

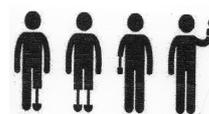


MOVING FORWARD

LIMB LOSS SUPPORT GROUP

NEWSLETTER

2nd Edition – October 2013



MOVING FORWARD

FEATURE STORY

Philip's Story – Conclusion

– Written by Julie Randolph

In the early years as Philip grew, several sets of prosthetic legs had to be made, each involving 2 trips to Grand Rapids for several days at a time. When Philip was 5 we began having his prosthetic services done at several facilities in Louisville, thereby eliminating the trips to Grand Rapids.

At around 3 years old, doctors at Louisville Hand Surgery did reconstruction on Philip's left hand and made him 2 short finger digits that were later lengthened. With these 2 digits Philip learned to use a fork or spoon to feed himself and to hold a pencil or crayons to print, draw, or color. He became so adept at using his pincer grip that he could pick up a dime or a kernel of rice from a flat surface. He amazed us! For larger items, he used his left hand & his right wrist together. I was fascinated to watch Philip sit & stack blocks meticulously, lining up every edge & corner perfectly. He seemed to concentrate on details.

Philip started showing an interest & a natural ability in music at an early age. When he was a small child before he was even able to sing any of the words, he would hum the tunes of many of the praise choruses & hymns we sang at church, with perfect pitch, never missing a note. You would always find him humming, singing, or drumming. As he has grown older, he loves to harmonize with any music that may be playing, or sometimes he just sings or harmonizes with a melody that he has on his mind with no music at all.

Philip started showing an early interest in drums, too, by drumming with pencils or anything he could get ahold of. We got him a child size drum set when he was around 6 and he spent many happy hours on it. When he was a teenager, a friend who was the drummer at my brother's church in Arkansas was so impressed by Philip that he gave him a studio drum set to take home with him. So began Philip's drumming career. With the help of a long-time family friend who designed custom



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AMPUTEE COALITION ADVICE

inMotion Volume 15 • Issue 4 • July/August 2005

Survival Guide for Caregivers

De-Stressing to Stay Healthy

– by Scott McNutt

If you:

- use prescription drugs for depression, anxiety or insomnia 2-3 times more often than the general population
- lose an average of \$659,000 in wages, pensions and Social Security benefits over a lifetime
- are age 66 to 96 and have a 63 percent higher risk of dying than other people your age

What are you?

Answer: One stressed-out caregiver.

More than 50 million Americans are providing unpaid care for family members who are elderly, chronically ill or who have a disability. Sadly, studies show that these caregivers (also called informal or family caregivers) are less likely to take proper care of themselves. To focus on caring for their loved ones, these caregivers often feel little choice but to let their own health and well-being slide.

Much of the wear and tear on caregivers is linked to the stress their responsibilities place on them. In the Spring 2005 issue of *Take Care!*, Suzanne Mintz, president of the National Family Caregivers Association (NFCA), wrote of the dangers of stress to family caregivers. "We need to get family caregivers to recognize that they are at risk and that failing to acknowledge their severe stress will undermine their own health and, in turn, their ability to provide good care," she warned.

Caring for Themselves

Although caregivers have many demands on their time, it is important that they allow for self-care periods and do some essential self-maintenance practices. Abigail Joyce, NFCA Manager of Communications, says that caregivers can practice self-care by adhering to the NFCA's Principles of Family Caregiver Self Advocacy.

These principles are:

- Choose to Take Charge of Your Life.
- Love, Honor, and Value Yourself.
- Seek, Accept, and at Times Demand Help.
- Stand Up and Be Counted.

(For a more detailed explanation of these principles, visit the NFCA Web site at

www.thefamilycaregiver.org/about/philosophy.cfm)

"It is really up to the caregiver as to what helps them de-stress," says Joyce. "But caregivers do need to remember that

– Continued on Page 2 Column 2 –

Philip's Story – Conclusion (cont'd)

drumstick holders, Philip was off & running! The holders were made of leather & strapped to his forearms by heavy elastic straps; then the drumsticks slid down into a pocket made for them & were held there securely, ready for hours of drumming. Philip has since worn out that first set of drum holders. When they could no longer be repaired, Philip's aunt made him 3 more sets that were stronger & more durable than the first. Never having known any other way, Philip has learned to play with this adaptive equipment as well as any normal drummer. In his teen years, Philip took drum lessons for several years so he could learn basic techniques.

