



NEWSLETTER ♦ 20th Edition ♦ Apr. 2015 ♦ Limb Loss Awareness Month

MOVING FORWARD FEATURE HOW DO I SHOW MY METTLE ????

– by Belinda Jacobi

Let me start by giving you a few limb loss statistics. There are over 2 million people living with limb loss in the United States. Among those living with limb loss, the main causes are vascular disease 54% (including diabetes and peripheral artery disease), trauma 45%, and cancer 1%. Every day more than 500 Americans lose a limb. Two hundred and fifty people lose a limb each day due to complications of diabetes. The Amputee Coalition, the largest national organization dedicated to helping those with limb loss, has designated the month of April as Limb Loss Awareness Month. As a member organization of the Amputee Coalition, we will be doing our part to raise awareness in our community. We will do this by submitting news releases to area newspapers, distributing our group brochures and information to hospitals, rehab facilities, and prosthetic offices, and continuing to reach out to amputees in our community through peer visits.

The Amputee Coalition has designated April 25th as "Show Your Mettle Day". One's mettle is his/her strength of character. The concept is simple – to show your mettle, the ability to cope well with difficulties, or to face a demanding situation in a spirited and resilient way, by showing your metal device or wheelchair. The goal is to raise awareness of limb loss in our community and to empower those affected by limb loss to achieve their full potential. Now I will go back to the original question, "How do I show my mettle?" I know that personally, I have had to show mine many times in the last 5 1/2 years of living as an amputee. I have also been a witness countless times to fellow members showing theirs as well. It may be something as simple as releasing that death grip from the parallel bars and having the courage to take those first steps on your prosthesis. It may be facing yet another surgery when you are afraid and not sure that your body can take much more. It may be going back to work for the first time since you lost your limb. It may be going out on a date with someone not knowing how they will react when they find out that you are an amputee. It may be moving into an apartment on your own, while not being totally sure that you will be able to handle it. It may be going home following your rehab to take care of a spouse or loved one, when you are not sure that you will even be able to take care of yourself. It may be going swimming for the first time since you lost a limb, not knowing if you will sink or swim, not to mention that first time being seen in a bathing suit. It may be coming to your first support group meeting when you aren't really comfortable talking to a bunch of strangers. It may be speaking up to someone that you feel is treating you

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AMPUTEE COALITION ADVICE

This article was taken from the Amputee Coalition's website.

MANAGEMENT OF RESIDUAL LIMB PAIN

What is residual limb pain (RLP)? This is the pain that originates in the remaining part of your limb. It can be caused by a variety of conditions related to your surgery or it can be caused by conditions you had prior to your amputation. You and your healthcare team will want to work together carefully to understand the origin and cause of your pain in order to treat it successfully. Possible causes of residual limb pain include:

- Underlying disease process such as skin problems and infection and nerve pain (neuropathy), especially if you have diabetes or circulatory problems
- Surgical trauma, including decreased blood supply to your limb or poor tissue coverage at the end of the bone
- Neuroma formation
- Entrapment of nerves in scar tissue.

Underlying Disease Processes

Key to managing symptoms of pain that have to do with a pre-existing condition like diabetes is to make sure that the condition is managed as well as possible.

For example, if you have diabetes, keep your blood sugar under good control. If you have poor circulation, follow your physician's instructions for diet, exercise, and medications. Managing pre-existing conditions after surgery is as important as ever.

Surgical Trauma

Poor tissue coverage can be caused by the bone at the end of your residual limb not being properly trimmed at the time of surgery, and this can cause pain when you wear your prosthesis. If padding and other methods are not successful, surgery may be required to revise your residual limb so as to decrease your pain and allow you to wear your prosthesis.

Neuromas

A neuroma is a collection, or bundle, of nerve endings that forms under the skin of your residual limb. Think of it like a tangle of hair. It can become very sensitive, especially if the tangle is pressing against your prosthesis.

Because neuromas are made up of nerve endings, possible treatments include medications that help with nerve pain, such as:

- Non-steroidal anti-inflammatory medications
- Specific antidepressants and anticonvulsants that have been found to be effective for nerve pain
- Steroid injections.

Non-medication options include:

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HOW DO I SHOW MY METTLE???? (cont'd)

differently because you have a disability. It may be eating in public using your prosthetic arms, not knowing if the food is going to land in your mouth or in your lap. Many of these things may seem simple to a person with all four limbs, but I assure you, to an amputee they are not. As amputees we must show our mettle many times and in many ways if we choose to *move forward* following limb loss. I encourage you to join us on April 25th for our meeting and dinner. As a group we will show our mettle and celebrate both our own personal accomplishments and those of the group as we keep on *moving forward*.

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## SPOTLIGHT *- by Belinda*

While trying to decide which group member to ask to be in our spotlight column this month, it occurred to me that with "Show Your Mettle Day" being April 25<sup>th</sup>, this would be the perfect month to ask William "Bill" Titus. For those of you who have met Bill, I am sure you will agree that he should be included in the dictionary under the definition of "mettle". Bill himself may not agree, because he is a very modest man and is uncomfortable when someone says that he is an inspiration to them or in any way suggests that he is doing something special. He always shrugs his shoulders and says, "I am just doing what I have to do to survive and to get on with my life." It is the way that he is getting on with his life that shows his mettle. I know you will truly enjoy and be uplifted by getting to know my good friend Bill a little better .....

