

The Task at Hand

Occupational therapists guide patient after rare hand transplant surgery

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By Danielle Bullen

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Imagine not being able to pet your beloved dog, hold your significant other's hand, or sign your own name. All these simple everyday acts require the use of your hands. Some people, however, as a result of disease, infection or genetics, are upper extremity amputees. A very select group of those amputees have been given the gift of transplanted hands.

One such recipient is Lindsay Ess, 30, of Richmond, Va. In 2007, an infection led to the amputation of both her hands and both her feet. As time went by, Ess grew adept at maneuvering around on her prosthetic legs. But her prosthetic hands were another story.

The hook-like apparatuses made activities of daily living, like brushing her hair, challenging. She relied on her family for the most basic elements of care.

Help came in the form of a multidisciplinary team from the University of Pennsylvania Health System (Penn Medicine). In September 2011, Ess underwent an 11-and-a-half hour operation conducted by a team of 12 surgeons, 15 nurses and three anesthesiologists.

During the procedure, surgeons meticulously attached the bones, blood vessels, nerves, muscles, tendons, and skin of two donor hands to Ess' body. The operation was a success. Yet when they finally rolled her out of the operating room, the hard work had just begun.



HELPING HANDS: Gayle Severance, MS, OTR/L, CHT (left), and Laura Walsh, MS, OTR/L, CHT (right), guided patient Lindsay Ess after a rare double hand transplant.

Vital Therapy

Because double upper extremity transplantation is still so rare, rehab protocols remain works-in-progress. One thing is for certain, though - occupational therapists played a vital role in getting Ess' function back.

Although Ess' care team consisted of 20 different specialties, Gayle K. Severance, MS, OTR/L, CHT, and Laura Walsh, MS, OTR/L, CHT, led the occupational therapy team.

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"It's a more intimate relationship than with other patients," added Severance. "It expands the borders of the therapy relationship."

The rehab process began long before Ess' first occupational therapy session. Walsh and Severance reached out to their counterparts at the University of Pittsburgh Medical Center and the Christine M. Kleinert Institute in Louisville, Ky., where successful hand transplants had been previously completed. Still, there was very little precedent to follow, and the therapists had to rely on their own clinical expertise and judgment.

Treatment planning and research was time consuming. The American Society of Reconstructive Transplantation was founded by surgeons to share knowledge and best practices, but the Penn OTs discovered that little research exists pertaining to rehabilitation of this unique population.

"We've worked hard to open up that communication in the therapy world," said Severance. "This is not going to be a common event. Having therapists share info across centers is very important."

The early phases of occupational therapy were all about protecting Ess' transplanted limbs, including bones, tendons, muscles, and nerves. Severance and Walsh worked on passive range of motion. They fabricated splints for protection and to allow the structures to heal in the correct manner, but had to keep refashioning them because Ess' skin was so sensitive.

Creativity Matters

While she was in the hospital, Ess received up to four hours of occupational therapy daily. Two weeks after surgery, she was up and walking. Three weeks post-op, the doctors let her use her arms for light activities of daily living. The OTs crafted adaptive equipment that allowed Ess to feed herself and use a pen on a keyboard to write.

As a transplant patient, Ess will be on anti-rejection medication the rest of her life. Her occupational therapists were instructed to keep their eyes peeled for rash and edema - two hallmark signs of rejection.

Just four weeks after surgery, Ess left the hospital for inpatient rehabilitation at Penn's Institute for Rehabilitation Medicine. Seven weeks after surgery, still relocated in Pennsylvania, Ess and her mother moved to the Clyde F. Barker Penn Medicine Transplant House in downtown Philadelphia, and she began daily outpatient occupational therapy for two to four hours per day, five days per week.

Once she was out of the hospital, Ess' rehab took on a new focus. "Her brain needed to accept the limbs as a new part of her body," said Walsh. By December 2011, she gained wrist and finger motion, and her OTs moved her from wrist splints to hand-based splints.

Everyone was surprised at the rate of her recovery. Ess was not expected to have fine motor control at that point, and yet in January 2012, she could pick up objects.

Still, there were challenges. "We didn't anticipate the other needs," explained Walsh. "We were focused on the arms. But her balance was thrown off. She had weight gain from anti-rejection meds that caused her lower limb prosthetics not to fit right." Physical therapy was called in to deal with mobility issues they had never considered.

"Once patients get their transplants, they're ready for them to work right away," noted Severance. "The waiting and recovery process can be frustrating."

"She pushed us every step of the way," said Walsh. Ess wanted to brush her hair; her OTs had to design unique adaptive equipment to meet that goal. She wanted to use a computer; that required different equipment.

Home Sweet Home

In February 2012, Ess returned home to Virginia, a move Walsh and Severance called "bittersweet." Occupational therapy remains a 24-7 job for Ess, as she's still building functional independence. Her use of fine and intrinsic muscles will return very slowly.