In Dec 2010 we learned about the Ertl Procedure from a friend who is an anesthesiologist in our area. We secured an appointment at the Ortho Clinic at Wishard Hospital in Indianapolis on Mar. 17, 2011. We met Dr. Janos Ertl, whose grandfather, Janos von Ertl, Sr., developed the Ertl Procedure & came to America from Hungary in 1951. Please refer to the following websites for a technical explanation & graphic pictures of this unique procedure which rectifies many of the common problems facing amputees:

<http://ertlreconstruction.com>

http://www.oandp.com/articles/2007-02_02.asp

<http://www.ertlguy.net/documents/whytheertlprocedure.html>

<http://www.bonebridge.com/bonebridge.html>

The Ertl Procedure creates a bone bridge between the ends of the 2 bones, the tibia & fibula, in an amputated limb. This gives the amputee a much stronger, more viable residual limb.

Philip had the privilege to have the Ertl Procedure done on his right leg on May 20, 2011, and he had this procedure done on his left leg on Jan. 20, 2012. In layman's terms, Dr. Ertl straightened & braced the bones that were growing crooked below the knee in each leg, made a bone bridge, trimmed the ends of the frayed nerves, & reworked the muscles to make 2 much stronger limbs.

Of course, Philip had to be fitted for a new prosthetic leg after each surgery. Dr. Ertl referred us to Superior Prosthetic Solutions in Newport, KY, who works closely with him and follows up many of his surgeries by making new prosthetic limbs. In Sep. of 2011 Philip received his new prosthetic right leg and he received his new prosthetic left leg in Apr. of 2012.

Due to changes in limb sizes after two surgeries, it was necessary to have 2 new legs made in the spring of 2013. We loved our prosthetist in Newport, KY, but because of the driving distance of 2 hours each way, we found it necessary to look for a prosthetist in the Louisville area. We discovered Louisville Prosthetics, who made Philip's latest set of legs, and have grown to love them as well.

Through them, we learned about a support group called *MOVING FORWARD* Limb Loss Support. In April Philip & I began attending their meetings & events. We have had a lot of fun & have learned a great deal, not to mention making many new friends. – Continued on Page 3 Column 1 –

Survival Guide for Caregivers (cont'd)

they need to take care of their bodies – whether it be by alternative therapies or regular exercise or hot baths. Caregivers need to take care of themselves because the person they are taking care of relies on them.”

Getting Help From Others

Joyce further emphasizes that caregivers must remember that they are part of a community. “Many caregivers feel isolated and alone,” she says. “Caregivers should remember that they are not alone, that there are many other caregivers, and just like with anything else, tomorrow is a new day. As a caregiver you will have good days and bad days. Don't be so hard on yourself on those bad days.”

Zanda Hilger, LPC, a consultant with many years of experience in caregiving and a family caregiver herself, shares this sentiment: “This is not a ‘do-it-by-yourself’ job,” she says, noting that “asking for specific help from others, especially family members,” is crucial to caregivers having the necessary time to take care of themselves.

Organization Is One of the Keys

Getting organized is also a frequently cited way to lower stress. One of the most useful things caregivers can do is “prioritizing what has to be done while setting healthy boundaries and limits,” says Hilger. “What do you have control over and what can you influence?”

Joyce too acknowledges that getting organized is important, but she also points out the need for flexibility, saying, “Sometimes even the best-laid plans get pushed aside because unexpected situations come up when you are a caregiver.”

However, some parts of getting organized are simple to do, and, once done, they will help limit the stress of everyday tasks. The following three organizational ideas might be useful, for example:

- Write down and prioritize your daily routine and eliminate non-essential, distracting elements in it.
- Ensure that your care receiver's financial, legal, and medical records are in order and easily accessible.
- Post lists of phone numbers, medicines, and other important information where you can easily find them.

Staying Healthy

The NFCA and other caregiving organizations offer additional self-care recommendations for helping caregivers stay healthy and manage stress. Specific guidelines vary, but they have many basic points in common. The following guidelines should be beneficial:

- Eat healthful meals each day.
- Get sufficient rest and sleep.
- Exercise regularly; monitor your physical health.
- Accept and express feelings; monitor your emotional health.
- Set aside time for yourself.
- Seek and accept the support of others.
- Sustain your spiritual side.