Bill has lived in the Newburg area of Louisville almost his entire life. He has 2 children, a son and a daughter. I have been fortunate enough to meet his lovely daughter and witness the strong bond that they share. Bill also has 4 grandchildren with whom he enjoys spending time. He is a carpenter by trade and has always taken pride in doing excellent, quality work. He worked with the construction company that built the Tumbleweed restaurants. One of the first things that he said to group member Mike Portman was, "I wonder what type of job I will be able to get." He has a desire to get back to his career field in some way, and with his talent and desire, I am sure he will find a way to accomplish that.



Bill became an amputee in December of 2013 due to complications during a surgery for an aneurysm. Both legs were amputated above-the-knee at that time. He woke up from a coma, and his life as he knew it had forever been changed. In January, both of his arms were amputated below the elbow.

It doesn't take much time when you meet Bill to find out that he is a man of faith in the Lord. He is a member of the Canaan Christian Church on Hikes Lane, and attends services there weekly. He also teaches Sunday School and Bible Study at the church, and leads a Bible Study class at the rehab facility where he has resided since leaving the hospital following his surgeries. He spends his days going up and down the halls visiting with and encouraging the other residents there. He is often called upon by staff members when a new amputee comes to the facility. He has become quite the advocate for the other patients. He says that his stay there has taught him to be a more compassionate person. He also says that it has taught him to never say, "I know what you are going through." He went on to say that when you look at someone like him it is very apparent the struggles he must go through each day, but sometimes it isn't so apparent, and you can't visually see the problem, but that person may have deep emotional wounds. He stresses that is why you should treat each person you meet with compassion.

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## MANAGEMENT OF RESIDUAL LIMB PAIN (cont'd)

- Ultrasound, which is essentially a machine that uses sound waves to generate heat within a body part; it can help increase blood flow so that inflammation and swelling can be decreased
- Massage, which also helps decrease inflammation and helps desensitize your residual limb to touch
- Vibration, which creates a mild shaking to contract muscles, to decrease inflammation and pain
- Percussion/finger tapping at the point of pain, which also helps desensitize your residual limb
- Acupuncture, manipulating thin, solid needles that have been inserted into specific acupuncture points in the skin
- TENS (transcutaneous electrical nerve stimulation), which produces a mild "pins and needles" sensation, overriding some of the pain that your body is producing

Modifying the prosthesis socket to prevent rubbing at the sensitive part of your limb may also be helpful.

Unfortunately, surgery to remove neuromas is not usually successful, because they often simply reform.

### Heterotopic Bone

Occasionally, excess bone forms abnormally around the end of the amputated limb; this is sometimes called a "bone spur." The "extra" bone may cause pressure points that interfere with the fit of your prosthesis; this occurs more frequently in children than adults. If the problem cannot be solved with changes to the prosthesis, surgery can remove the excess bone. For children, this is best done after the bone stops growing.

### Entrapment of Nerves in Scar Tissue

As your incision begins to heal, your doctor will let you know when you can start massaging your residual limb. This will help to prevent nerves from being "caught" in scar tissue. You will also be taught how to wrap your limb using elastic wraps. This not only helps to prevent scarring but also helps with prosthesis fit.

### Normal Postoperative Pain

After surgery, your postoperative pain will diminish over the first few weeks. After you are discharged from the hospital, you may still be taking pain pills, but should be able to decrease the number of pills fairly quickly.

Methods to decrease swelling will also help reduce your pain, including elastic wraps and residual limb socks, light massage and finger tapping, and cold packs. Residual limb pain is different from this normal postop pain. For example, it commonly occurs after your postoperative pain has ended. It is frequently described as sharp, aching, throbbing, or burning in nature. Your entire healthcare team, including your doctors, therapists, and prosthetist, will work with you to determine the cause of this pain and decide what treatments might be most effective.

### Pain Management Principles

No matter the cause of residual limb pain, the following methods can help you manage your pain:

- Begin exercises as soon as your surgeon allows it. Standing, walking, and muscle stretching not only improve your general health, but also interrupt pain signals.
- Desensitize your residual limb, following the instructions of your physical or occupational therapist; this includes both massaging and wrapping your residual limb.
- Work with your prosthetist to maintain proper prosthetic alignment and to choose prosthetic components that are appropriate to your needs.
- Keep a pain journal. Keeping track of your symptoms and sharing them with your healthcare team will help you find

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## SPOTLIGHT (cont'd)

When asked what advice he would give to new amputees, he said, "To not give up and to learn to rely upon yourself. Other people are there to help you, but you are the one that has to see it through." I went on to ask him how he has found the strength and determination to see it through. His answer was, "My trust in God." He said that the Lord promises that He will never bring you to a place that He can't keep you. He also told me of a sermon he once heard from Bob Rogers, a minister at Evangel Christian Life Church. The minister said that when an egg is cracked and the shells are all broken to pieces, you can't put it back together again. What you can do, though, is to combine it with other ingredients and turn it into something wonderful. Bill said that although there may not be much left of his physical body, he has become a better person both spiritually and emotionally since losing his limbs. He also stated that he has learned to thank God in the middle of the storm, not just at the end. He said that his legacy to his children won't be money or a big house, but that they will know that he was a Godly man.

