The O&P EDGE

Elective Amputation: Making the Decision

August 2011 **By Judith Philipps Otto**

For prosthetists, therapists, and other members of the rehab team, limb loss presents a threshold to new possibilities—a first step toward functional mobility. For the individual struggling with the decision to sacrifice a body part, amputation is often a horror too alien to grasp. An elective amputation typically entails far more than the simple mechanics of an anatomical adjustment and consequential lifestyle change. Individuals confronting the decision to amputate also face issues of grieving the loss of the limb, dealing with social stigma, and the sometimes uncertain aspect of needing to connect with peers to get a realistic picture of what life with an amputation will be like.

Scott Rigsby, who in 2007 set a record as the first bilateral amputee to complete an Ironman triathlon, reflected on the conditions and attitudes prevalent in 1986, following the accident that claimed his right leg and severely damaged his left leg.

Photograph of Scott Rigsby courtesy of The Scott Rigsby Foundation.

"I grew up in a town of 5,000 people, where you just didn't see athletic amputees back then," Rigsby says. "You saw people just kind of getting around."

With no social media, just three or four TV channels, and no cable—there were no clues that amputees could lead active lives.

"My parents begged the doctor to please save one leg," he recalls. "At the time, they believed that even a makeshift, manmade, piecemeal biological leg was better than a prosthetic replacement leg—which is certainly not the case today."

Rigsby underwent multiple surgeries to replace his missing calcaneus (heel bone). Muscle grafts from his left shoulder and abdomen and skin from his thigh were used to create a housing for the bone chips taken from his spine.

"I was in a wheelchair for months, on a walker, then on crutches," he recalls. "I had to wait a year just to find out if I'd be able to walk."

When he did walk, it was still difficult because he had no lateral movement and only 20 percent dorsiflexion/plantarflexion. He discovered that his right leg (with the prosthesis) was carrying all his weight and compensating for the shortcomings of the remaining biological limb.

Twelve years later, after a steady stream of surgeries to correct a seam on the bottom of his foot that would bleed whenever he was active, Rigsby was having success with a new prosthetic running foot, but he was frustrated because his other foot was breaking down. "The usefulness of my makeshift leg was diminishing, and improvements in prosthetics were growing exponentially," he says. "A doctor in Athens, Georgia, mentioned the possibility of amputation—he planted the seed in my head. I thought about it for several months, then made the decision."

After making his decision, Rigsby had to deal with red tape and undergo a neuropsychological evaluation, which validated his choice. "The neuropsychiatrist said I should never have had the reconstructive [surgery]—I should have had both legs taken off at the same time. It would have saved me a lot of heartache and most of the 26 surgeries I have had. For 12 years I had been enslaved to thinking that this was the best that life was going to get for me."

Chino Acosta with grandson, Andres. Photograph courtesy of Advanced Arm Dynamics.

Other amputees have had similar experiences with extensive limb-salvage efforts and lengthy delays before ultimately moving forward with their amputation.

Chino Acosta, a victim of a work-related injury that crushed his hand, describes how doctors tried for more than a year to save just one finger, transplanting it to another position on his hand, where it provided very little function. A large muscle/skin graft was performed, using "a piece of meat, like a steak, from my leg," Acosta says.

During a conversation with a therapist from Advanced Arm Dynamics (AAD), headquartered in Redondo Beach, California, Acosta learned about the possibility of a prosthesis and the need for an amputation. "I had no doubt that it was time for me to do it," he says.

Oliver Ravenell's decision to amputate was medically necessary: "I had neuropathy and I had already lost a toe on that foot; my doctor was trying everything he could to save it, but when it wouldn't heal and gangrene started, there was only one choice."

Heather Wood, CPO, with Oliver Ravenell.

Ravenell's experiences during his months in rehab prior to the amputation, as well as the support he received from his family and rehabilitation team, helped. "Seeing all those other people that had problems helped me grow into it," he says. "There's no room for self pity.... I always was active, and I know if I didn't have [the] amputation, I wouldn't be able to be active anymore."

Knowing his prosthetist, Heather Wood, CPO, was in the operating room alongside the surgeon gave him confidence—and waking up in recovery to find a temporary transtibial prosthesis already in place was a wonderful surprise, Ravenell says. "It really lifted my spirit up—especially when I was able to take a few steps the very next day."

