



Amputation Through the Waist

by Douglas G. Smith, MD

As we have discussed lower-limb amputations, the tone has grown increasingly serious as the amputation levels have gotten higher. This is not because one amputation is more “serious” than another. Rather, the higher the amputation level and the closer the surgical site is to the core of the body, the greater the physical and emotional challenges. Issues of life and death may even be involved, especially with amputations at the pelvis and waist.

In this column, our final one on lower-level amputations, we discuss the waist-level amputation. The changes brought about by this type of amputation are, without a doubt, profound. The tone of this column is, therefore, the most serious to date.

Though the outcome of amputation surgery can be amazing, with people living renewed lives as they move beyond the injuries or disease that led to their amputations, we should acknowledge and understand that sometimes the outcome isn't optimal, and sometimes none of the choices are good. Occasionally, decisions are made that, to others, may not seem right. People may choose not to have a particular surgery, even if it means their disease will progress. But I think it's important for patients, their families and friends, and healthcare professionals to recognize that some decisions are indeed uniquely individual. There's just not a universal “right answer” for everybody. This is especially true with amputations at the waist.

The waist-level amputation, which is also called the translumbar amputation, transabdominal amputation, or hemicorporectomy (HCP), is the most extensive and extreme of all amputation levels in terms of structure and function. This type of surgery is described in one text as a “heroic effort to save the patient's life in the face of severe trauma, infection or cancer.” It can also be an option for spinal-cord injury patients who have a long history of debilitating backside ulcerations and bone infections when no less-extreme medical or surgical options for treatment remain.

This amputation level is unique, too,

in that it involves loss of functions other than walking, grasping and touch. The waist-level amputation also means the loss of the organs for reproduction, bladder and bowel functions and the loss of sitting ability.

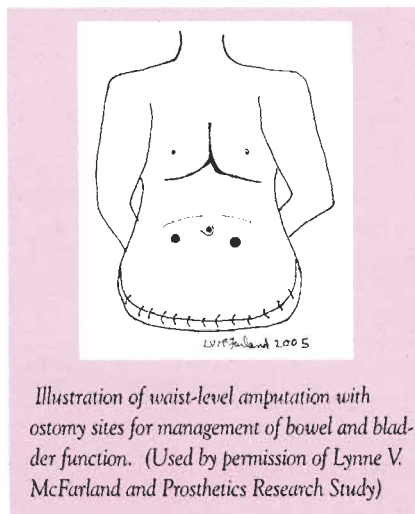


Illustration of waist-level amputation with ostomy sites for management of bowel and bladder function. (Used by permission of Lynne V. McFarland and Prosthetics Research Study)

Because so many bodily structures and functions are affected by transabdominal amputations, a large surgical team is required. Though most amputations are performed by one surgeon with a team of assistants, transabdominal amputations can require the skills of an orthopedic surgeon, a neurosurgeon, a general surgeon, a urology surgeon, and a plastic surgeon. An orthopedic surgeon is needed for the muscles and skeleton, a neurosurgeon for dividing and managing the spinal cord, a general surgeon for managing the colon, a urologist for

dealing with the bladder and kidneys, and a plastic surgeon for managing the complex closure of the surgical site. Getting five surgeons and surgical teams to coordinate this complex and staged procedure is indeed quite a challenge.

A Difficult Decision

The decision to have or not to have a waist-level amputation is a life-changing decision. The person loses everything below the waist. In addition to bones, muscles and tendons, the urethra, colon, rectum and sexual organs are removed, and ostomies are, therefore, needed for bowel and bladder function. The surgical procedure can last up to 13 hours, and survival is not certain. In addition, recovery and rehabilitation involve major life adjustments. When making a decision about this type of surgery, therefore, patients understandably want to consider it carefully, primarily because of quality-of-life issues.

Though this amputation level was pioneered in 1960, there are fewer indications for it than there used to be, and it is rarely performed today. Diagnostic techniques have improved since the '60s, and chemotherapy and radiation treatments have become more effective, leaving fewer people with the need to consider this difficult choice.