Bill will soon be facing a new challenge. He will be moving to an apartment and will be living on his own for the first time since becoming an amputee. He also will be starting the process of receiving his first prosthetic legs and learning to walk using them. He has been walking on "stubbies" and was also getting quite proficient in the use of his prosthetic arms until the sockets no longer fit him due to an increase in muscle size in his arms. He will be getting new sockets and his new legs in the next few months.

We ended our talk by my asking him about our support group. He said that he appreciates the camaraderie, the love and caring that the group expresses toward each other, and the compassion that they show to other amputees.

I was given a compliment recently about *MOVING FORWARD*. A lady told me that she thought it was wonderful the way the members of the group had taken a tragedy in their lives and turned it into something beautiful. I think we would all agree that is exactly what Bill is doing. I know he will shrug his shoulders when he reads this part, but I have to say it, "You are an inspiration to me as well as to many others, and I am honored to be able to call you my friend."

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J'm Moving Forward . . .

Each month we are including a picture of one of our members *moving forward* after limb loss.



Bill Titus *moving forward* by attending his first group event, the 2014 Christmas Party.

** If you would like to submit a picture of you *moving forward*, send it to Belinda or Julie. **

MANAGEMENT OF RESIDUAL LIMB PAIN (cont'd)

the right treatments for you.

- Practice relaxation. We know that tension and stress increase pain. It is estimated that 50 percent of pain can be reduced by relaxation.

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## **Dealing With Painful Peripheral Neuropathy**

— by Neil M. Scheffler, DPM, FACFAS

**Peripheral neuropathy is a disorder characterized by damage to the nerves that transmit sensation to the central nervous system, which consists of the spinal cord and the brain. The peripheral nerves that are affected first are generally in the hands and feet. Unfortunately, the problem can be progressive and can lead to foot ulcers, amputation and death.**

Peripheral neuropathy can have many causes. The Physicians' Desk Reference (PDR) lists more than 60 drugs that can cause neuropathy. Alcoholics can also get neuropathy from the toxic effect of alcohol on their nerves. The most common cause of peripheral neuropathy, however, is diabetes. When diabetes is determined to be the cause, the problem is called diabetic peripheral neuropathy (DPN), which is the focus of this article.

Although DPN affects 50 to 60 percent of those who have diabetes, it is also one of the least understood of the many complications of the disease. While there has been much speculation about the cause of this damage to the nerves, most experts agree that persistent increases in blood sugar levels are to blame. The longer a person's blood sugar is elevated, the more likely he or she is to develop DPN.

### **The Components of DPN**

DPN has three components: motor, autonomic, and sensory.

Motor neuropathy affects the muscles, causing weakness and wasting. An imbalance of the muscles in the feet can, in turn, lead to contractures and hammertoe deformities. Unfortunately, foot deformities, such as hammertoes and bunions, are a major risk factor for additional complications in people with diabetes. These deformities, therefore, require special care, and a consultation with a podiatrist is vital. Autonomic neuropathy of the feet causes a decrease in sweating, with dryness and cracking of the skin. These cracks can be portals for bacteria, which can cause infections and must be treated promptly and aggressively. People with autonomic DPN must lubricate their feet on a regular basis, often twice daily. If over-the-counter preparations do not work, a foot specialist (all people with diabetes should have a podiatrist) may suggest an alternative product or write a prescription.

Sensory neuropathy causes the person not to feel pain at all or to feel too much pain in the affected area. If sensation decreases due to peripheral neuropathy, minor trauma to the skin may go unnoticed and, therefore, may not be treated. As a result, the skin could ulcerate and become infected. This is a common precursor to amputation.

Sometimes, especially in the early stages of DPN, instead of a decrease in sensation, pain is present. The pain may present as intense burning, a dull aching feeling, or as sharp, stabbing, sudden jolts. Pain is a serious symptom and can affect every aspect of a person's life. Many people report that the pain is worse at night and can affect their ability to sleep.

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## RECAP OF MARCH

The group kicked off the month with our **MARCH MADNESS CHILI SUPPER**. We had our largest crowd yet with a total of 64 people in attendance. Two newcomers to the group won this year's chili cook-off. The Judge's Choice award went to Anita Steineck, who made a delicious Mexican-style chili, and the People's Choice was awarded to Mary Jo Kolb. Both ladies received a *MOVING FORWARD* Chili Cook-off Apron. The aprons were designed by our own Mike Portman. The Best-Dressed Fan was a tough decision this year with so many children and adults wearing their finest



team gear. The winners were chosen by who received the most applause from the crowd. The children were all given a prize, because they were so adorable it was just too hard to choose. For the adult's, the finalists were Kelly, Beverly, and Philip. With a huge round of applause, Philip ended up winning the award. The basketball trivia contest was



won by the team of Shelton, Carter, and Deklan Jacobi. They correctly named 26 of the 30 team's coaches in the trivia game. Councilwoman Madonna Flood came in a close 2nd with 25 correct. A chili-pot raffle was held with the proceeds to be donated to the Amputee

Coalition Paddy Rossbach Youth Camp. The chili pot was full of useful items and was beautifully put together and decorated by Stacey White of **Wrap It Up**. The donation will be made during the month of April, and the amount raised will be announced at that time. The winner of the raffle was Sylvia Worrall. The evening ended with the children playing games while the adults had time to visit with each other. It was a wonderful evening that everyone enjoyed.