Following are some tips on these guidelines, compiled from numerous sources. In addition, several books, videotapes, and websites on caregiver self-care are available, and organizations like the NFCA stand ready to help.

Meals

- Eat lots of fruits, vegetables and whole grains. Ask your physician about vitamin supplements.

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Philip's Story – Conclusion (cont'd)

In the process of being out of his prosthetic legs to recuperate from 2 leg revisions, Philip had put his drums on the back burner for over 2 years. Thanks to so much encouragement from our support group friends, he has begun playing again and it's almost as if he had never missed a lick!

Philip is looking forward to meeting new amputees in our area, making new friends, & being a help or encouragement to anyone that he possibly can.

** We hope that you have enjoyed reading Philip's story, and now we want to encourage you to write your own story and share it with us. These stories will be compiled into a book to share with our members. Contact Julie or Belinda if you would like your story published in the newsletter. **

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## SPOTLIGHT

Each month in this section we will get to know one of our members a little better. I wasn't able to do the interview that I intended to do this month, so instead I will spotlight my caregiver, who is my husband of 35 years. I would also like to take this time to thank him for his support, encouragement, understanding, pushing me a little when I needed it, and most of all for not making me feel that I was anything less in his eyes because I lost my limb. *— by Belinda Jacobi*

Name: Shelton Jacobi  
Hometown: Sellersburg, IN  
Hobbies: playing with the grandsons, tennis, biking, hiking  
Favorite Sports Team: IU basketball, Indianapolis Colts, and Cincinnati Reds

What has been the hardest thing for you since your wife lost her limb? In the beginning, not knowing if things would turn out okay, and not knowing anything about cancer or limb loss

What advice would you give to other caregivers? Try to stay as positive as possible and find ways to relieve your stress.

How has the support group helped you to move forward? I've made new friends and have learned a lot by listening to their experiences. I've learned that when faced with a challenge, to deal with it the best that I can and then to move on and to never give up.

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QUOTE OF THE MONTH



"It's not how you finish in a race that matters. It's having the courage to start it."

Survival Guide for Caregivers (cont'd)

- Drink plenty of water & other non-alcoholic, non-caffeinated fluids.
- Indulge in a favorite dish if you are stressed. "Comfort foods" like pasta & potatoes that are high in complex carbohydrates may actually make you feel better.
- Prepare extra portions when you are cooking. Put leftovers in individual containers and place them in the freezer for quick, ready-to-heat meals; don't forget to label the packages.
- For occasional time off from meal-making, take advantage of groups like Meals on Wheels that will provide nutritious meals to older people and people with disabilities for free or for a minimal charge.

Rest & Sleep

- Maintain a regular sleep schedule, and follow a consistent bedtime routine if possible.
- Don't exercise too close to bedtime.
- Don't consume caffeine or alcohol in the evenings.
- Turn down the thermostat. Cooler temperatures help induce sleep.
- Listen to relaxation tapes to lull yourself to sleep.

Exercise and Physical Health

- Schedule and keep regular physical checkups.
- Make activities you enjoy your exercise regimen. Whether it's walking, swimming, biking, dancing, gardening or playing with children or pets, find an exercise outlet in a regular physical activity that already appeals to you.
- If you enjoy participating in team sports or competitive sports, combine exercise and social interaction by making sports "dates" with friends.
- Stretch. Stretching is a great physical picker-upper that can be done anywhere, even if you have only five or 10 minutes. Just a brief series of stretching exercises will help reduce tension and maintain muscle tone.