Even when it is an option, with thorough education and the

understanding of all involved, it has become very rare for patients and surgeons to decide to embark on this course. Education is extremely important for all concerned because even most healthcare workers have never been exposed to this amputation level. Though the first instinct of physicians and patients alike can be, "We're going to save life and that's the most important thing," with an understanding of the dramatic changes that will occur in the person's quality of life, the decision-making process becomes much more complex.

Prosthetics: The Primary Goal Is Sitting

This amputation level radically changes our concept of prosthetics. In other lower-limb amputations, the prosthesis is used to replace the foot or the leg and is designed for walking. In upper-limb amputations, the prosthesis replaces the hand or arm and is designed for grasping, manipulating objects, and using tools. In waist-level amputations, however, the initial prosthetic goals are simply for sitting. Still, some notable patients were able to successfully tolerate sitting and the pressure the prosthesis placed on their abdomen and ribs and then advanced to some level of walking. They would use standing prosthetic limbs with crutches or a walker and do a swing-through walking technique. This allowed them a bit more independence and improved their ability to reintegrate into life outside the home.

To meet the initial goals of the waist-level amputee, the socket and prosthesis are designed solely to get the person upright. Because sitting typically involves the buttocks and backs of the thighs, traditional sitting is no longer possible because there is simply nothing to sit on anymore. Since the buttocks and pelvis are removed in a transabdominal amputation, it becomes necessary to design a prosthetic system to get the person upright, which is, in a sense, sitting. Without a prosthetic support, the only options are to lie face up or face down.

As we discussed in our series on the hip disarticulation and transpelvic

amputation levels, as you get close to the core of the body, a socket looks less like what we typically envision as a conventional socket. It is no longer a socket that fits onto the end of a limb; in the case of a transabdominal amputation level, it encompasses the abdomen and lower ribs.

A person typically won't use a transabdominal prosthesis throughout the day. While we can make a device that supports the abdomen, back and the ribs, most people choose not to use a prosthesis because it pushes up on the abdomen and ribs, making it very difficult to breathe. Generally, it's not well tolerated for more than short periods at a time.

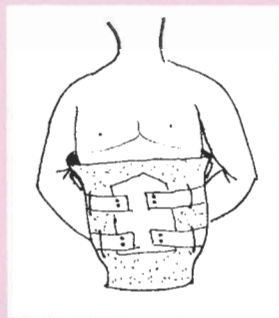


Illustration of sitting prosthesis for individual with waist-level amputation. (Used by permission of Lynne V. McFarland and Prosthetics Research Study)

For those individuals who do master sitting and can breathe comfortably with the increased pressures on the rib cage, a few are able to advance to short periods of walking. Wearing prosthetic limbs that allow them to remain upright in a standing posture, they walk for short periods using crutches or a walker. The typical walking technique is positioning the



Illustration of standing prosthesis for individual with a waist-level amputation. This type of prosthesis places even higher pressures on the remaining abdominal area and the rib cage, making deep breathing difficult. (Used by permission of Lynne V. McFarland and Prosthetics Research Study)

crutches ahead, leaning forward on the crutches and then swinging the body and prosthesis forward through the crutches.

Though walking in this manner is limited, it does allow the person a bit more freedom and mobility. A few folks are even able to drive in specially designed vehicles that allow them to use the accelerator and brakes with hand-controlled devices.

If You Can't Sit, Then What? The Prone Cart

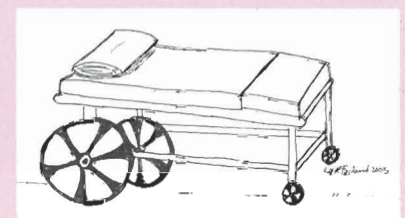


Illustration of a prone cart. (Used by permission of Lynne V. McFarland and Prosthetics Research Study)

Because of breathing and comfort problems associated with the socket and sitting up, many individuals with this amputation level lie on their backs or bellies. Unfortunately, there are problems with this too.

When you lie on your back, your arms and hands are in a nonfunctional position for mobility. If you tip the bed up, the pressure returns to your ribs and abdomen, making it difficult to breathe.