Our Indiana meeting was very memorable with special guest speaker, Sharon Wright, telling the group of some of her experiences growing up with a disability. Sharon was stricken with polio at the age of two but went on to become a teacher, wife, mother, and grandmother. She still tutors both children and adults, and she especially enjoys teaching them to read. We welcomed 3 new members to the group, Debbie Troutman, and Elizabeth and Thomas Montgomery.

At the Louisville group meeting, we also welcomed 3 new members, Albert & Teresa Howard, and Gary Crawford. We were delighted to have Sharon Morehead in attendance and to see how well she is doing following her surgery. There were a lot of questions regarding the various types of suspension systems for prostheses, so we ended up having a show-and-tell of what type we have and what we like and don't like about it. As always, there were many brochures, magazines, and other information available for our members to take home with them.

During the business portion of the meeting, we discussed upcoming events, our Care Package project, and fundraising ideas. Members were reminded to sign up for the Kroger Community Rewards Program, if they haven't already done

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## Dealing With Painful Peripheral Neuropathy (cont'd)

### Diagnosis and Treatment

A doctor may confirm the diagnosis of DPN with a number of neurological tests. He or she might test the patient's ability to feel light touch with a monofilament fiber (similar to a piece of fishing line), check for temperature sensation, evaluate the patient's ability to feel vibrations with a tuning fork or electronic vibration machine, or perform nerve conduction studies that time the transmission of an electrical stimulus across a nerve. If you have diabetes and these symptoms trouble you, your doctor will have many options for treatment. First, most physicians agree that the first step toward preventing or treating DPN is optimal control of blood glucose. Let your doctor know that you would like to very tightly control your diabetes and ask for his or her advice. Treatment can include diet, exercise, and medication. Testing your blood glucose levels multiple times a day can tell you if you are on track. For tight control, you may also need to consult an endocrinologist, a doctor who specializes in the treatment of diabetes. Burning pain or tingling in the skin of the feet is caused by damage to the nerves in, or directly below, the skin. If the problem is mild, I usually suggest very conservative treatment with a topical product, such as BenGay or Biofreeze. If the pain continues, my next step is to try a cream containing capsaicin. Since capsaicin is made from hot peppers, the initial applications can cause an increase in burning. To achieve success, however, the patient must continue the applications despite the discomfort. It is applied three to four times daily and generally takes two to four weeks before we know how well it has worked. I have seen remarkable results with this topical preparation.

Another topical medication contains the local anesthetic lidocaine, which is available in patch form (Lidoderm). Worn for 12 hours a day, these patches reduce pain in some patients. If the pain continues, I then progress to oral medications, such as gabapentin (Neurontin) or carbamazepine (Tegretol), both of which were originally used for seizures, or pregabalin (Lyrica), a fairly new medication indicated for the treatment of DPN pain or the pain caused by shingles. With pregabalin, results are usually seen within the first week of treatment. If your kidneys are not working well, which is a common problem in people with diabetes, the dosage of this drug needs to be reduced. Another recent medication that shows promise for DPN is duloxetine (Cymbalta).

Shooting, stabbing, or pins-and-needles pain is usually treated with oral medications as a first line of therapy. In addition to the drugs above, antidepressants, such as amitriptyline (Elavil), have proven to be very useful. Care must be taken with these drugs, however, since the side-effects (headaches, dry mouth and dizziness when standing) can be troublesome, especially in seniors.

Nonsteroidal anti-inflammatory drugs (NSAIDs) do not seem to work very well and, with long-term use, could cause gastrointestinal (GI) problems, including GI bleeding. Narcotic pain relievers, such as oxycodone (OxyContin), work well but also have side-effects, such as nausea and constipation. Tramadol (Ultram) has also proven to be effective in relieving DPN pain. Some practitioners have also used dietary supplements, such as alpha lipoic acid and evening primrose oil, to try to improve nerve function. Vitamins B6, B12 and folate may also help. Electrical stimulation devices, infrared light therapy and acupuncture treatments have been studied and reported to be effective in some cases. Magnetic insoles, however, apparently only have a placebo effect.

### More Than Just Physical Pain

The psychological impact of chronic pain should not be

- Continued on Page 5 Column 2 -

## RECAP OF MARCH (cont'd)

so. This is a great way to show your support for our group, and it does not affect your personal Kroger points. Kroger sends us a check quarterly, based on a percentage of what our members who have signed up for the program spend in their stores. If you want more information on this, you can find it at Kroger's website or ask at the service desk of your local Kroger store.



## UPCOMING EVENTS

Pardon the pun, but **HOLD ON TO YOUR HORSES!** This month is going to make you feel like **YOU'RE OFF TO THE RACES!** (OK, I promise I will stop with that one). It is getting closer to the Kentucky Derby, though, and we do have a lot of really fun things going on this month.