Opting for Amputation

Smith

Douglas Smith, MD, orthopedic surgeon and professor of orthopedic surgery at the University of Washington (UW), Seattle, and a UW Medicine orthopedic surgeon at the Harborview Medical Center, also in Seattle, says that there are a variety of factors that lead patients to abandon limb-salvage in favor of amputation. "The one that leads to the amputation decision most abruptly is infection. Often, there is less discussion when it is infection-related because it is a real medical problem; they feel sick. There's the risk of the infection spreading further, and the added risk of severe sepsis that could stress their heart.

"Another factor that can drive the decision is an inability to actually get the bone to heal or the soft tissue envelope to really heal and cover things," Smith explains. " Several months into the salvage, if healing is not successful, it can lead to increasingly elaborate efforts that require additional grafts."

"At this point, sometimes people start realizing that other parts of their body are continuing to be harvested to save a limb, and they start asking themselves if they want to give up more skin. Another flap? Another bone graft? They may decide, finally, that it's not worth continuing to take other parts of their body to save this arm or leg. "Other reasons Smith cite

are pain, lack of function, and a sense that life would be better with amputation and a prosthesis.

Pain Drives Decision Making

Although pain is expected with injury and surgery, most people expect it to gradually diminish, Smith points out. "When people get into a chronic pain situation, it's incredibly difficult. It's there all the time and drives their thinking, it changes how they look at things, it makes it hard to be positive interacting with family and friends."

Patients begin to consider if an amputation would relieve their pain and assume that when the painful part of their anatomy is gone, the pain will be gone, which is not always the case, Smith cautions. "Pain after amputation is very unpredictable; 12 to 15 percent of amputees have really severe pain; many more have pain at moderate levels. In medicine, we expect the treatment to get rid of the pain in 90 percent of the cases, and amputation is not like that. Patients need to be made aware of this before they make a pain-based decision."


Miguelez

John Miguelez, CP, FAAOP, president and senior clinical director at AAD, notes that it is difficult for some patients to decide if the pain is bad enough to justify amputation. "Chronic pain doesn't necessarily need to be a ten on a one-to-ten scale of intensity to really wear you down. If it's a four, but it's a four for 21 months, that wears you down," he says. "Many patients have struggled with the question and realized that unremitting chronic pain was really limiting them; they want to live their life today. But at the same time, young patients may be looking at another 50 years ahead and want to be sure they don't do something today that they may regret in 25 years when new solutions may be available."

Wendy Beattie, CPO, FAAOP, Becker Orthopedic, Troy, Michigan, also warns against hasty amputation choices in pursuit of pain relief. "Maybe amputation isn't the right answer for someone in pain," she says. "There are some people who are in pain that amputation won't help with the pain. You still have to weight bear through your joints—so if it's a joint pain, it may not help." Many patients with chronic pain have reflex sympathetic dystrophy (RSD), and amputation may not get rid of the pain, Beattie explains. "It may just move more proximal, so instead of having pain in their foot, they have pain in their knee or their hip. That's part of what we tell the patient—that it's not a simple decision."


Beattie

Lack of Function also Motivates

"If they go through salvage, trying to save their limb for a year or a year and a half, and they still can't put their weight on the limb, people ask themselves, 'What good is my leg if I can't walk on it? If I have an amputation, can I go through prosthetic fitting and rehab and walk again?'" Smith says, adding, "and that will drive decision making."

Predicting functionality following an upper-limb amputation and prosthetic fitting is more difficult. "There are many people who have arm amputations who are disappointed," Smith reports. "Even with the most advanced arms, they are still disappointed in the function."

Miguelez notes that for potential upper-limb amputees, the conversation about amputation typically starts somewhere between eight and 21 months after the initial injury and salvage effort and is largely prompted by chronic pain and/or a significant functional deficit, as with a flail arm or brachioplexus injury. "The nerves can be reattached through surgery, or they can regenerate on their own, but if some return of function hasn't occurred within that eight-to-21-month window, it's highly unlikely that it's going to occur. So then the patient says, 'This is in my way all the time and it's painful; what are my other options?'

"It always comes back to the patient making that personal decision. I don't ever want to be in a situation where I've talked a patient into revision or amputation surgery," Miguelez adds.

Each person deals with the decision at his or her pace, based on his or her own level of tolerance. **Mac-Julian Lang, CPO,** clinical director of Advanced Arm Dynamics' Northwest Center of Excellence, Portland, Oregon, mentions people who, like Rigsby, have elected to have amputations as many as 15 to 20 years after their initial injury.

