NOTES From the Medical Director

Higher Challenges

Amputations at the Hip and Pelvis, Part 2

by Douglas G. Smith, MD

In Part 2 of our look at hip disarticulation and transpelvic amputations, we examine the impact of age on healing and rehabilitation, the difficulties in locating the prosthetic hip joint, prosthesis issues, sitting problems, and why recovery and rehabilitation require a different approach at these levels.

The Impact of Age

Age is a major factor in recovery and rehabilitation following any amputation, but its significance increases with each higher amputation level. For lower-limb amputees, the age factor can be most dramatic when the amputation is at the hip or pelvis. Generally, the younger people are when they have one of these high-level amputations, the more quickly and naturally they adjust and adapt. Those born with a limb difference often perform remarkably well with the only body they've ever known. The congenital limb difference is, in a sense, normal for them. Likewise, very young children adapt after the loss and incorporate the change into their patterns of learning, balance and endurance. However, these high amputation levels are a challenge for teens, a struggle for young adults, and a big battle for older adults.

Just like for most physical things in life, the younger you are, the easier it is to learn something new and do it. You might, for example, have seen people in their 60s, 70s and even older skiing down the slopes with such grace and ease that they make it look absolutely effortless. Chances are, however, that they learned to ski when they were very young and have been doing it for so many decades that it literally has become second nature to them.

Contrast that with a person of the same age who is just learning to ski. Even if he or she finally becomes adept enough to ski without falling (well, not falling often anyway), that person will probably never exhibit the form and grace of someone the same age who has made skiing a lifelong activity. It's also quite possible that a person this age who is just learning to ski won't stick with it. Those bumps, bangs and falls we endure with smiles as children take a bigger toll as we get older. Sure, you can get up from a tumble at most ages, but you'll be feeling the effects of it the next morning far more when you're 70 than when you're 7.

Mary Novotny

One person who illustrates very well the way youth plays an important factor in these high amputation levels is Mary Novotny, the founder of the Amputee Coalition of America. Mary, a registered nurse, had a hip disarticulation when she was a young teen-ager. Despite being told it couldn't be done, she learned to walk with a prosthesis. She went to college. She became an orthopedic nurse. She earned a master's degree. At work and on her days off, she uses her artificial limb every day, from morning to night.

I met Mary when I was a medical student at the University of Chicago. I didn't have a clue about amputation levels when I first saw this energetic nurse who frequently was called in to talk with young kids and their families about bone tumors and amputation. I knew Mary had an amputation, but I didn't know the level. When I found out, I was really surprised because she had, and has, energy, agility, and fluidity of motion in her walk. She moves with a rhythmic, flowing asymmetry that comes with years of practice. Yes, there's a limp. But Mary doesn't look as if she struggles when she walks. Her gait looks good.

This illustrates the differences in walking styles between a person who has grown up following a hip disarticulation and someone who has one of these amputations much later in life. That person might always look as if it's a struggle to walk. Rather than mastering the limp, the person may be mastered by it and have some limitations. Mary has the agility and energetic, flowing rhythm in her walk that comes with decades of practice and confidence.

Many individuals who have the same high amputation level look at Mary and think, "She has a hip disarticulation. She's

walking. She's active. Why can't I do that?" Mary's drive and determination are exemplary. Whenever someone told her she couldn't do something, she found a way to do it. Mary learned to walk again as a young teen-ager and has had a lifetime to work on it.

I'm reluctant to say that Mary could not have learned to use a prosthesis if her amputation had occurred decades later, but it would be extremely unusual for a person in his or her 50s or 60s who has just had a hip disarticulation to use a prosthetic leg full time. Those who can't or decide not to should not think less of themselves. Age and circumstances play large roles in many aspects of our lives, and recovering from an amputation is no different. It's important to remember that we all measure success in our own ways.

"You can do what you want to do, accomplish what you want to accomplish, attain any reasonable objective you have in mind – not all of a sudden, perhaps not in one sweeping act of achievement – but you can do it gradually, day by day and play by play, if you want to do it, if you work to do it, over a sufficiently long period of time."

