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PEER SUPPORT FOR AMPUTEES

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In our article in the last issue of *Amplified*, we outlined our research project, which we have been conducting at four rehabilitation centres across Victoria. As part of our study, we interviewed 60 people who were in-patients at these centres—2 in metropolitan Melbourne and 2 in regional centres—following the recent amputation of their leg(s).

Receiving support from other amputees

Social support plays a very important role in the lives of people who have recently undergone an amputation. Support comes from a range of sources—from family and friends, through health service(s), or from people who fall in between these two groups, support group members (such as yourselves) and peer support volunteers. Research has shown that, even while inpatients, doing rehabilitation in an amputee-specific environment provides important support and reassurance for many recent amputees as, through this, individuals are able to imagine themselves several weeks in the future (de Noordhout et al., 2004). For example, when you were an in-patient, there may have been other in-patients who had had their amputation a few weeks before you; seeing what they were doing provided you with a type of encouragement.

Many of our research participants reported that this was beneficial to them, and felt that seeing other in-patients 'doing well' (i.e. regaining mobility) was inspiring and provided them with an impetus to be actively involved in their own rehabilitation. For example, one man said he knew what to expect during his rehabilitation; other in-patients reassured him that he would regain his walking (bipedal) mobility (and therefore, his independence), and that this would happen more quickly than he originally thought. Having peer role models is important to enhance psychological and emotional health and wellbeing, particularly during vulnerable times such as soon after the loss of a limb. In a similar way, seeing long-term amputees visiting the rehabilitation clinic (such as during fittings with their prosthetist or outpatient clinic) was encouraging and inspiring.

Peer support volunteers helped recent amputees feel better about their situation, alleviated fears that accompanied the amputation, and responded to worries and concerns. A number of our participants had visits from peer support people around their amputation, which they found beneficial, not only helping them to become aware of what they could do physically after their amputation, but also to help them to come

to terms with their loss. Receiving a peer support visit had significant mental health benefits for recent amputees, as these visits allowed them to see that a 'normal' life was possible. For them, this often meant a life not dramatically different from before. This understanding of returning to their normal lives was particularly important for those who were depressed after their amputation and felt that the amputation was the end of their lives. Where they had no opportunity to chat with a long(er) term amputee, participants often expressed their desire to do so, and when they did, found that the opportunity to discuss their experiences with another amputee was a defining moment in their rehabilitation process. While formal aspects of rehabilitation largely stop upon discharge from the rehabilitation hospital, many very important parts of the adaptation process occurred outside of the hospital, when individuals need to re-learn many aspects of daily life and the basic skills associated with managing their amputation in their home environment. Peer support was important in this respect.

Providing support to more recent amputees

Many peer support volunteers had received support which had assisted them, and this helped them in turn to provide support for more recent amputees. For example, one younger long-term amputee (and support group member) had a friend who was a long-term amputee. Following his own amputation (from an accident), his friend provided him with a role model for what he could achieve. Knowing another amputee shaped individuals' desires to provide similar support to others. Others became involved in peer support organizations "just give a little bit back and give what I've taken out." For example, through being involved in a local, hospital-based peer support group, as with other support volunteers, one participant felt that he provided reassurance for new amputees in a time of uncertainty: "The deal is that you stay to talk. If they're a bit down, then the fact that I can walk in, walk out gives them a bit of a go of it, I think."

Continual involvement in support organisations also offers members ways to manage unexpected events that may occur during day-to-day life, from examples such as dealing with pressure sores from wearing a prostheses to issues around returning to work. One participant is an active member of on-line as well as local community-based amputee support groups; he finds that his participation in support organisations allows him to simultaneously provide and receive support. What makes this special is its uniqueness: it tends to be the type of support which cannot be accessed elsewhere: "The online community is basically about sharing tips and ideas, things we know what to. Sometimes you just have really, really bad days, now and then. And similarly there are people out there that are having a bad day as well... So it's the shared experience of amputation, I suppose, and the support." Knowing and accessing other amputees has been of central importance to his support group involvement, and has encouraged his formal and informal peer support visits.

What is unique about support groups is the way in which shared experiences enhance those of all of the group members; it is therefore greater than the sum of its parts. Each individual member of the support group brings their own experiences, skills and knowledge to the group; these then become part of the shared resources and, in this way, are able to be accessed by all of the group members.



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