Emotional Health

- Share your feelings. When a friend or family member asks how you are, answer truthfully.
- Don't isolate yourself. As cramped for time as you may be, schedule visits with friends and family.
- Write your thoughts and feelings in a personal journal. This is a healthy way to both express and monitor your feelings.
- Develop your problem-solving skills. This will reduce your anxiety about issues confronting you.
- Remember to laugh. Stock up on humorous books, magazines and videos, and build a list of links to humor-oriented websites and check them often. Strive to share a laugh with your care receiver at least once a day.
- Learn calming exercises, such as deep breathing and meditation.
- Develop the habit of embracing loved ones and friends and petting animals. Studies show that these behaviors lower the body's output of cortisol, a stress hormone. When cortisol dips, two "feel-good" brain chemicals – serotonin and dopamine – surge.
- Pursue activities that offer emotional satisfaction and give you "time away" from yourself and your situation,

– Continued on Page 4 Column 2 –



RECAP OF SEPTEMBER

A 2nd yard sale was held on Sept. 14th, and another \$124.00 was raised for our group.

The total for the two sales was \$718.00. We want to thank everyone for their donations. The remaining items will be donated to charity.

On Sept. 21st the group hosted a Pie & Ice Cream Social at the Okolona Fire Station. A delicious assortment of pies and homemade ice cream were enjoyed by all. We were entertained by Philip Randolph on drums accompanied by Sylvia Worrall on keyboard. There were games and prizes for the children in attendance. Three new members were welcomed into our group during the event. They are Brittany Bley, Bradley McDaniel, and Leigh Pope. It was a wonderful way to spend a Saturday afternoon!

At our monthly meeting which was held on September 26th, the topic of discussion was dealing with pain after limb loss. Members talked about their experience with pain and told how they cope with phantom pain and sensations. A new member, Gary Rock, was in attendance and shared with us the story of how he recently lost his legs in a farm accident. We were all very inspired by his positive attitude & his desire to help others. We concluded the meeting after discussing our upcoming events.

A Brunch Cruise on the Belle of Louisville was enjoyed by some members of the group on Sept. 29th. Even though it was a rainy day, we enjoyed the brunch, the beautiful views along the Ohio River, and the music provided by a DJ.



UPCOMING EVENTS

Sat., Oct. 19 – WALK & ROLL & PICNIC AT SAM PEDEN COMMUNITY PARK: The park is located on Grant Line Road in New Albany. Please call or email for directions. The Walk & Roll will be a fundraiser for our group with proceeds going to make "Care" packages to distribute to amputees in our community. Participants will go on the approximately 1 mile path (sidewalk) around the lake. It is easily accessible by wheelchairs and scooters. We will walk/roll together as a group and our youngest member, 4-year-old Reid, will lead us. The registration fee will be \$10.00 for participants 14 years of age and over. Children under the age of 14 accompanied by an adult may participate for free. Friends and family are encouraged to join us, as well as anyone in the community who would like to help support our cause. Members of *MOVING FORWARD* are encouraged to wear your group T-shirts. If you haven't received one, they will be available at the registration table. The member who gets the most people to participate in the event will receive a prize. If you would like to help with the event but can't take part, we will need people to help with registration and you can cheer the participants as they cross the finish line. Registration will begin at 10:30 with the Walk & Roll starting at 11:00.



– Continued on Page 5 Column 1 –

Survival Guide for Caregivers (cont'd)

such as listening to (or playing) music, reading poetry, meditating, communing with nature, or other creative pastimes.

- Don't self-medicate with alcohol, overwork or drugs.
- Common signs of depression include loss of appetite, sleeplessness, irritability, crying jags, inability to concentrate, and forgetfulness. If you are experiencing these symptoms, contact a mental health professional for help.

Taking Time for Yourself

- Accept that it's OK to do things that you enjoy. Whatever your favorite pastime may be, always take the time to engage in it, at least once a week and more often if possible.
- Use family, friends, your religious group, respite care, home healthcare, or other services to arrange to take a break.
- Reward yourself. Acknowledge that you deserve the occasional pampering.
- Try to engage in activities that give your brain some "fun work" and that can be stopped at any time and resumed later. Reading a good book is one such activity. Jigsaw puzzles, acrostics, crossword puzzles, and similar brain teasers or chess and other games of strategy are others.

Accepting the Support of Others

- When someone offers help, don't let shame or guilt stop you from accepting.
- Keep a list of chores, errands and jobs you want to get done, and show it to people who offer to help.
- Be clear, be specific, and keep requests simple. Break complex tasks into discrete steps. It's easier for others to help if the job doesn't seem overwhelming.
- Match tasks to talents; ask the aspiring chefs who enjoy cooking for help with meals, green-thumb friends for help in the yard, and people who actually enjoy cleaning for help around the house.
- Take comfort in knowing you are not alone. Join a caregiver support group.