- William E. Holler, motivational speaker

There Is No Residual Limb

When amputations are done at the hip or pelvic level, the entire leg is removed. These are the only amputations of a lower limb in which the person does not retain a residual limb. Instead, the person has an incision line and padding at the core of the body, up in the hip or pelvic area. The amputation actually occurs where the limb meets the trunk, and this has a tremendous impact, physically, emotionally and psychologically. Amputation in the body's core has a greater effect on our sense of self and well-being. The closer you get to the heart, the greater our sense of mortality.

The junctions between our lower limbs and body core are unique. They're designed for both positioning and stabilizing. The hip acts as a lever to bring the thigh forward and direct where your foot will go when you are walking. It also allows you to bring your thigh back and stabilize the knee when you are standing. The hip abductors and extensors – the gluteus and buttock muscles – provide strength so your leg supports your weight and doesn't buckle. These wonderful muscles allow us to comfortably stand and sit for long periods of time. While a portion of these muscles might remain after a hip disarticulation, they're no longer connected to the part of the leg that makes them work. With an amputation at the hip or pelvis, the core's junction with the limb has been lost.

As you lose segments of the lower limb, you lose the ability to make certain motions to control swing and stance and stabilize the prosthesis. A person with a partial-foot amputation still has part of the foot, the calf, the knee, the thigh, and the hip for leg strength and flexibility to move and to keep from falling. A transtibial (below-knee) amputee can use the thigh, the knee, and part of the lower leg for control and positioning. Transfemoral (above-knee) amputees use their hip strength and buttock muscles to flex and extend the hip for control and stabilization. At any of these amputation levels, if a person feels the leg buckling, he or she can move the hip and residual limb to stabilize the knee and keep from falling.

But an individual with a hip- or pelvic-level amputation has none of these "motion segments" for control and balance. Control of the prosthetic limb must come from the pelvis and lower back. Getting the leg to move forward requires both speed and twisting body motions. People commonly rotate their pelvis to drive the artificial limb forward through swing phase, then use Cirque du Soleil-like torso movements to get the pelvis and back into a stable position over the prosthesis so it won't collapse when they reach stance phase and load their body weight onto the prosthesis. These motions are extremely demanding, and it takes a great deal of practice, determination and perseverance to become capable of doing them.

Used by permission of Prosthetics Research Study, Seattle, Washington

A Socket for Your Body, Not for Your Limb

In every amputation where part of the limb is retained, the socket fits over the residual limb. But there is no residual limb with a hip- or pelvic-level amputation. In these cases, the socket is designed to be an interface between the prosthesis and the core of the body. A socket for a residual limb is very different from a socket for your trunk. Some have asked whether the interface for a hip- or pelvic-level prosthesis is more like a body jacket used in spine surgery. In essence, it grabs the pelvis and lower spine. It's really a kind of transition device between a typical socket and a body jacket with features of both.

While no one has called it such, I'd like to talk about "the body socket." The young man in the photo has a hip disarticulation on his left side and a transfemoral amputation on his right side. The transfemoral socket on his right leg goes over his remaining thigh and supports it. Though the socket also supports his pelvis and ischium, it doesn't totally encase them. In contrast, the socket on his left side fits onto his body. This body socket is sometimes referred to, rather crudely, as a "bucket" because it wraps around your pelvis and butt and may rise above the belt line. Openings are made for your sound leg, the perineum and the rectum, but, otherwise, your lower body is literally encased in the socket. The body socket also affects where the new hip joint will go.

Where Do You Put the New Hip Joint?

One of the major questions in surgical reconstruction at the hip or pelvic level is, "Where do you put the new hip joint?" For other lower-level amputations, we can put the artificial ankle or knee pretty close to where the biological ankle or knee was. But it's different in the hip and pelvis.

It's often confusing to some people why the hip joint can't go in its original location. But it simply can't. After the amputation, the original location is usually covered by 1 to 2 inches of soft-tissue padding. Then, once we add the thickness of the socket and the connector to attach the hip to the socket, the hip joint will have to be 3 to 4 inches away from its original center, either to the outside, down below the anatomic location, to the front, or to the back.

