

Amputee Support Groups: Patient Advocacy in Action

by Dee Malchow M.N., R.N.

When any crisis or significant loss occurs in an individual's life, there is a profound sense of loneliness and fear of the unknown. As the reality and the permanence of the loss settle in, one can 'know' that others have experienced this type of loss and yet feel afraid and alone in his/her own unique situation. People who undergo an amputation, death of a spouse or child, or other significant losses can experience these feelings intensely.

These emotions lead people to seek out others who have undergone a similar loss or experience. From these efforts, support groups develop. They meet many needs and can function in a variety of ways.

Probably the most common needs are for information and camaraderie, not necessarily in that order. There are so many things to learn about. How can one move on with life after so great a loss? To hear others share the facts but more, the understanding of the pain, fear and confusion, is of immeasurable value. One's experience is validated as others relate to the threat to identity, self esteem, and independence.

In Seattle, as in many other parts of the country, there is an Amputee Support Group at Harborview Medical Center, the area's Level I Trauma Center. It was established nearly 20 years ago for the express purpose of assisting with the amputation experience. This group meets weekly and is facilitated by a clinical nurse specialist who is, herself, an amputee. Other groups in the Northwest have emerged from this one in areas beyond Seattle.

As referred to above, there is typically a desire to find another person who has been down this road. In this instance, 'the road' is the experience of losing a limb. It is foreign territory to nearly everyone and a myriad of questions come to mind, including:

- what's going to happen to me now?
- how long before I heal, get a prosthesis, walk?
- are my feelings normal or am I going crazy too?
- who am I now? I don't feel as strong, capable, desirable, productive, etc. Am I still me?
- what are these 'phantom' feelings where my missing limb used to be?

Depending on how comfortable the members are with each other, a number of abstract as well as tangible issues may be raised in these groups. Recently, a male participant shared that he became tearful while singing in church last week. It stimulated a wide discussion about the grief process and individual variances involved in adjusting to limb loss.

Frequently, members will demonstrate their prosthetic limbs and answer questions about components, potential function, and suspension systems (how they stay on). Typically, people with new amputations are very grateful to have this type of exposure as they desire to become informed consumers in a high-tech field that they previously knew very little about. Pre-amputees are also encouraged to participate, as talking to others who are already moving on with their lives can defuse some of the fear of the impending surgery.

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The process of all this information gathering serves to establish the camaraderie. People come away from the group with comments like, "I don't feel so alone in this project now," and "It's good to know I'm not the only one who wonders what they did with my leg." People's feelings and questions are normalized as they listen and talk with others who have the same thoughts.

The Harborview Group was established by a nurse facilitator who knew from firsthand experience the great desire for information and support in adjusting to an amputation. Most support groups for amputees arise from this same awareness of need. Typically, the groups are not led by professionals but are lay persons reaching out to each other. Their approach to this goal can be varied.

Some groups have a structured style with formal presentations about common issues (medical, prosthetic, driving, sports, etc.). Typically, an informal question/answer session is included or fol-

lows these presentations. Other groups are traditionally informal and meet as almost a social gathering with regular lunches and annual picnics. Many groups are a mix of these two.

There is a national organization called the Amputee Coalition of America which has information on establishing, maintaining or locating a support group in a particular geographic area. It provides information that is valuable in forming new groups, setting up peer visitation programs, and even developing a newsletter.

The peer visitation program, a matching of trained visitors with similar amputations and lifestyles, is especially valuable as an outreach to new amputees. Besides the obvious benefit to the person with a new amputation, there is a heightened sense of purpose to his/her own loss as the visitor is now helping someone else recover.

Probably one of the choicest benefits of an amputee support group is the sense of empowerment experienced as patients learn from and share with each other. When a limb is removed, a feeling of helplessness or hopelessness may accompany it. Like most patients, a temporary dependence on the health care providers is necessary.

Someone has aptly stated, 'knowledge is power'. As the information and knowledge is shared, a realistic plan for recovery provides strength. Knowing what to expect minimizes the fear. People become survivors as they view others as survivors of a similar event. It becomes possible to get through the woods because others have done it and are willing to illuminate the path.

The important factor here is that one chooses to move out of the helpless patient role. Informed decisions put patients in charge of their medical care and give them the ability to gather further information from the health care providers. Decisions based on their own values and life experience replace those that might otherwise be made by doctors, nurses, therapists or prosthetists.

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