



NOTES From the  **Medical Director** by Doug Smith, MD, ACA Medical Director

Supporting A Sense of Community

*“Whereas a traveler’s chief aim should be to help make men wiser and better.
— Gulliver’s Travels, by Jonathan Swift*

Those with limb loss can be like travelers to a foreign country. Suddenly, they can feel like a stranger in a strange land, one that is not designed with them in mind. Life has become different, and sometimes difficult. One’s sense of place, and even self, is shaken and has changed.

And like those journeying to a new shore, individuals with limb loss can, at times, gain large benefits from being with others who are like themselves. Sometimes, there is a need to discuss common experiences and problems. Other times, it is an eager desire to tell about recent discoveries, such as a fantastic new device or a knowledgeable and capable healthcare provider. Moreover, it can be beneficial to be with other folks who have personal insight of how you now see the world.

For the traveler, there are gathering spots to mingle with other people who are far from home. Most major cities across the globe have at least one Americanized pub serving familiar food and decorated with baseball banners, college pennants and other reminders of home. Here, culturally overwhelmed visitors from the states find refuge and mix with others in similar circumstances. They feel understood here, and supported.

For the person with limb loss, a support group also can provide tremendous comfort and relief. Locating or forming a good support group is the important first step toward finding that special place. The people in that place can provide helpful answers and insights for both the expected and

unexpected. And, like it says in the theme song to the television show *Cheers*, sometimes it’s nice to be “where you can see our troubles are all the same ... and everybody knows your name.”

For the person reaching a foreign land for the first time, just facing the customs agents can be a bewildering experience. Having a more experienced companion along to act as a guide helps get the newcomer through passport control. With help, he or she has taken that first major step. No longer en route, the traveler is now in a new land and has a guide to help explain the wonders and pitfalls that lie ahead.

A peer visitor program in a hospital can provide that important introduction for the person with limb loss from another person who has already experienced it. After undergoing the devastating loss of amputation, the person with limb loss meets someone else, a guide, who is capable, confident and self-assured. In short, the peer visitor does not look, nor act, handicapped. The peer visitor is there to say, “Life does go on and it can be very rewarding.”

The person in the hospital bed is removed from the handicap mindset to begin the journey of recovering a capable and active lifestyle. The amputee peer visitor can be very helpful as a role model and in providing answers to pressing day-to-day questions. As the new amputee learns more, he or she feels increasingly comfortable interacting with other amputees and in discussing limb loss issues.

The peer visitor does need to be very

aware that every traveler takes a slightly different path. Not every provider is a perfect match for every amputee. Not every device is appropriate for every situation. The visitor is a guide and an advocate, and must maintain a broad and open perspective.

After leaving the hospital, the new amputee may find, or even form, a support group outside the clinical setting. The Amputee Coalition of America can be very helpful in this regard, with resources and knowledgeable members to help with such an undertaking. The support group is made up of people who have shared many common and uncommon experiences and can impart their unique wisdom. They have learned that many hurdles can be subtler than learning to walk with a prosthesis or learning to dress with one arm. A newcomer benefits from the experiences of others who have lived with limb loss for a longer period of time.

And, like students with their teachers, as the students learn and grow they eventually become experienced, knowledgeable and confident enough to shine a light to guide others. Occasionally inviting nurses, doctors and therapists can increase the learning experience – especially for the healthcare providers. I, personally, have learned a tremendous amount from those participating in our groups in Seattle.

Information and knowledge about the expected and unexpected, from others who have faced the same challenges as you, can provide answers to a wide variety of questions:

- “At night I have to get up and hop on one foot to the bathroom, or I have to stop first to put on my prosthesis. Either way, I’m wide awake. Is there a way to do it so I can fall back to sleep easily when I get back into bed?”
- “How in the world do I sew a button on my shirt with one arm?”
- “Is there a place I can buy a soft-sided bathtub? I need to sit on the side of the tub before I get in, and those shower-door railings feel awful.”

The experiences of others who have overcome the hurdles and resumed active lives are invaluable as teaching tools. They know the score. For example, it probably wouldn’t occur to a person who has not experienced the loss of a lower limb how to gauge when you might become tired, or in danger of “overusing” the residual limb.

I know a woman who lost a foot when she was 19. She says she has learned over time that she has a certain number of “good” steps per day. To be precise, we have measured and she has 3,400 “good” steps in a day. She paces herself according to her schedule so that she doesn’t exhaust her “good” steps before her tasks are completed. If she has a busy afternoon ahead, she adjusts so that her activities in the morning are less physically demanding. Her experience and practice have taught her these important lessons and now she can pass that knowledge along to newcomers.

It can be emotionally helpful to share with others the frustrations a person with limb loss feels when he or she visits healthcare providers who have little or no expertise in amputee issues. I recall a woman telling me how angry she felt when she explained a problem to her doctor and he responded, “That’s the first time I’ve heard of that.” She told him, “That’s not what I want to hear.” For her, the knowledgeable members of a local support group can provide the answers when someone asks, “Where

are the doctors, prosthetists and rehabilitation specialists I need?”

As ACA Board Member Charlie Steele of New York City points out, it is equally important, if not more so, for people to feel that they have something to contribute back to others. “People need to feel needed,” says Charlie, himself a support group leader. “When you have information that is helpful to someone else, it makes you feel good about yourself to share it.”

People with limb loss who are part of a supportive family frequently find more success following surgery, rehabilitation and recovery than those who are on their own. But that doesn’t mean problems won’t arise even in supportive households. Members of a supportive family, while having good intentions, can inadvertently make a situation more difficult for the person with limb loss.

Many people have a deeply rooted need to feel self-sufficient and capable

of taking care of themselves. Unintentionally, this can cause a rift in the family. You may hurt “Aunt Betty’s” feelings because she cares for you and says she wants to help. Aunt Betty’s heart is in the right place, but she has not experienced life with limb loss. She means well but can be totally clueless of what you really need. Members of a support group can be of more help because they have the experience that Aunt Betty lacks. And they may know just the right way to tell Aunt Betty, “Thank you for your concern, but I want to do this myself.”

One goal of the ACA is to assist those with limb loss in contacting fellow amputees to help them get over the trouble spots – the major ones, as well as those nagging day-to-day ones. Frequently, the answer to a problem is just a question away. What’s important is that someone is there to provide the answer. ■