

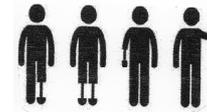


MOVING FORWARD

LIMB LOSS SUPPORT GROUP

NEWSLETTER

4th Edition – December 2013



MOVING FORWARD

FEATURE STORY

Through the Eyes of Our Children

— by *Belinda Jacobi*



Carter & Deklan Jacobi

With the holiday season upon us, our thoughts are quite often centered upon our children or grandchildren. Whether it's trying to find the perfect gift to make their eyes light up on Christmas Day, baking cookies, or decorating the tree with them; children can bring us great joy. The December issue is dedicated to the children in our group.

I have talked to many new amputees who are deeply concerned about how their child or grandchild will be affected by their limb loss. They wonder if the child will be afraid of them because they look different, that they won't be able to do the things with them that they once enjoyed doing; or in the case of teenagers, that they will be embarrassed to be seen with them. The two AMPUTEE COALITION articles in this month's issue have a lot of excellent advice on these subjects, and I encourage you to read them.

I remember having these same concerns when I lost my leg. My grandson Carter was 2½ at the time. In the beginning, I hid my leg under a blanket fearing that it would frighten him. I remember the first time he saw my stump. My leg was really hurting, and I needed to take off my prosthesis. I hesitated as long as I could but things didn't improve so it had to come off. He was playing on the floor and at first didn't notice it. He got up to retrieve another toy and that is when it caught his eye. He looked at me frightened. My heart sank, but then I held out my arms and told him to come to me and that Nana was ok. He ran into my arms and I picked him up and held him. From that moment on, it was no longer an issue for Carter or me.

That's not to say that it isn't a challenge sometimes, but during the last 4½ years I have found that I can still do almost everything with him that a grandmother with 2 legs can do. I watch him with great pride as he explains to other children what is wrong with his grandpa's leg.

One day I picked him up after school, and he couldn't wait to tell me about a conversation he had with a little girl. He said, "Nana, you aren't going to

— Continued on Page 2 Column 1 —

AMPUTEE COALITION ADVICE

inMotion Volume 11 • Issue 3 • May/June 2001

When a Parent Loses a Limb: Helping Children Cope

by *Pat Isenberg*

Common questions that children ask include:

- Where is your arm/leg?
- What happened to it?
- Did it break off?

Be prepared to assist the child with an answer that is appropriate for his or her age and developmental level.

Pain is scary to children; the longer pain endures, the more frightened the child will be. Talk about different types of pain in terms the child can understand. (Remember the time you burned your finger? Or, the time you fell off your bike?) Remind the child that sometimes pain is short-lived; at other times, pain lasts for days, but eventually pain gets better.

- Avoid giving children too much information, such as details about a complicated disease process or the amputation surgery.
- Can this happen to me? Alleviate fears by giving information that kids can understand. Telling a child that someone was asleep when his or her leg was removed can develop into a fear of bedtime. Remember that your explanations need to be planned to avoid creating additional fears or anxiety.
- Is this my fault? Younger children are egocentric; when things happen, they feel responsible. Make certain children know that they did not do anything to make this happen.
- Limb loss is not a punishment; however, if it's the result of an accident, you may want to talk about safety issues at an appropriate time.
- Children will not "catch" this. Hugging and touching are still safe and very important parts of healing for the entire family.
- The parent is still a mommy or daddy regardless of the limb difference. Talk about what is important - daddy can still read a bedtime story; mommy will still brush your hair.
- You may also want to discuss which things may be different. Mom may have to learn a new way to bake chocolate chip cookies; dad may not be able to walk the dog for a few weeks (or months).
- Call upon the child's natural desire to help. You can be mommy's right hand until she learns to use the new one.
- Explain the new words: prosthesis, limb, residual limb, and prosthetist. Make a game out of spelling or pronunciation of these words.
- Avoid adverse reactions: a child who cries or screams in response to seeing a parent for the first time; a child who

— Continued on Page 2 Column 2 —

Through the Eyes of Our Children (cont'd)

believe this, but Kenley didn't even know what an amputee is and she is in the 2nd Grade." Carter is in the 1st Grade, so he had thought surely someone a whole year older than him should know such a thing. I asked him if he had explained it to her, and he assured me that he had. So take heart, fellow amputees, Carter is out there educating the world about limb loss – one child at a time.