### MEETINGS

**April 20th (Mon.) from 6:30 - 8:00 p.m.** at Southern IN Rehab Hospital, 3104 Blackiston Blvd., New Albany IN. We meet in the Conference Room. You can ask for directions at the front desk. This will be an open discussion meeting.

**April 25th (Sat.) from 2:00 - 3:30 p.m.** at Baptist East, Room 2B, in the 2nd Floor Education Center. We will be celebrating "SHOW YOUR METTLE DAY" at this very special meeting. For the first time, our group will be using **Skype** during the meeting. We will have a guest speaker, Jeff Huber, who will be addressing us from San Francisco, California. Jeff was born with a congenital birth defect and has been an amputee all his life. He attended NC State University and studied Economics and Industrial Engineering. He went on to start his own company, Standard Cyborg, which creates prosthetic devices. He will be talking to the group about his life, his company, and a new low-cost waterproof leg that he has developed that can be worn in the shower or at the beach. He will also be available to answer any questions we may have for him. Following the meeting, we invite you to join us at O'Charleys Restaurant on Breckenridge Lane for dinner. Our reservation is for 4:00 p.m., so we will be going straight over following the meeting. Everyone will be responsible for paying for their own meal, and O'Charleys has agreed to give 10% of the total receipt back to **MOVING FORWARD** as a donation to the group. In order to do this, they ask that we do pay in cash only, so no credit or debit cards please. This promises to be a very special day with an informative and motivational meeting followed by sharing a meal, good company, and laughter with friends. We encourage you to join us.



\*\*\* **If you plan on attending the O'Charleys dinner, you must contact Belinda by phone or email by April 24th. We have to let the restaurant know our total attendance so that they will have the room set up for us. \*\*\***

**EVENTS**  
**April 30th (Thu.)** Louisville Prosthetics will be hosting their 3rd Annual Pegasus Parade Picnic at their office on 742 E. Broadway. They have once again invited our group to attend this fun event. Plan on arriving between 3:30 - 4:30 p.m. (Broadway closes down around 4:30). There is plenty of free parking in their lot. The picnic will begin at 4:30. Drinks and sandwiches will be provided. If you would like to bring a covered dish, it would be appreciated. Also, don't forget to bring along a chair for viewing the parade. The parade starts at 5:00. We hope to see you there!!

**Lots of other fun activities are being planned, so stay tuned :)**

## Dealing With Painful Peripheral Neuropathy (cont'd)

ignored. Having diabetes alone can be very difficult to deal with, even without neuropathy. Repeatedly sticking your fingers, keeping up with exercise programs and special diets, and maintaining medication schedules all at the same time can certainly affect your quality of life. Add to this the aspect of chronic pain, and such a situation can clearly be psychologically draining. A consultation with a mental health professional may, therefore, be a good idea for many people facing these issues.

What works for one person may not work for another, and sometimes a combination of therapies is necessary for the relief of symptoms. If your current doctor says there is nothing more he or she can do, consult another doctor, perhaps in a different specialty. Doctors who treat DPN may be in general practice, internal medicine, rehabilitative medicine (physiatry), neurology, neurosurgery, plastic surgery, pain management, anesthesiology, endocrinology, psychiatry or podiatry. Those of us who treat DPN know that every patient is different. Even if you have tried many types of treatments that have been unsuccessful in relieving your symptoms, don't give up; the next medication you try may be the one that works best for you.

### About the Author

Neil M. Scheffler, DPM, FACFAS, is a podiatrist in private practice in Baltimore, Maryland. He is a fellow of the American College of Foot and Ankle Surgeons and is board certified in foot and ankle surgery. He is also the attending podiatrist for the Prosthetics Clinic, Sinai Hospital of Baltimore. Dr. Scheffler is a past president, Health Care & Education, Mid-Atlantic Region, American Diabetes Association (ADA), and is the author of *101 Tips on Foot Care for People with Diabetes, 2nd Edition*, published by the ADA.



## TEST YOUR KNOWLEDGE



Unscramble these words and then use the letters in the parentheses to finish the sentence. You can find the answer at the bottom of PAGE 8.

GOUCREA \_\_\_\_\_ ( )  
 SEIENRICEL \_\_\_\_\_ ( ) \_\_\_\_\_ ( )  
 SGHTNERT \_\_\_\_\_ ( ) \_\_\_\_\_  
 YATTINCE \_\_\_\_\_ ( ) \_\_\_\_\_  
 XIOME \_\_\_\_\_ ( ) \_\_\_\_\_

BY DISPLAYING THESE TRAITS AN AMPUTEE CAN SHOW HIS / HER \_\_\_\_\_.



## QUOTE OF THE MONTH

### Just For Today

- I will be thankful.
- I will focus on one thing at a time.
- I will take time for myself.
- I will accept who I am right now.
- I will not give up.
- I will be nice to myself.
- I will accept my feelings.
- I will celebrate each step forward.
- I will not give up!

