

Caregivers Are Key to Recovery, Success

FOR INDIVIDUALS AFTER AMPUTATION

By Betta Ferrendelli

IN AUGUST 2007, Merlyna Valentine was an elementary school principal planning for another school year in LaPlace, Louisiana, when she first felt an excruciating pain in her side.

While she waited for treatment, a nearly 10mm kidney stone caused a blockage, which allowed an infection to spread throughout her body. She experienced sepsis and complications including renal, heart, and respiratory failure. Blood flow to her limbs was compromised and eventually caused the tissue in her hands and feet to die, resulting in amputation.

When she was released from a lengthy hospital stay, she needed 24-hour care.

At the time Valentine was not married to her husband, Tory, who stayed by her side the entire time she was in the hospital. (The couple married in 2011.)

"He lived more than an hour away, but nothing stopped him from being there," Valentine says. "It wasn't long before Tory decided to move to my city and asked me to become his wife. He had already committed to making my dream of being a principal again his priority."

Tory has been his wife's caregiver since 2008 and says caregivers should work diligently to provide a safe, nurturing, and supportive environment for their loved ones through their words and actions.

"My biggest role is to provide my wife with the emotional and spiritual support she deserves," he says. "I've learned the power of my words in helping her build her resiliency and emotional well-being. My response to challenging times impacts her feelings and ability to persevere."



The Importance of Caregiving

The caregivers are often the cogs that hold this medically fragile situation together. Caregivers are important for direct physical care such as transportation, appointments, transfers, and dressing changes, as well as emotional support as their charges cope with the loss of a limb. Indirect physical needs are also important—filling in for such things as childcare and home care, our clinicians say.

“An amputation is a loss for our patients, and they must go through the grieving process following surgery. A support system is invaluable both for emotional and logistical help following amputation,” says Chris Lemonis, CPO/LP, Orthotics and Prosthetics Center (OPC), Charlotte, North Carolina.

Facing the unknowns and the obvious challenges of amputations is hard, says Matt Bulow, CP, Bulow Orthotic and

Prosthetic Solutions, Nashville, Tennessee. He notes some of the ways that having a partner is especially key in the first year. “Helping to manage appointments, offering physical assistance as needed, and simply being there as a friend are key examples.”

Carina Hill, OTR, MOT, and Rob Dodson, CPO/L, Arm Dynamics Southwest Center of Excellence, Dallas, are the care team for Valentine’s upper-limb prostheses. Caregivers, they say, are not just the physical assistance that a person with an amputation may need, they may also end up being the social and mental health support system.

Hill and Dodson cite the World Health Organization’s definition of health: a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity. “If the person who had the amputation has no other avenues to address the mental

health or social support, they may be leaning heavily on the caregiver to fulfill these needs as well,” they say.

Tori Felten, CPO/L, CTP, Hanger Clinic, Rochester, Minnesota, provides care for Jim Ellefson, whose wife Donna acts as his caregiver. Ellefson has a lower-limb amputation and a host of other health problems.

“In working with patients and caregivers, it is helpful when a patient has a strong support system, especially after losing a limb,” Felten says. “Early on in recovery there are many incisions and volume checks the surgeon will likely be performing, so having someone who is willing to bring you to appointments and keep you company is beneficial.

“Caregivers are an amazing part of a patient’s well-being by providing companionship and emotional support, so the patient does not feel they have to walk the journey alone.” ➔



Tory has been his wife's caregiver since 2008, and she says he has become an expert in helping her apply her makeup.
Photograph courtesy of Merlyna and Tory Valentine.

Holistic Care: Where, When to Begin

How early should caregivers be part of their loved ones' recovery and rehabilitation process?

As early as possible, says Zach Harvey, CPO, Hanger Clinic, Denver, who provides care for Christine Lentz. Lentz lost her hands and feet due to sepsis and toxic shock syndrome in January 2014. "The thought of losing a limb can be overwhelming, and the more knowledgeable a caregiver is, the more he/she can be there to talk about decisions," Harvey says. "During appointments it can be helpful to have another person there to ask questions that the affected person may not think of."

Caregivers should be involved in every step of the process, ideally even before the amputation surgery, Lemonis says. "Being prepared for their loved one's amputation by knowing what to expect helps caregivers to provide that best support possible."