When my second grandson Deklan was born, I knew that he would only know me as I am now. He is going to turn 3 this month and loves to play doctor. He has a toy doctor's kit and usually that is the first thing he gets out to play with when he comes over. He listens to my heart with the stethoscope, makes me stick out my tongue and say "ah", puts bandages on anything that slightly resembles a "booboo", and then he gets out his toy toolbox. He then proceeds to fixing my leg with his toy hammer, saw, and screw drivers.

As you can probably tell, both of my grandsons bring me great joy. They also motivate me to do things that I wouldn't do without them. This is another thing that I have been told numerous times by other amputees. The desire to be able to participate in their child's or grandchild's life has given them the motivation to move forward. They've also told me that they want to set a good example, to let them know that when something bad happens, you don't give up.

I asked Mike and Kelly from our group to share some experiences that they have had with children dealing with their limb loss. Mike said that all but his youngest grandchild were familiar with limb loss, because their Uncle Steve, who is also a member of our group, is an amputee. His youngest, 3-year-old Maggie, is fascinated by his prosthetic leg and wants to help him put it on and push the button. He also stated that it's important not to let your limb loss keep you from doing things with your grandchildren. Mike enjoys fishing with his grandsons and brought them along to our fishing event last spring.

Kelly has been an amputee since she was a child. She says, "It has been very helpful to allow children to touch/see her hands/fingers or her prosthetics. It helps them to realize that, for example, my fingers look different, but it's still skin and bones just like theirs. It really helps kids lose their fear. I remember



Abby & Grant Reitz

once as a teenager, a little boy that I went to church with and had babysat for overheard his parents and grandparents talking about my fingers. He interrupted their conversation and said that there isn't anything wrong with Kelly's fingers, that she just has little hands. Kelly has two young children at home: Grant is 3,

Abby is 5 & is in kindergarten. If you have a story to share, please let me know. I would love to hear it.

I wish you all a Merry Christmas and a Happy New Year!!!!

~~~~~

## When a Parent Loses a Limb (cont'd)

runs from the room each time the prosthesis is removed. Explain differences in advance to prepare the child. Show pictures of other people with limb loss (available from the prosthetist or therapist or inMotion magazine) to desensitize the child.

- Focus on the similarities, but prepare gently for the differences. Have the child talk or write about his or her feelings.
- Children are curious. Remove the mystery from the prosthesis by asking the prosthetist to spend time with the child, explaining the materials and components used. The child should be encouraged to manipulate the components.
- If possible, have the child talk with other children whose parents have lost a limb.
- Encourage the child to express his or her feelings through drawing, poetry, or telling and writing a story.

*Excerpt from Limb Loss Education & Awareness Program, © 2001 Amputee Coalition by Pat Isenberg, Amputee Coalition Outreach Education Coordinator*

\*\*\*\*\*

*inMotion* Volume 13 • Issue 6 • November/December 2003

## "What Happened to Your Leg, Grandma?"

*By Christina DiMartino*

June DiMenna had suffered with diabetes for years when, after exhausting every treatment available, she had to have her left foot amputated. The procedure took place a week after she celebrated her 67th birthday.

"I quickly realized that there are many details to think about when one has a limb amputated," she says. "The list stacks up over time – especially for people like me who have always been independent. But there was one thing that I didn't anticipate, or even think about, that turned out to be a critical detail - how my grandchildren would understand and accept what had happened to me."



DiMenna lives near her three daughters and four grandchildren who range in age from 3 to 10. "It isn't unusual for me to see all of my grandchildren several times a week," DiMenna says. "We have always spent ample and valuable time together. The thought that they wouldn't understand - or that they might try to reject my affection - was devastating."

Melinda Hinkle, who suffered a left below-knee amputation in an auto accident 20 years ago, has similar concerns. Hinkle's son, daughter-in-law and two grandchildren, ages 2 and 4, live on the opposite side of the country from her, and between visits back and forth, she only sees the children about four times each year.

"They are growing up, and I know the time will come when they will begin to realize that their grandmother is different. I don't know how to explain my amputation to them. I'm afraid it will frighten them, or they will think that the same thing will happen to them. It is time for me to have a plan prepared so I know how to answer the questions they will have. I want them to feel free to discuss my amputation with me any time they want."

"Honesty is the best policy" applies when explaining an amputation to grandchildren. Stephen T. Wegener, PhD, is an

*– Continued on Page 3 Column 2 –*



## SPOTLIGHT

This month since we are dedicating the newsletter to the children in our group, I decided to shine the spotlight on a special boy who helped me in my recovery process, and that is my grandson, Carter. As anyone who is a member of our group knows, he is one of our biggest advocates and is very devoted to *MOVING FORWARD*:

Name: Carter Ray Jacobi

Age: Will be 7 years old on Dec 20<sup>th</sup>

Grade: 1<sup>st</sup> Grade

Hometown: New Albany, IN

Favorite sports team: IU basketball

Sports that you play: basketball, baseball, tennis

Favorite TV shows: Turtleman, Gator Boys, and Octonauts

Favorite movies: The Lion King, Monster University, and Monsters Inc.

Favorite food: Anything that Mawmaw or Nana cooks

Favorite things to do: Go to Nana & Poppop's house, and go to Disney World

What do you like to do with your Nana? Play school and sports. We like to read to each other too.

What do you like about the support group? The events are really fun.

What has been your favorite event so far? The Belle of Louisville Cruise was awesome.

What are some things that you have learned since Nana lost her leg? I learned what an amputee is, and I learned that it is ok to be different.