## LET'S GET MOVING! – by Belinda

I have often wondered why there is not more emphasis placed on strengthening the upper body for those amputees who have lost a leg or legs either BK or AK. I know much of the reason is because of our insurance industry. Most plans will just pay for a very limited number of physical therapy sessions so, of course, the therapist is going to concentrate on the lower body. Think how much more you use your arms since your amputation. The transfers alone require much upper body strength. If you use a walker or crutches or a non-motorized wheelchair, once again you depend on your upper body strength. Most of us, as amputees, have found ourselves at various times requiring the use of a wheelchair. It may be immediately following our amputation surgery or after revision surgery or for diabetics, it may be due to a non-healing wound on the sound limb. Whatever the reason, we tend to think of this as down time, but instead, we could use this as a time to work on our upper body strength. We are including an article from the Amputee Coalition *inMotion* magazine on upper body exercises that can be done while sitting in a wheelchair. Whether in a wheelchair or not, these exercises are a good way to start developing more upper body strength. Of course as always, we caution you to check with your doctor to make sure that you are physically ready to start an exercise program.

**So come on everyone, Let's Get Moving!!!**

### Wheelchair Exercises

– by Cindy Asch-Martin

When we think of exercise, there are some who may think that only fit or able-bodied people are capable of doing it. But exercise is meant to be a part of everyone's lives, regardless of your physical or emotional condition. Exercise provides many positive aspects to our everyday life, such as releasing endorphins for a happier you, to helping alleviate the pain of arthritis, to strengthening our bodies, to name just a few benefits. Just because some of us may be restricted in what we can do and how we can do it doesn't mean exercise is out of the question. For example, there are sports designed specifically for wheelchair users, as well as daily exercises that one can do in a wheelchair. There are various reasons why some amputees may choose to use a wheelchair – for example, it may be too painful to wear a prosthesis; a prosthesis may be in need of repair; or one may be unable to afford a prosthesis. If you belong to a gym you have many forms of exercises to choose from. Depending on your abilities, you may be able to transfer yourself from your wheelchair to a piece of equipment; this will also provide extra strengthening in simply maneuvering over to the bench. All upper-body exercises (trapezius, shoulders, chest, back, triceps, and biceps) can be done with dumbbells, kettle bells, or machines. If you don't have access to a gym, then home exercises are available to help you stay strong and healthy. For those who can transfer to a bed, chair, or the floor, the possibilities are greater for more variety than if you must exercise only in your wheelchair, but you, too, can benefit with a good number of exercises to keep you strong. The category you fit into will also determine how many different exercises you can do.

If you are a bilateral amputee without prostheses, then you should be able to strengthen your upper body. If you are an AK, BK or knee disarticulation amputee, then you have the ability to exercise at least one leg as well as your upper body. Working your own body weight is one of the more productive ways to exercise. It is actually harder to use your own body than it is to pull or push a piece of equipment. Let's try a home workout in a wheelchair as our example for exercises. You can do these even if you're not in the mood to go to the gym! If you don't have access to a gym, then home exercises are available to help you stay strong and healthy.

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## Q & A

– by Belinda

For the month of April, I am continuing with the discussion and answers to the questions from the March Q&A regarding prosthetic feet. Last month, we discussed the different types of prosthetic feet and this month we will be discussing K- levels. I am including an article from the Amputee Coalition *inMotion* Magazine which explains K-levels and the important role that your K-level plays in determining what type of prosthetic foot your insurance company will pay for. I will conclude the discussion of prosthetic feet in the May issue by talking about some of the different models of prosthetic feet on the market today. Some members of the group will share with us what type of foot they are currently using and tell their likes and dislikes about it. This will not be an endorsement of any specific product, but we will be sharing our experiences to provide more information to help you in your search for the best prosthetic foot for **you**.

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### Do You Know Your K-Level?

*An interview with Interim President & CEO Sue Stout about the importance of amputees knowing their K-levels*

*inMotion | What is a "K-level" and why is it important?*

**Sue** | K-levels are a rating system used by Medicare to indicate a person's rehabilitation potential. The system is a rating from 0 through 4 and it indicates a person's potential to use a prosthetic device if they had a device that worked well for them and they completed rehabilitation to use the device properly. Your K-level designation is important because it is the driving factor in the decision on what prosthetic device to provide to you and the payment for that prosthetic device. Simply stated, payment by Medicare (and many insurers as well) is guided by the person's K-level designation.

*inMotion | Why does it matter to Medicare what my rehabilitation potential is?*

**Sue** | Medicare wants to ensure that when they pay for someone's prosthesis, that person will likely be able to use the device. They do not want to pay for an expensive device only to have it sit in the closet unused because it is unrealistic for the person to be up and about. On the other hand, they also want to be sure that if the person has the potential for walking about in the community and getting back into sports, etc., that they receive a device that will allow that to happen. The prosthetic device should match the person's need and potential.

*inMotion | Tell us a little more about K-levels.*

**Sue** | The current approach for classifying amputee activity levels is determined using the Medicare Functional Classification Level (MFCL), also known as K-levels. K-levels are used by the Centers for Medicare & Medicaid Services (CMS) to ensure uniformity in determining which prosthetic devices are medically necessary for each patient. For example, if your physician feels you have the potential to be able to walk around the house, but you will not have the strength or ability to walk on uneven surfaces or to climb curbs and stairs, you would be rated as a household ambulator (walker), ability level K1.

*inMotion | How many K-levels are there, and what are the definitions?*

**Sue** | K-levels run 0-4 and Medicare defines them as follows:

**LEVEL ZERO** – The patient 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. This level does not warrant a prescription for a prosthesis.