In early designs, the hip joint was commonly put out to the side or down below the socket several inches below the original anatomic location. The traditional device before 1954 consisted of a leather socket and a lateral locking hip joint called a "tilting table prosthesis." Very few people were successful with this type of prosthetic fitting. For decades, surgeons and prosthetists had struggled with the challenge of finding a good prosthetic fit. Then, in 1954, a Canadian named Colin

A young man with bilateral amputations illustrating the differences between a transfemoral socket and a hip disarticulation socket. *Used by permission of Prosthetics Research Study, Seattle, Washington*

McLaurin published a report describing his success using a socket style with the hip joint located in front of the original anatomic spot. It was a tiny, but radical, move, and it made a world of difference. Success rates improved dramatically. The Canadian-style hip disarticulation prosthesis really showed the benefits of positioning the hip in front of the socket. This design places the body's weight behind the center of the hip joint motion, so the hip doesn't bend backward into extension. The hip is solid and locks when needed to support the body.

Walking's Tough, But Sitting Can Be a Real Pain

When you walk, both the hip and the knee must bend to get your foot through the swing phase of your stride. If both the prosthetic hip and knee joints stayed straight, your foot would hit the ground and you'd trip or you'd have to lean far to the side to get your foot around you and out in front. The challenge in swing phase is for both the knee and the hip to bend enough so that your foot clears the ground while your prosthesis is moving and for them to remain stable enough not to collapse as your weight shifts onto your prosthesis. Getting

your body mass centered over the right joint at the right time is tricky. Balance is a big issue with these higher amputation levels, especially on uneven or slick surfaces, so people often use crutches or a cane to keep from falling.

Though walking is difficult for a person with a hip disarticulation or transpelvic amputation, sitting comfort can be an even bigger problem. For some, it is the biggest issue. That's because the prosthetic device encases the groin, the hip, the pelvic area, and even the lower back. Prosthetists build these sockets to encase you and support you in the upright position. When you sit down, however, the socket doesn't bend and can be uncomfortable because it digs into soft tissue.

The socket and added padding also cause you to tip to one side when you sit. Unless you have a customized seat that's lower on one side to accommodate the extra prosthetic material, your pelvis will be tipped to the side whenever you sit. You're always sitting with your lower back curved, and this can lead to stiffness, discomfort or pain. And you're unable to sit with your lower body at a real 90-degree angle to your torso. Many people must literally sit on the edge of the seat because the socket prevents them from sliding back into the seat into a typical sitting position.

Without a prosthesis, you tip to the amputated side. But with the prosthesis on, you tip the other way. Either way, you never feel square to the sitting surface, which comes from equal support on your right and left sides.

Think about this as you sit: If you have no amputations, you have four main points of contact with the chair – the left ischium, the left thigh, the right ischium and the right thigh. You can shift back and forth to redistribute your weight and give your behind a rest. With a partial-foot amputation, you still have the four points of contact plus your feet to nudge yourself into position. If you have a transtibial amputation and aren't wearing a prosthesis, you still have the four points of contact, as well as knee and thigh strength. With a transfemoral amputation, you have the four points of contact, but one of them – the back of the amputated thigh – is significantly weakened.

A person with a hip disarticulation amputation has three points of contact, no hip or leg power, and generally poor padding. The remaining point on the amputated side also tends to be more tender and irritated because there's less padding there. Many people shift their weight to distribute it to the two sitting points on the nonamputated side. Also, a prosthesis loads chiefly on the tenderest of the three remaining points so the person may tend to lean more to the side to try to relieve that pressure. A person with a transpelvic amputation has just two points of contact, poor padding, and scar tissue. Certain individuals need customized sitting systems or, occasionally, customized clothing to replace the symmetry and padding that's lost.