Extra eyes and ears can only benefit the patient, Hill and Dobson say. "The person with the amputation may not have the mental bandwidth to comprehend all the pieces that are set into motion from the onset of the injury," they say. "From understanding surgeries and medication management, to setting appointments with providers and wound-care management, and eventually exploring long-term needs, having a second set of eyes and ears is beneficial in optimizing outcomes."

Lentz spent seven months in the hospital in 2014 and went through 20 surgeries before she was able to return home. "The patient can't recover without the caregiver. An amputee, especially a quad, is quite helpless in the early stages of recovery," says Lentz, who was unable to speak, eat, or move on her own and relied on her husband, Mike, to help with caregiving. "I needed to know I had someone I could trust 100 percent to care for me while doing the most basic and often most demeaning tasks. I had a long recovery and I needed to know that my caregiver was committed to stick with me and be my cheerleader for the long ride."



Lentz relied on her husband, Mike, to help with caregiving after returning home from seven months in the hospital.

Photograph courtesy of Christine and Mike Lentz.

How Can Clinicians Help?

What advice, tips, and suggestions can clinicians offer to help caregivers care for their loved ones and be part of the rehabilitation team?

Addressing caregivers in conversations with the patient is key, Harvey says. "That empowers them to ask questions, talk about concerns, and figure out their role. It also acknowledges their sacrifice in the added responsibility they may be facing."

The most important thing clinicians can do is put themselves in the seat of the patient, Bulow says. "What would you need to hear? What type of an approach would you find most appealing? Would it help you if someone wrote down a few key notes for you to remember? Asking yourself these types of questions can lead to awesome personalized prosthetic care and something we should challenge ourselves to do."

Educate, educate, educate, Hill and Dodson say. "I'm a big proponent of writing things down, so I try to advocate for the patient and their caregiver to create a binder or notebook that encompasses their care," Hill says. "Each provider has their specialty, and they may or may not communicate with other providers, so it is incumbent for the patient and the caregiver to manage that themselves."

Felten has worked with the Ellefsons since February when Ellefson had a lower-limb amputation. "After fitting Jim with his prosthesis, I worked closely with Donna to show her how to help Jim use his new leg."

Donna's background as a registered nurse for 30 years is evident as she cares for her husband, Felten says. "She is a very detail-oriented caregiver who shows great compassion to her husband while

taking care of him. She states that her home is a 'mini hospital.' She knows it is a lot of work, but she'd rather have him home to be best cared for than in a care center."

Too Much Care?

Our clinicians and families agree there is such a thing as too much care.

From a clinical perspective, caregivers can, inadvertently, keep their loved ones from pushing themselves forward in rehabilitation due to their own fears, Lemonis says. "Walking with a prosthesis is difficult," he says. "There's no other way to sugarcoat it. To be successful ambulators, amputees must be willing to push past their comfort zones."

The question of too much care is tricky, according to Hill and Dodson.

"It all goes back to the patient. Perhaps the patient has dissociated as a result of the trauma and engaging in tasks requires more effort than it did previously. The caregiver may need to step in and help more," they say. "If the patient is fully aware and capable of making decisions, yet the caregiver attempts to make decisions contrary to the patient's wishes, then, yes, they may be overstepping their bounds."

When a caregiver takes too much of a lead and talks over the patient, too much care can be disruptive, Harvey says. "Taking too much of a lead can make the patient shut down or become argumentative," he says.

From a caregiver's point of view, Donna says, "You do not need to do everything for the patient." Rather, encourage them to do as much as possible for themselves for as long as they are able, she says. "Provide them with positive feedback and encouragement so that they may realize they can continue to improve."

Caregivers must continue to communicate with patients to determine the level of care needed, Tory says. "I communicate with my wife and let her lead me in the amount of support needed," he says. "As she recovered and reclaimed her quality of life, she worked to become more independent. I offered assistance until she expressed that she was ready to try things on her own."



The Ellefsons recently celebrated their 50th wedding anniversary. Donna says caring for her husband can be a lot of work, but she'd rather have him home than in a care center.
Photograph courtesy of Donna and Jim Ellefson.

Tory says it is challenging at times to determine when he needs to step back and allow his wife to attempt new tasks independently. "As her husband, I want to protect her from difficult situations, but she will remind me that she will only feel like a failure if she gives up, never tries, and quits," he says. "Caregivers can give too much care in their attempts to serve the patient. They must allow the patient to work toward more independence when possible."