**LEVEL ONE** – The patient has the ability or potential to use a prosthesis for transfers or ambulation on level surfaces at fixed cadence. This is typical of a household ambulator or a person who only walks about in their own home.

**LEVEL TWO** – The patient has the ability or potential for ambulation

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## LET'S GET MOVING! (cont'd)

**SHRUGS** – Let's start with shrugs for our trapezius muscles. You can use hand weights if you have them; if not, you can find something around the house to hold in your hands. Without bending your elbows, simply lift your shoulders to touch your ears. Stop at the top and hold at the bottom without using any momentum.

**CHEST AND BACK** – For this exercise, hold a dumbbell or object of similar size and weight in your hands. Hold it at eye level with each hand on either side of the object. Push it away from you and stop, then bring it back to you and stop. This works your chest and your back, and if you sit up without pressing your back against your wheelchair, it also works your abdominal muscles.

**TRICEPS** – Next, let's try our hand at a triceps extension by holding one object up in the air. Place your other hand against your upper arm to help steady your arm. Now bend your elbow, stop, and then push the weight back up and stop.

**BICEPS** – This final exercise consists of biceps curls with weights in one or both hands – the choice is yours. With your palms up and wrists tucked in, curl the weight(s) up three-fourths of the way and stop, then lower back down very slowly and stop.

All exercises should consist of 10-12 repetitions with two to three sets – more than three sets are unnecessary. Safety is always the first priority – be sure to breathe in and out and avoid holding your breath while exercising. Keep your tummy tight to help protect your back; it also works your abdominal muscles! There are many more exercises that can be done in a wheelchair – be sure to check back for more suggestions.

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Krafty Kids by Beverly

This is a fun, easy activity to do with your kiddos this spring:

Spring Twist on a Classic Treat: Rice Krispies Bird's Nests with Chocolate Robin Eggs!

What You Will Need:

6 Cups Kellogg's Rice Krispies Cereal (Snap, Crackle, and Pop baby!)

1 Bag (10 oz.) Marshmallows

3 Tablespoons butter or margarine

Cupcake Tins

1 Bag Cadbury Mini Chocolate

Robin Eggs (or whatever eggs you would like to use)

Cooking spray

How to Make Them:

First, you need to make your Rice Krispies treats. This is super easy and anyone can do it! You can use the stove top or the microwave but I chose the microwave because it is quick and easy. Pour your marshmallows into a microwave safe bowl with your 3 tablespoons of butter. Pop it in the microwave for 1 minute and 20 seconds! Stir well when you take it out and it should have a liquid consistency. If not, continue to microwave until it is soupy (but not overdone).

Next, stir in your 6 cups of Rice Krispies cereal. You want to make sure the cereal is completely coated so that the "nests" will stick together well.

Before they cool too much, pack them firmly into well-greased cupcake tins. The fuller you can get the tins the better your nests will be so don't be afraid to push them down in there.

Now, walk away and play with your kids for a while because these need to cool in order to stick together well. If you try

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Q & A (cont'd)

with the ability to traverse low-level environmental barriers such as curbs, stairs or uneven surfaces. This is typical of the limited community ambulator.

LEVEL THREE – The patient has the ability or potential for ambulation with variable cadence. A person at level 3 is typically a community ambulator who also has the ability to traverse most environmental barriers and may have vocational, therapeutic or exercise activity that demands prosthetic use beyond simple locomotion.

LEVEL FOUR – The patient has the ability or potential for prosthetic ambulation that exceeds basic ambulation skills, exhibiting high impact, stress, or energy levels. This is typical of the prosthetic demands of the child, active adult or athlete.

inMotion | How are different prosthetic devices selected for each amputee patient, and how is insurance coverage determined?

Sue | Let's take Medicare as our example because many private insurance companies pattern their practices on what Medicare does. In Medicare, the Durable Medical Equipment Medical Administrative Contractors (DME MAC) have jurisdiction for processing claims from prosthetists for artificial limbs. If Medicare has questions about a claim, the Medicare contractor may request medical records to demonstrate that the prosthetic arm or leg was reasonable and necessary – or what is called "medically necessary." Since the prosthetist is a supplier, the prosthetist's records must be corroborated by the information in your patient's medical record. It is the treating physician's records, not the prosthetist's, which are used to justify payment.

inMotion | Can you tell our readers more about how medical necessity is determined?

Sue | "Medical necessity" means that the physician can prove that your medical condition warrants the service provided. You might think, "Of course my prosthesis is medically necessary; it's plain to see that I don't have a limb." However, medical necessity is more of a determination of whether or not the service ordered is the appropriate service for your condition. For example, if you are bedridden due to severe lung problems that make it impossible for you to move around, even if you are an amputee, your physician may determine that it is not medically necessary for you to have a computerized prosthetic leg. Your physician is required to determine your potential functional ability to move around, or ambulate. This determination is described as a K-level. In the above example, your K-level would be 0. Even though you are an amputee, because your rehabilitation potential is determined to be K-level 0, Medicare would say it is not medically necessary for you to have a prosthetic leg.

inMotion | How does the physician make a decision about what is medically necessary for me?