It's not walking and the prosthesis that emphasize the chief difference between a hip disarticulation and a transpelvic

amputation level. Rather, it's the points of sitting balance and sitting both with and without a prosthesis. A person with a transfemoral amputation has four points of contact when seated, a person with a hip disarticulation has three, and a person with a transpelvic amputation two. People with a hip disarticulation or transpelvic amputation have two normal points of contact when sitting, and their prosthesis makes the third. The sitting experience isn't much different for each with the prosthesis, but it's dramatically different without it. Without the prosthesis, the person with the transpelvic amputation has just two points of sitting contact, both on the same side.

The Importance of Sequential Learning

Following amputations at these levels, rehabilitation takes many different paths for different people. It's not as protocol-driven as it is for some lower-level amputations. For example, a person who loses part of a foot receives a partial-foot prosthesis and fairly standard training in how to use it and become mobile again. The main goal for most lower-limb amputations is for the person to walk again.

But at the hip and pelvic levels, we need to understand stepwise progress. It's especially important that the things a person needs to know – such as the vital skills – be learned in a specific sequence. When you try to learn Step 2 before learning Step 1, it leads mostly to failure and frustration. It would be like trying to learn algebra before you've learned arithmetic.

Age and the rigors of learning to use a prosthesis for a hip disarticulation or transpelvic amputation are important factors in determining whether a person uses a prosthetic device full time, part time, or not at all. Our previous series on the transfemoral amputation level emphasized the importance of learning and performing "the three vital skills" – transferring independently, going from sitting to standing without assistance, and walking in parallel bars or with a walker for at least 25 feet – before your doctor should prescribe a prosthesis. These skills are even more important for hip disarticulation and transpelvic amputees. I don't think there's any real chance of learning to use a prosthesis if the person doesn't first master these essential skills.

The other big goal, distinct from walking, is sitting and balance. Sitting balance is a real issue, and wearing a prosthesis does not necessarily make sitting easier. Special pads can help. Many people with these amputations, unfortunately, never adjust to using a prosthesis or they use one only on a very limited basis.

The Importance of an "Active Choice"

These amputation levels also tend to be the first ones where people work extremely hard to master the use of a prosthesis, then choose not to use it. They often come back to me and say, "I needed to know that I could do it so I could choose not to do it." Don't underestimate the importance of knowing you've accomplished a task so that you can let it go. If people are never given a chance to try, they can become frustrated and angry. It's easier to accept the choice of not using a prosthesis when you know in your heart you tried, then decided not to use it. It's an active choice, rather than not using it because you never had the chance or choosing not to use it because you couldn't master it.

Having the chance to use a prosthesis is not cheap, however. A hip disarticulation prosthesis can cost $20,000 to $50,000, and an insurance company may ask for assurances that the money will be well-spent and that the person is going to use the prosthesis. Unfortunately, there's no "crystal ball" to predict this. Many people succeed. Some don't. A person thinks, "I deserve a chance to try," but it's expensive, and there are no guarantees of success. I understand insurance companies' concerns, but is spending tens of thousands of dollars to give a person a chance worth it? Personally, I believe it is.

In my practice and clinic, I've seen four common scenarios concerning prostheses for individuals with these high-level amputations. Some folks are never given a prosthesis, and they always wonder if they could have learned to use it. There's no answer to "Could I have done it?" Often, they're angry because nobody gave them the chance. A second group of people, although given the chance, never really learn to use the prosthesis with full safety or confidence. While it's frustrating, they're often glad that they at least got the chance to try. They've accepted that there are some things in this world we just can't quite do. A third group of individuals are those who try a prosthesis, do master it, but then decide, "It's not for me." This is an active, informed choice. They feel good about having been given the opportunity and about being able to choose. Finally, there is the group of people we all envision being like. These folks try a prosthesis, master it, and choose to make it a part of their lives. But in reality, with these high-level amputations, this is not the most common outcome.

Because of the challenges of the prosthesis, people may partition their lives into those times when they really want to use one and those times when they don't. They make active choices concerning using a prosthesis. It takes a special kind of understanding and attitude to deal with amputation issues at this degree of complexity. We'll cover more of these issues in Part 3. ■

"Nothing can stop the man with the right mental attitude from achieving his goal; nothing on Earth can help the man with the wrong mental attitude."

- Thomas Jefferson