Mike says it isn't so much too much care as it is the wrong type of care.

"If you do things for the patient that they should learn to do themselves so as to be more independent, then you are delaying their progression," he says. "You can't let the patient get lazy and have everyone do everything for them. It may seem great for the patient in the short term, but in the long run they will feel like a child having everyone do everything for them."

Neighbors and Golf

It is often said that the hardest part of being a caregiver is being the caregiver. Often their wants and needs are ignored, typically because caregivers must provide so much support to their loved ones, from doing household chores and tasks to providing personal care and being the patient's best advocate.

"The adage is true," Tory says. "You can't pour from an empty cup. Being a caregiver is an important role and puts significant demands on the caregiver." To do what's needed, the caregiver must be healthy and stable, says Tory, who finds his best outlet is playing a round of golf—and he says his wife lets him know when he hasn't played in a while.

The patient needs an outlet, too, says Valentine, who retired in 2013 after returning to work as a principal in 2011 and has become a motivational speaker. "I love a good book," she says. "But what really recharges me is being able to step ➔

on stage and share my message.”

Donna says their next-door neighbor is a blessing. She comes over with her calendar to help Donna plan for care for her and her husband.

“If the caregiver does not care for themselves, they can develop burnout, exhaustion and fatigue, as well as health issues of their own,” Donna says. “When this happens, it is almost impossible to give good care to your patient.”

Common suggestions for caregivers can eliminate these issues, however, they do not always apply to everyone’s personal situation, she says, so it can take some extra consideration to find the right options. “That may include getting some help from family so you can get out occasionally with friends or shopping or maybe for lunch,” says Donna, who likes getting away from the house for a while to have a manicure and pedicure. “Getting support from VA caregivers to come in and spend time so you can get a break, or even a neighbor, which I have done.



So blessed to have the best neighbors right next door.”

From a clinical perspective, “We all need to recognize when we are tapped out and find ways to recharge so we can reengage in life,” say Hill and Dodson.

“When your role now includes being a caregiver for someone else, there needs to be some recognition that someone else is now depending on you,” they say. “Does the caregiver have the self-awareness, and can they be honest enough with themselves to recognize what they are able to give? Do they have an outlet as well to care for themselves?”

What suggestions can clinicians give caregivers to help them with their own care and well-being?

“First, try to shed any expectations—whether it’s been placed on them by others or themselves,” say Hill and Dodson. “This is unknown territory for most people. How they respond is valid and they should not be made to feel otherwise.” ➔



Secondly, Hill and Dodson say caregivers need to try to recognize what they're able to give and, as it relates to that, realize that it's okay to reach out to others for help.

Thirdly, caregivers need to recognize that their loved ones may still be going through the healing process internally and may not be able to communicate effectively, Hill and Dodson say.

Caregivers are often under-recognized in their extra efforts, Harvey says. It's important to recognize their sacrifice and support them as someone wanting to help, he says. Offering to help—dropping off a meal, offering to take care of pets or kids, or simply some kind words—can go a long way, he says. “As clinicians, we can help educate on expectations, timeframes, and resources,” he says. “Asking the right questions and addressing the patient and the caretaker can prompt this discussion.”

Caregivers should recognize that it is not their responsibility to do everything for their loved ones following amputation, says Lemonis. “Truly, they should be encouraging the amputee to return to the tasks they performed prior to amputation,” he says. “They should also understand that rehabilitation following amputation is a long process.”

Following amputation, it takes about one full year for individuals to return to performing all the daily activities that they engaged in prior to amputation, Lemonis says. “They will continually add new capabilities over that first year,” he says. “There will be good days and bad days, and it is all part of the process.”

The person being cared for should also support their caregiver, says Lentz. “How can the amputee help? Mike and I do this by me having friends and family that I spend time with, by me getting my driver's license so I have

more independence, and me having a part-time job so that I am busy during the day and can contribute a little to the household expenses.”

Though being a caregiver can be demanding, and by nine p.m. most nights Mike is spent, he says his job is much easier than his wife's.

“It is such an extreme in the world of amputees that it was very difficult to comprehend how life was going to be once she came home from the hospital,” he says. “But the earth is going to keep spinning no matter what you do, so you figure things out as you go, and you don't sweat the small stuff. If the kitchen is a mess and you want to go to bed, go to bed. The kitchen can be cleaned in the morning.” **O&P EDGE**

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