~~~~~

RECAP OF NOVEMBER



On Nov 9th MOVING FORWARD hosted a brunch and program to honor our veterans at the Okolona Fire Station. We would like to thank everyone for the delicious food that they brought, and an extra big thank you goes out to Shelton, Kelly, and Sylvia for all their hard work in the kitchen. The program was a really memorable event. We would like to thank our two guest speakers, Pat Shader and Tommy Miller. Pat spoke about the role that the VA Auxiliary plays in supporting our veterans and the hardships faced by our military in combat. Tommy talked about his time in the military having been deployed to both Iraq and Afghanistan. Some of our group members participated in the program, including: Sylvia Worrall who led in the singing of the National Anthem, Sam Gaylord who led us in the Pledge of Allegiance, and Kelly Reitz who recited a poem. A special tribute to the military was provided by Philip Randolph who played his drums along with patriotic music and a video. We would like to thank Philip and his mother Julie for their hard work in putting the musical tribute together for us. It truly touched our hearts. The program concluded with a gift being presented to each veteran in attendance.

Due to the Thanksgiving holiday, there wasn't a monthly meeting in November.

"What Happened to Your Leg, Grandma?" (cont'd)

associate professor, Vice-Chairman and Chief of Rehabilitation Psychology at Johns Hopkins University School of Medicine, Physical Medicine and Rehabilitation Division. His clinical activity is focused on providing psychological services to people with chronic illness or traumatic injuries including rheumatic disease, chronic pain, amputations and spinal cord injury. He says that children generally ask questions at an age when they can handle the answers. "Children are highly comparative and very observant," Dr. Wegener says. "The answer to 'When should you explain your amputation to your grandchild?' is 'When they begin asking.'"

Two issues are relevant to communicating the details of an amputation to a child, Dr. Wegener says. "One is the age of the child, and the other is how the child interacts with the amputation - and this can be quite different, depending on the circumstances. If the child has grown up familiar with your amputation, he or she may react differently than if you have an amputation procedure during the child's youth. In the latter case, the child will, of course, realize that something has happened to make the grandparent different."

This does not mean that the child will automatically be traumatized, says Dr. Wegener. Instead, he suggests some general guidelines to help the child gain acceptance and understanding. "A child's response to the amputation event will mirror that of the person with the amputation," he says. "Children will always respond to an adult's emotional tone. How you respond will help guide the child's response. First, give a response that is age-appropriate. Younger children require less specific details. Older children may require a more complex response to be satisfied with the answers you provide. It is best to anticipate the child's questions. Depending on the child's personality, you might consider opening the conversation yourself. Say to the child, 'Let me tell you what happened to me.' Or, 'I had to have my leg removed so I could be healthy again.' Having a good understanding of how the child will react is a good idea. Does he or she worry easily? The amputation may have been performed to improve your health, but it might make the child fearful that his or her leg will also be amputated or cause other fearful and worrisome thoughts."

Children can say (and think) the strangest things - but they aren't strange at all to them.

Children can say (and think) the strangest things - but they aren't strange at all to them. Dr. Wegener says he has never heard of a child asking where the leg went after the doctor took it off - but it might be a good idea to be prepared for such a question. He says most children accept the explanation that the doctor disposed of the amputated limb somehow. But if a child does ask, merely tell him or her that the doctor took care of it and that you are no longer worried about where it is.

"When the conversation does begin with your grandchildren about your amputation, it is a good opportunity to discuss the differences between all people in the world," Dr. Wegener says. "Take advantage of the time to talk about diversity and acceptance, and explain how this is just one of the many ways that people can be different."