The other option is to lie face down, which is called prone. For mobility, a person with a transabdominal amputation may use a device called a prone cart. It's about waist high and has four wheels. Lying face down, the person uses his or her arms and hands to move and guide the cart. Unfortunately, to look forward or from side to side, the neck must be hyperextended upward. But thanks to advances in technology, newer models can be motor-driven, with the operator propelling and guiding the cart using a hand-held device.

When There Are No Easy Choices

Most programs that performed waist-level amputations have stopped doing them

over the past couple of decades because of quality-of-life issues.

In my 16 years of surgical practice at Harborview Medical Center in Seattle, Washington, I've encountered five or six people who were possible candidates for transabdominal amputations. With each patient, we discussed the complexities of surgery, reviewed photographs, and outlined rehabilitation and life with a waist-level amputation. Each person said, "I'd never want to live like that," and decided not to have this drastic procedure. It's not unusual for a person facing a waist-level amputation to make an active choice not to do it.

Issues of death and dying are also a major part of the decision to have or not to have a transabdominal amputation, as they are with many other medical conditions. For example, people in the latest stages of severe diabetes may have to confront incredible complications, which can include circulatory and neurological problems in the extremities, heart and stroke issues, kidney failure and dialysis, and loss of vision. For many people in these late stages, the event that often pushes them to make a decision about living or dying is a severe infection or gangrene. They must decide whether to have an amputation, often at the thigh level or higher, or to let Mother Nature take its course and get their final affairs in order.

With some medical conditions, there can be options. People with kidney disease almost always choose to undergo dialysis to extend life, hoping someday to receive a kidney transplant, even though dialysis is very time-consuming and the treatments must be done at least three times a week and can last for four to nine hours per session.

The person spends that time hooked up to a machine that removes the blood from the body, cleanses it, and returns it to the body, taking over the function of the kidneys. It's not easy. The person's whole life can soon revolve around the continuous need for dialysis treatments.

Though the medical equipment involved has improved in recent years

and is more widely available than ever before, the need for dialysis is relentless, and most people hope they'll have an option later for a transplant that will allow them to live a dialysis-free life. But if at some point they feel their quality of life has deteriorated too much, they may choose to discontinue dialysis, which will lead to death.

A very wise physician who specialized in geriatric medicine taught me that many people in the very late stages of diabetes feel as if they're on a medical roller coaster that won't stop and that they can't get off. Having seen the extreme emotional upheavals a person can be subject to at this time, a doctor may educate people in the end stages who are undergoing dialysis that they have a choice to discontinue treatments if they want to. Many people don't realize that they are free to make such a choice. In fact, one patient told me that he thought he would be breaking the law if he asked for dialysis to be stopped. When people stop dialysis, they develop uremia, which is a buildup of the toxins that our kidneys normally remove. They become sleepy and lethargic. They say there's no pain. Usually, a person passes away sometime between one and three weeks after stopping dialysis.

The geriatrics physician I mentioned makes a strong point that "knowledge of this option and having a choice" are what's important to people, not the cessation of dialysis. He told me that very, very few people actually choose to stop dialysis. But the patients feel much better knowing that they have a choice. Knowing we have options makes it easier to deal with the emotional ups and downs of the medical roller coaster. Knowledge and choice empower people and can liberate them from feeling trapped.

It's sad, but nonetheless true, that many people in the very late stages of life feel pressure from their families to keep fighting a terminal battle. Families sometimes don't realize or want to acknowledge that a person's final wish can be to pass away with dignity and respect. When asked, most people would

say they don't want to die on the medical roller coaster in the midst of heroic procedures. I'm often intrigued when I meet those in the late stages of life who show in their eyes that they know their time has come. They want it to happen with peace, dignity and respect, while they are surrounded by understanding loved ones. But sometimes their families continue throwing out words like "fighting," "battling" and "winning the war." I often see terminally ill people surrender to the family's wishes and continue on this very rough and ragged medical roller coaster. They give up their final dream to die with peace and dignity.