While Ess returns to Penn Medicine for quarterly evaluations, most recently in June 2013, the bulk of her occupational therapy now rests with Kathy Jarrell, OTR, CHT, hand therapist at The Rehabilitation Center at Parham Doctors' Hospital in Richmond.

Jarrell first heard about Ess' operation in a newspaper profile. She was shocked when Walsh reached out to her, saying she had been recommended as an occupational therapist to work with Ess after her discharge from Penn. Jarrell described the ongoing experience of working with Ess as scary, exciting and rewarding.

"One of the big things we worked on was splinting her hand in a good position," Jarrell said. The literature suggests that friction on donor skin can lead to rejection, so she used more padding than she ever had before. The attention to detail paid off, and Ess experienced no splint-related problems.

Even so, "The honeymoon was over and she was beginning to realize how hard this was going to be," recalled Jarrell. By June 2012, her new hands could sense hot and cold. As the nerves woke up, she had a constant tingling and needles sensation. Ess learned to reframe her discomfort as a positive sign of

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"Remembering how to use her hands was a really big deal," noted Jarrell. One early success at Parnam Doctors was Ess picking up "Hershey," a 6-inch teddy bear. As she progressed, Jarrell had her practice lateral pinch by grabbing 1-inch plastic fish and playing tic-tac-toe with 3D game pieces. She's now working on hand intrinsics, like tip-to-tip pinch with her index fingers and thumbs, which requires concentration and recovery of motor memory.

Like her counterparts in Pennsylvania, Jarrell had to think outside the box when engaging Ess in rehab. She attached a paint brush with Velcro to compressive sleeves on Ess' fingers. Painting became "an expressive way to for her to get her frustrations out," Jarrell explained.

Another breakthrough came when Jarrell used a simple mirror to help Ess achieve finger extension on her right hand. Seeing the movements of her left hand encouraged her brain to make the connections needed for those movements.

Jarrell also worked with an aquatics instructor to get Ess swimming again, which Jarrell described as uplifting. One momentous day occurred when Ess was able to put on her lower extremity prosthetics by herself. And she can now legibly write out a grocery list without using any aids. Recently, Ess produced a benefit fashion show for 200 people, organizing models, clothes, lighting, food and music - all to raise money for organ donation.

As Jarrell put it, "Every aspect of her benefited from being in occupational therapy." Currently, Ess tries to make it to outpatient occupational therapy three times each week.

Opportunity of a Lifetime

For Jarrell, "Seeing [Lindsay] turn from a fragile thing in wheelchair to a capable woman doing amazing things in her life" has been the most rewarding part of her journey. "I never thought I'd have this opportunity. She's been the highlight of my career."

Back in Pennsylvania, her OTs echoed those sentiments. "It's very rare that you get to treat a condition for the first time," observed Severance.

"Because I met Lindsay before her transplant, every time I look at her, it takes my breath away to see her using her hands," Walsh said.

Resources

1. Donovan, J., & Marsh, M. Double hand transplant patient relearns how to hold. Accessed via <http://abcnews.go.com/Health/double-hand-transplant-relearns-hold/story?id=18133638#.Ua3zGNI-Y0W>
2. Penn medicine performs bilateral hand transplant. Accessed via www.upenn.edu/spotlights/penn-medicine-performs-bilateral-hand-transplant

Danielle Bullen is on staff at ADVANCE. Contact: dbullen@advanceweb.com

SIDEBAR: WORTH THE COST?

A 2010 study by researchers at the University of Michigan Health System compared the lifetime costs of hand transplantation vs. prosthetic use. Kevin Chung, MD, director of the University of Michigan Hand Center, and colleagues surveyed medical students to assess the utilities of single- and double-hand transplantation and the use of hand prostheses. Quality-adjusted life years (QALYs) were calculated for each outcome.

Costs for medical care were estimated based on Medicare fee schedules using CPT codes for forearm replantation and the cost of immunosuppressive therapy was estimated based on the wholesale price of drugs.

For unilateral hand amputation, prosthetic use was favored over hand transplantation (30.00 QALYs versus 28.81 QALYs; $p = 0.03$).

Double hand transplantation was favored over the use of prostheses (26.73 QALYs versus 25.20 QALYs; $p = 0.01$).

The incremental cost-utility ratio of double transplantation when compared with prostheses was \$381,961/QALY, exceeding the traditionally accepted cost-effectiveness threshold of \$50,000/QALY.

Authors concluded that prosthetic adoption is the dominant strategy for unilateral hand amputation. For bilateral hand amputation, double hand transplantation exceeds the societally acceptable threshold for general adoption. Improvements in immunosuppressive strategies may change the incremental cost-utility ratio for hand transplantation.

Results were published in the Feb. 2010 issue of *Plastic and Reconstructive Surgery*.

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