Children, Dr. Wegener suggests, are most concerned about their own security. If you have always spent valuable time with the child, he or she may worry that your amputation will change your relationship.

"The child may ask, 'Does this mean that I can't come to your house anymore, Grandpa?'" he says. "It is very important to communicate that things are going to be okay and that you

- Continued on Page 4 Column 2 -



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 5.

- ___ () ___ () ___ TNAPCEEI
- ___ () () ___ SHNYOET
- () _____ () ___ CCCPNATEEA
- __ () __ () ___ STTUR
- _____ () () ___ DKWEEGONL
- () _____ () ___ () ___ OIDSNSSCUI

These things are needed to help a child in _____ his or her parent's limb loss.



Q & A



In this section, 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 I keep from feeling sad all of the time?"

We all deal with sadness from time to time, but around the holidays it can become overwhelming. You are not only dealing with adjusting to your limb loss, but then here comes all the added tension that the holiday season can bring. You may feel left out, if you can't do some of the activities that you normally do, or you may feel guilty for not being able to do all the cooking or shopping. If this is your first holiday season since becoming an amputee, please give yourself the gift of letting go. Let others take over some of the duties this year. Many times people are there who are willing to help, but our pride gets in the way. You may even find some new family traditions. Sit back and enjoy watching your grandchildren decorate the tree or coaching your daughter on how to make the perfect turkey. Try shopping on line or giving gift cards. You may decide that you enjoy a less stressful holiday.

I asked several members of the group what they did when they were feeling sad, and here are their responses:

Sam takes inventory of what good things that he does have in his life.

Beverly tries to spend as much time out in the sun as possible. The sunshine and fresh air can help when you're feeling sad.

Philip thinks about his hobbies or things that he likes to do.

Julie thinks about activities or events she is looking

- Continued on Page 5 Column 1 -

"What Happened to Your Leg, Grandma?" (cont'd)

will still spend valuable time with the child. Discuss these issues with the child's parents and work together to ensure that you will continue to spend time with the child. You may also have to explain to the child why you cannot do some of the things you did together in the past. Perhaps you took regular walks after school. Suggest you begin playing computer games, engage in art and craft projects or spend more time reading together, for example."

There is also the issue of the hospital and rehabilitation center, when and if they apply. If a child is fearful of hospitals, it is not advisable to force a confrontation.

"Don't force the child to confront the limb loss either," Dr. Wegener says. "Children will find their own time to deal with it. I have never seen a case where a child is traumatized or has serious anxiety or depression in such a situation, but if it happens, the parents should confer with a medical professional. It is best to not assume that there will be a problem, however. The majority of children find their own way - and time - and they deal with such things with surprising resilience."

Teens who are sensitive to peer pressure may have a different type of difficulty dealing with a grandparent's amputation, Dr. Wegener says.

"Adolescents may feel somewhat embarrassed, and may even try to avoid the grandparent," he says. "It is best for the person with the amputation to engage in a conversation directly with the child - rather than allowing a parent to do it. Limb loss can also be an opportunity for teens to learn about change. As a grandparent, you can be a mentor for such a learning experience."

There is a caveat to explaining an amputation to a grandchild who doesn't ask about it, however. Some children are timid and shy, Dr. Wegener says, and they may need some prompting or intervention to get them engaged in a conversation.

"A parent may ask a child with this type of personality, 'How do you think your grandfather is doing? Are you worried about him?'" Dr. Wegener says. "Once the child acknowledges the amputation, then you can begin offering explanations."

The most important thing to remember is that children bounce back quickly. Once they understand why the amputation was necessary and how it will change the circumstances of their lives, they will likely move on and accept the "new normal."



CARE PACKAGES

We have decided to begin working on our "Care Packages" in January. That will give us more time to collect items and prepare the packages. Also, in December so many groups give donations that we thought it would be better to start ours in January, since it is going to be an ongoing project and not just a one-time gift. If you would like to help with this project either by collecting items or putting the packages together, please contact Belinda.



CONTACT INFO



MOVING FORWARD Support Group

moving4wdamputeegroup@gmail.com

Belinda Jacobi, President

belindajacobi@yahoo.com

812-620-3694

Sam Gaylord, Vice-President

gaylordm@aol.com

812-989-4177

Sylvia Worrall, Secretary

hiswife4life@outlook.com

502-498-9500

Kelly Reitz, Treasurer

Kireitz2012@gmail.com

812-572-7955

Mike Portman, Board Member-at-Large

mdportman712@gmail.com

502-262-8344

-- Edited by Julie Randolph