.

The programs' advantages to the providers are immediate payment, less paperwork, and no "red tape" in getting approval for services provided. Advantages to the patient are discounted medical fees, no deductibles, no pre-existing condition clauses, unlimited use of services, no claim forms to fill out, and relatively low "premiums" or fees.

Most of the companies stress that this is not insurance and should not replace existing insurance. However, for those who are uninsurable or cannot afford insurance coverage, this may be an alternative worth investigating. Since all of these companies are relatively new and have not established an extensive track record, it would be wise to thoroughly check out any company before making a commitment. Read all the fine print, make sure all your questions are answered to your satisfaction, and consider consulting the Better Business Bureau to see if complaints have been registered.

Examples of medical discount programs currently available are:

POWERx Medical Benefits Network

www.powerx.net/
800/421-4943

HealthCove

www.healthcove.com/
800/796-5558

Care Entrée

www.careentree.com/
800/820-6474

All of these sources can help you begin locating funding for your needs. If you need additional assistance or information, please contact the Amputee Coalition of America toll-free at 1-888/AMP-KNOW (267-5669).

DIABETES: PREVENTING LOWER- EXTREMITY AMPUTATIONS

by Frank Vinicor, MD, MPH

The facts are devastating. Diabetes is the number one cause of nontraumatic amputations among Americans, with over 86,000 lower-extremity amputations occurring each year. That is about 236 lower-extremity amputations every day!

The good news is that it is often possible to prevent these amputations. Reliable and simple risk factors can identify those among the estimated 16 million Americans with diabetes who are at special risk for foot ulcers that often lead to amputations, and, with proper care, about 50 percent of lower-extremity amputations in people with diabetes can be prevented. Even when complications are already present, we can do a lot to stop them from getting worse.

Most people think of diabetes mellitus in two major forms: type 1 or type 2. Type 1 diabetes, previously called juvenile-onset or insulin-dependent diabetes, typically occurs in people under age 30 and it happens much more frequently in the white population than in minority communities. It seems to be caused by an autoimmune or “self-destructive” process involving the beta or insulin-producing cells in the pancreas. Because these cells are destroyed by the body’s own immune system, people with type 1 diabetes have to take insulin to replace what the beta cells no longer make. Stopping insulin replacement in these people results in a rapid breakdown in fat and muscle tissues, with severe acidosis (too much acid in the body) and coma.

Type 2 diabetes, previously called adult-onset or non-insulin-dependent diabetes, typically appears after age 40 and is closely associated with weight gain and physical inactivity. Type 2 diabetes accounts for at least 90 percent of all cases in the United States and is especially common in minority communities. Proper diet and activity, along with oral medications, can often control the blood sugar in people with type 2 diabetes; however, as the disease progresses, these people might also need insulin treatment.

While the basic causes of these two common types of diabetes are different, they both result in abnormal body metabolism (especially high blood sugars), abnormal fat metabolism and



often high blood pressure. If the abnormal metabolism cannot be brought under reasonable control with diet and medicine, people with both types of diabetes can develop complications, including eye, kidney, nerve, feet, and heart problems.

Scientific studies, however, indicate that if people with diabetes tightly control their blood glucose, blood pressure, and blood fat levels, their chances of developing these problems can be significantly decreased. We have also learned that detecting changes in foot shape, sensation, and blood flow, with three relatively simple and inexpensive office tests, allows us to predict those who are at greater risk to develop ulcers and amputations.

FACTS ABOUT LOWER- EXTREMITY AMPUTATIONS

- More than half occur in people with diagnosed diabetes, who represent only 3 percent of the United States population.
- They are a significant complication for people with diabetes, and blacks and the elderly are disproportionately affected.
- Almost 60 percent occur among people age 65 or older.
- Between 1983 and 1996, the rates increased 24 percent.

Living with diabetes is a daily challenge. Many things people take for granted, such as eating any time and exercising freely, become real problems for people with diabetes, who must carefully balance food, physical activity, and medication to prevent complications.

Diabetes also poses problems for us as a



nation. First, the prevalence of diabetes has increased dramatically over the past decade in the United States and throughout the world. By the year 2025, the five countries with the highest incidence of diabetes will be India, China, the United States, Pakistan, and Indonesia. In the United States, there has been a 33 percent increase in the frequency of diabetes over the last eight years; at the same time, there has been an increase in weight gain and physical inactivity. This increase in the number of people with diabetes represents new cases, not just better detection of those with diabetes.

Secondly, the onset of diabetes, especially type 2 diabetes, seems to be occurring at younger ages. In the past, people were typically in the 50s when they were diagnosed with type 2 diabetes. Now we are seeing a greater increase in diabetes among people ages 30 to 39, which means that they will have the condition for a longer time.

Finally, we are concerned that with more cases of diabetes of longer duration, we will see more of the potentially devastating complications, including nerve and foot disease – and, ultimately, more lower-extremity amputations.

Facing these scientific data and concerns, we must ask ourselves what the public health community is doing about these problems. Government agencies and the private sector have different responsibilities to address the challenges of diabetes by finding a cure or preventing the disease.

Recently, there has been a lot of media coverage around the possibility of a “cure” for type 1 diabetes. In an important study from Canada, several patients with longstanding type 1 diabetes received injections of isolated beta cells (insulin-producing cells obtained from

recently deceased individuals). These patients also received special experimental medicines to prevent rejection of these “foreign cells,” and after about a year, they were able to control their blood sugars without insulin injections. A much larger study is now in progress where people with type 1 diabetes are receiving the so-called “Edmonton protocol.” The results of this study should give us important information about how effective this approach is.

There are, unfortunately, no promising long-term scientific studies supporting a “cure” for type 2 diabetes, which has a different disease process from type 1.

Research on primary prevention falls within the purview of the National Institutes of Health (NIH). Important and exciting clinical trials are under way to determine how both types of diabetes can be prevented, and results are expected in a couple of years.

Once reliable scientific studies are published and discussed, it becomes primarily the responsibility of the CDC to “translate” the findings into communities through programs that will improve the daily management of diabetes. The CDC supports 59 Diabetes Control Programs (DCPs) in all states and territories. These DCPs, in cooperation with many partners – such as the American Diabetes Association (ADA) and the American Association of Diabetes Educators (AADE) – work through community education projects to help people keep abnormal metabolism in check. With this strong base of

scientific information, other government and private sector programs can also improve their delivery of care for people with diabetes and foster improved insurance coverage for these prevention programs.

Sometimes, however, despite valiant efforts by everyone, diabetes complications still develop. Once they do, CDC programs strive to identify



them early and treat them aggressively to prevent progression.

We are all working for and anticipating the great day that we will find a cure for diabetes or successful ways to prevent it. But today, we can do a better job in helping people with diabetes keep their limbs and lead satisfying, productive, and happy lives. To accomplish this, we must work together toward this goal every day. What can you do to help? If you have diabetes, get regular treatment and follow your health professional's advice to prevent severe complications. Reach out to family and friends and encourage them to be physically active and pay attention to their nutritional needs to prevent obesity and maybe diabetes.

For more information about diabetes, call the CDC's Diabetes Inquiry Line toll-free at 1-877-CDC-DIAB or 232-3422 (English and Spanish) or visit the Web site at www.cdc.gov/diabetes

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