Sue | This is important because your functional capabilities are crucial to establishing the medical necessity for a prosthesis. Many prosthetic components are restricted to specific functional levels, so it is critical that your doctor thoroughly documents your functional capabilities, both before and after amputation. Your doctor should assess your physical and cognitive capabilities. This assessment typically includes:

- History of your present condition(s) and past medical history relevant to functional deficits
- Symptoms limiting ambulation or dexterity
- Diagnoses causing these symptoms
- Other co-morbidities relating to ambulatory problems or impacting your use of a new prosthesis
- What ambulatory assistance (cane, walker, wheelchair, caregiver) you currently use (either in addition to the prosthesis or before amputation)
- Description of daily living activities and how they are impacted by deficit(s)
- Physical examination relevant to functional deficits
- Weight and height, including any recent weight loss/gain

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Krafty Kids (cont'd)

to shape them now, you're going to end up with a mess and possibly burned fingers. So, leave them for about 30 minutes so they can set well. Then come back and use the back of a spoon and/or your fingers to push down the middle of each "nest". You're going to have to put a little effort into this one because you've got to crush down the cereal, but you can do it! You will start to see the shape of a nest. Don't worry if it's not perfect – we'll fix that in a few steps! A helpful hint here is to put a little olive oil or spray some cooking spray on your fingers. It will allow you to better shape the treats without them sticking to your hands :-)

Once you have created the general shape, you want to let the "nests" cool completely. If you don't let them set, when you try to take them out of the cupcake tins, they will fall apart. So, once they are completely cool, use a butter knife to pop each one out of the cupcake tin. You can then sculpt them to take on more of the shape you are looking for. Be gentle because they are delicate, but know that you can bend and move them to create the look you want.

You now have your nest made! But what is a nest without something to go in it? So grab some Cadbury Chocolate eggs or a Peep and get creative with the contents of your nest!

Your final result will be cute, creative, fun, and above all – yummy! So get ready for the kids to "swarm!" Because you know they won't be able to turn down this Spring-inspired treat!

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### ... from Beverly's Kitchen

This is an easy and delicious recipe, and it would make a perfect addition to your Spring or Summer picnic.

#### Frozen Fruit Salad

- 8 oz. reduced-fat cream cheese (softened)
- 1/4 cup sugar
- 10 oz. pkg. (frozen sliced) strawberries
- 12 oz. can crushed pineapple with juice
- 2 bananas (sliced)
- 12 oz. carton Light Cool Whip

Mix cream cheese and sugar. Next, add the remaining ingredients. Pour into 2 loaf pans and freeze. Thaw 20 minutes before serving.

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CONTACT INFO

Call for meeting times & locations!

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Q & A (cont'd)

- Cardiopulmonary examination
- Musculoskeletal examination
 - Arm and leg strength and range of motion
- Neurological examination
 - Gait
 - Balance and coordination

The assessment points are not all-inclusive and your physician should tailor his/her history and examination to your condition, clearly describing your pre- and post-amputation capabilities. Your history should paint a picture of your functional abilities and limitations on a typical day. It should contain as much objective data as possible. The physical examination should focus on the body systems that are responsible for your ambulatory or upper-limb difficulties or impact your functional ability. You should be provided with a prescription for prosthetic components that are appropriate for your activity level. Components that are designed for higher activity levels would not be covered under the Medicare policy. Your physician determines your functional ability level. If your functional ability increases over time, your rating can be changed to a higher level.

inMotion | This is all very complex. What is the Amputee Coalition doing to help educate amputees about medical necessity so they can be sure they are getting the right level of prosthetic device?

Sue | An educated patient is better able to ensure he or she is getting the most appropriate prosthesis – and education is a core mission tenet for the Amputee Coalition. Working with our Scientific & Medical Advisory Committee, we are rolling out our "Know Your K-Level" campaign this fall. This campaign will provide information and tools for amputees to use with their doctors, prosthetists, and other healthcare providers involved in their amputation care system.

What Every Medicare Patient With Limb Loss Should Know

- 1) Do you know the K-level your physician has determined for you? This will be a number between 0 and 4.
- 2) Has your physician properly documented in your medical record all of the information needed to determine your K-level? Ask your physician how the documentation supports the need for your prosthesis.
- 3) Be sure your prosthetist fits you with a prosthesis that is appropriate for your K-level.
- 4) Your K-level affects the kind of foot and/or knee your prosthetist can incorporate into your prosthesis.
- 5) Visit your physician regularly (every 6-12 months) to maintain complete documentation of your prosthetic care. Discuss your prosthetic use with your physician, including your current and potential K-level; the condition of your residual limb; your socket fit; how your prosthesis is functioning; and any activities that you are unable to perform in your current prosthesis that you would like to be able to do.

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## AWARENESS MONTHS FOR APRIL

April – Limb Loss Awareness Month

April – Foot Health Awareness Month

April 24<sup>th</sup> – World Meningitis Day

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TEST YOUR KNOWLEDGE ANSWER (from Page 5)

COURAGE, RESILIENCE, STRENGTH, TENACITY, MOXIE

BY DISPLAYING THESE TRAITS, AN AMPUTEE CAN SHOW HIS / HER M E T T L E.