Lang

"Both patients said they wished they had done it ten years earlier," Lang says. "The weight of an arm that doesn't have any function takes a toll on their body; physically they can't handle having that weight there anymore. A prosthesis, if it's well-built and fit appropriately, should weigh less than the portion of the arm that ends up being amputated…."

The length of the decision-making period also may vary due to individual differences in getting through the grieving process.

Lang notes that the depth or severity of grief experienced over losing a limb has been compared to that of losing a spouse. "Expecting someone to just get through it on their own is not being the best advocate for that patient."


Rossbach

Paddy Rossbach, RN, former president and CEO of the Amputee Coalition, observes that many people working their way to an amputation decision do their grieving prior to the amputation. "It's an interesting thing—they want to save the leg or arm, and yet they're preparing to lose it," she notes. "I think they're quite surprised afterward that they can feel so good about it because the problems and pain that they had to deal with are gone and they can start looking ahead; the majority of them realize that they're better off. They don't grieve nearly as long afterward as somebody who has a traumatic amputation—and one day it's there and the next day it's gone, and they have to do all their grieving afterward."

Several sources cited multiple cases of individuals who struggled and suffered mightily in order to save arms or legs—and years later wished they had opted sooner for the amputation that dramatically improved the quality of their lives.

Judge Jack Farley, an amputee and peer visitor at Walter Reed Army Medical Center (WRAMC), Washington DC, recalls a young man, "one of the early injuries in OIF [Operation Iraqi Freedom], who had a shattered ankle, left the hospital, went home, went back to school, and tried to lead his life for a year—but 13 months later he came back to Walter Reed and said, 'I want an amputation.'

"He found the pain and the lack of mobility from his shattered ankle and foot were just limiting him," Farley continues. "He had the amputation, and eight weeks and one day later he was skiing in Colorado on his prosthesis—alongside me."


Farley

How Much Function Is Too Little to Live With?

The toughest call, Smith says, is when a person with a severe limb injury has salvaged some function but it isn't as much as they would like, prompting them to consider amputation.

Smith feels that when physicians discuss "salvaging" a limb, patients and families hear and expect a whole, "normal" limb—that will be as good as it was before, and they are thus horribly disappointed by the limb's great limitations.

Complicating their amputation decision is the recent media attention given to "miracle" bionic prostheses, encouraging great expectations from potential amputees.

"Historically, patients came to us believing that [limb loss] was worse than it really was," Smith says. "That actually made our job easier because they had an average outcome and they were happy. Now, especially within the last five years, many of the people are coming to us with overly optimistic views of how amputation and prosthetics work, and if we don't help educate them back into the realm of reality, they will have an average outcome and be horribly disappointed."

Beattie also stresses realism when she talks to pre-amputation patients. "If you were walking with a walker before the amputation, there's an excellent chance you're going to be walking with a walker after the amputation."

Farley notes that the military is providing extensive rehabilitation, realistic guidance and counseling regarding amputation, and that amputee peer visitors at WRAMC are regarded as part of the treatment team. He describes bringing friends to the bedside of a patient deliberating between a transfemoral amputation or a stiff knee. "We each stand on one side of the bed and we answer questions about the pros and cons of either decision; it just helps them gather information."

Every source agrees that the importance of peer exposure and influence can't be stressed enough. Peers provide non-judgmental input, personal testimony, and a level of understanding potential amputees can find nowhere else—but peers do not advise others regarding their personal decision—a vital distinction, all agree. That decision belongs to the patient alone.

Rossbach notes the importance of matching peers of similar ages, interests, and injuries, and Beattie agrees, further cautioning guidance regarding the type of contact your patient may be making. "That one poorly adjusted patient, still bitter after 15 years? What happens if your prospective amputee steps into a room filled with that kind of person? That's not going to help them make a good decision."

Instead, she prefers to set up meetings (ostensibly accidental, when necessary) in her own office, between successful and experienced patients and prospective new amputees—carefully matched in terms of age or potential—to offer them the best chance for a realistic view of their future with an amputation. "Success but realism for the individual is always the goal; you want them to be told the good with the bad so it is a decision made with knowledge of the potential outcomes."

"Everything I ever learned about being an amputee, I learned from other amputees," Farley concludes. "Too often in the past, decisions were made for amputees, not by amputees. But not anymore."

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