Sustaining Your Spirituality

- If you belong to a religious organization, attend services, talk to your spiritual guide, and ask for spiritual support from your group.
- Find significance in your role as a caregiver by seeking positive meaning in it and considering how you may become stronger through it.
- Whether religious or not, find faith in what you believe.

Further Reading

"Resources for Seniors With Limb Differences and Their Caregivers"

www.amputee-coalition.org/inmotion/jan_feb_03/seniors.html

"Who Cares for Caregivers?"

www.amputee-coalition.org/inmotion/jan_feb_00/caregivers.html



UPCOMING EVENTS (cont'd)



** The picnic will start at Noon & if you don't come to the walk/roll, you are still invited to the picnic. It will be a pitch-in, so please bring a covered dish. Drinks and utensils will be provided by the group. We

will be at the first shelter on the right after entering the park. There is a playground adjacent to the shelter as well as a restroom. The park has a fishing lake, horseshoe pits, a basketball court, tennis courts, 3 playground areas, and walking paths.

Thur., Oct. 24 – MEETING AT BAPTIST EAST from 6:00 - 8:00: At this meeting we will honor the Caregivers in attendance. November is National Caregivers Appreciation month, but since we won't have a meeting in November because of the Thanksgiving holiday; we will honor our caregivers in October. The topic of discussion will be issues that caregivers face and ways to help relieve stress. All caregivers in attendance will receive a gift and a drawing will be held for a gift certificate.



Sat., Nov. 9

VETERAN'S BRUNCH: The brunch will be held from 11:00 - 2:00 pm at the Okolona Fire Station, 8501 Preston Hwy. Louisville. This event will start with a pitch-in brunch followed by a program to honor our veterans. Each veteran in attendance will receive a memento of the occasion. We will have a guest speaker as well as musical entertainment.

** Please call or email Belinda if you are or know a veteran who would like to be honored at this program. If you do so, you will be sent a short form to fill out giving the details of your service. This info will be used in our Nov. issue of the newsletter which will have a special tribute to veterans.

Other Activities Being Discussed:

- Dance
- Bowling

We are researching adaptive sports and would like to see the group offer various sports clinics (tennis, golf, bowling, softball, etc.) as well as plans to start a program for children with limb loss.

If you have any questions regarding our upcoming events or suggestions for future events, please call or email. We look forward to seeing you.

** Remember, you don't have to be a member of MOVING FORWARD Limb Loss Support Group to attend meetings or events. EVERYONE is Welcome! **



TEST YOUR KNOWLEDGE

Unscramble these words and then use the letters in the squares to finish the sentence. You can find the answer on Page 6.

- () () _ _ _ _ _ eruppso
 () _ _ () _ _ _ tttdeiu
 () () _ _ _ yegnre
 _ () _ _ _ _ () teinomso

There are over 2 million _ _ _ _ _ _ _ _ _ _ living in the United States.



Q & A



In this column we ask you to submit questions pertaining to limb loss, & then we will get responses from members of Moving Forward Limb Loss Support Group. We are not offering medical advice, but will share tips & information to try to make living with limb loss easier. You may submit your question(s) by email to belindajacobi@yahoo.com or by calling 812-620-3694.

A question submitted this month is: How do you effectively deal with itching on your residual limb? Kelly says if it is a constant itch, she uses Gold Bond lotion, but if it is just a minor itch, she just tries to scratch it gently, being careful not to scratch open the skin. Sylvia likes to put a small amount of Eucerin lotion on her limb after bathing and lets it soak in well before putting on her liner. She also uses hydrocortisone cream when needed. I put just a small amount of lotion on at bedtime and gently massage my leg. I have a problem with dry skin, so this makes it feel better. I also keep Benadryl (antihistamine) on hand. There are certain medications that I have taken that cause me to itch and a pharmacist suggested taking an antihistamine. If I get really itchy, I take a Benadryl and it helps. If you are dealing with a rash, though, you should contact your doctor or prosthetist because you may be having a reaction to your liner or as issue with skin breakdown. I hope this helps, and encourage everyone to call or email me a question for the November issue of our newsletter.

– by Belinda Jacobi