Relatives may believe they're rallying the patient. The attitude is, "We always fight death. Never surrender." But they may not realize that they can be taking away the final wish of someone they love. People don't dream about dying in an emergency room, undergoing heroic measures that would give them just a bit more time shrouded in illness and pain. It's a difficult thing, but the best thing a loved one can do is ask the person, "What do you want?" The answer may not be easy to accept, but it is the loving thing to do. As noted science fiction writer Isaac Asimov said, "Life is pleasant. Death is peaceful. It's the transition that's troublesome."

Hospice Care

Dying certainly is something nobody looks forward to, nor do many of us even care to ponder our own mortality. But it is reality for everyone at some point. For many, hospice care under the guidance of skilled and specially trained health-care team members can be a preferable alternative for the final days or weeks. As wonderfully stated by Ralph Waldo Emerson, "Our fear of death is like our fear that summer will be short, but when we have had our swing of pleasure, our fill of fruit, and our swelter of heat we say we have had our day."

Hospice is a program designed to care for the dying and their special needs. The American Academy of Family Physicians recommends hospices provide the

following:

- Control of pain and other symptoms through medication, environmental adjustment and education
- Psychosocial support for the patient and his or her family, including all phases from diagnosis through bereavement
- Medical services to adequately meet the patient's needs
- An interdisciplinary team approach to care, patient and family support, and education
- Integration into existing facilities, when possible
- Personnel with expertise in the care of the dying and their families.

More information on hospice, comfort care, and end-of-life issues and needs can be obtained from your physician and other medical health professionals. There are numerous hospice-related Web sites, such as www.hospicenet.org and www.hospicefoundation.org. A book titled *The Comfort of Home*, by Maria N. Meyer, also details the various aspects of home care for patients, their families and healthcare professionals.

Some Concluding Thoughts on Lower-Limb Amputations

As we've taken this surgical journey from toes to waist, what emerges is that amputation of any kind is a challenging adjustment. There are universal factors, whether a person has an amputation of a toe or of an entire leg. The physical aspects are

clearly different at different levels and range from shoe trouble to gait challenges to an amputation where you can no longer even sit. Emotionally, the loss of part of your body also has a great impact, but the emotional response to this loss doesn't necessarily correspond to the amputation level. While I've tried to emphasize that it's physically more challenging when a person loses more, the emotional response is harder to predict. I've seen a person's life become totally derailed after the loss of a toe, while I've seen others lose an entire leg and rapidly get on track and move forward.

As I've tried to emphasize the challenges and difficulties related to amputation, it may have seemed that the tone of these discussions became more "negative" as the amputation levels moved higher. That certainly wasn't my intent, but the seriousness of these challenges is a reality that all people with these amputation levels and their families and friends must face. All amputations are serious, but as the surgical site moves closer to the core of the body, we see that people's emotional response to it becomes more and more pronounced. Survival and quality-of-life issues enter more and more into conversations between surgeon and patient.

But what I've also seen played and replayed in my years of surgical practice is that, frequently, wondrous and wonderful things happen for people as they overcome limb loss. I've enjoyed seeing many people return to the activities they love and take on new challenges as their lives progress. I've also seen the best of human nature emerge as people overcome the challenges and become more insightful, compassionate and understanding about themselves and others.

I've been blessed, for example, with opportunities to help care for a vast range of individuals, including seniors with vascular disease and diabetes, children who suffered traumatic injuries in lawn mower or traffic accidents, firefighters who lost a limb in the line of duty, workers injured while logging or fishing, and our brave soldiers fighting the war on terrorism.

Recently, I've been privileged to assist in the care of soldiers injured in Iraq and Afghanistan. While at Walter Reed and Brooke Army medical centers, I've come to realize that we, as a country, are incredibly fortunate to have such dedicated, heroic individuals willing to put their lives on the line for the good of our nation. I have no doubt that I've seen many of our future leaders and I've come away feeling lucky and optimistic. These injured young men and women are inspiring individuals who are now and will continue to be great leaders. They make me feel very good about the future of our country. ■

"A person who chooses to die or risk death demonstrates that there are values, principles, maxims that are more valuable to him than is life itself. In short, he places his immortal self above his mortal self."

— Henry David Thoreau