

AXIS

A NEWSLETTER OF SHEPHERD CENTER
PROVIDER OF MEDICAL TREATMENT, RESEARCH AND REHABILITATION



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SPRING 2016

What Dose Does It?

When it comes to the dose-response relationship in therapy after SCI, we're still learning.

By **Edelle Field-Fote, PT, Ph.D., FAPTA**



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When we pick up a bottle of aspirin and read the label for information about how many tablets to take, the label clearly indicates that we should take one to two tablets. That is a fairly specific dose recommendation, isn't it?

Years ago, during the time when it was thought that everyone should take low-dose aspirin to prevent stroke, I heard a lecture by a leading cardiologist. He said the best dose of low-dose aspirin was much like the number of eyes a person should have, "One is not enough, and three is too many." After I stopped laughing from the images that came to my mind, I remember being amazed by the preciseness of this recommendation about dosage. How did they know that? As it turns out, many millions of dollars are spent each year determining the best dose of medicine for the average consumer.

Questions of dosage are crucial to most areas of medicine and health. For example, the American College of Sports Medicine/American Heart Association's joint guidelines for physical activity make very specific recommendations about exercise for adults between the ages of 18 and 65 (Haskell et al. 2007). They recommend moderately intense cardio activities 30 minutes per day, five days per week or vigorously intense cardio 20 minutes per day three days per week, plus eight to 10 strength-training exercises with at least one set (eight to 12 repetitions) of each exercise two days per week. These recommendations provide us with excellent guidelines for cardiovascular health, an area that is of such great importance to our lives.

Unfortunately, these guidelines are among very few that are available and specific enough to help with planning health-promoting activity.

A recent systematic review, a large analysis of many published research articles, asked the question, "What is the best approach to improving function after spinal cord injury?"

The results of this review concluded that the most effective approaches to improve function after spinal cord injury are not the exciting, high-tech cellular transplants or pioneering drug treatments that get such great coverage in the news media. In fact, the most effective approaches were those that included rehabilitation (Gomes-Osman et al. 2016). Despite the fact that, as the systematic review shows, rehabilitation is the best medicine we have for improving function after spinal cord injury (and likely other health conditions that affect movement), the challenge is that we know surprisingly little about the best dose of rehabilitation for each individual.

In part, the difficulty in identifying the best dose of rehabilitation treatments is because dose is typically measured in terms of hours in therapy, rather than by the number of repetitions of the skill that is being developed. In animal studies of skill, the animals perform hundreds, even thousands, of repetitions of a task before meaningful changes in skill are observed. In contrast, according to one rehabilitation study, the average number of steps taken during walking training in outpatient rehabilitation is 292 steps per training session (Lang et al. 2007). This number of steps is about one-tenth the number of steps per day taken by community-dwelling individuals with chronic stroke (Michael et al. 2005).

The Shepherd Step program was developed for that very reason – to meet the need for an intensive walking program for people with spinal cord injury who have some movement and for whom functional ambulation is a realistic goal.

Understanding the dose of rehabilitation that is needed to improve movement is an important research question in itself – and one that we are addressing in some of our research.

Because Shepherd Step is so focused on walking, it gives clients a more realistic amount of therapy that mimics the number of steps they would take if they were out in their community. (Read more about the program at www.shepherd.org/shepherd-step.)

We all know the saying that practice makes perfect. Understanding the dose of rehabilitation that is needed to improve movement is an important research question in itself – and one that we are addressing in some of our research. Assuming that some movement is possible, as evidence that movement that the nervous system is plastic and amenable to training, as well as evidence that movement can be improved if there is adequate opportunity for practice.

On the other hand, it is also important not to overdose on rehabilitation. When all is said and done, having a well-rounded life that includes many different types of activities and opportunities for social participation is the real key to happy and healthy life.

Spinal Cord Injury Model Systems (SCIMS): One Grant Cycle Ends, and Another Begins What Have We Learned From the Database?

By Lesley M. Hudson, MA, SCIMS Co-Project Director



Lesley M. Hudson, MA

Spinal Cord Injury Model Systems (SCIMS) are specialized programs of care that were created so researchers can study and find ways to improve people's recovery and outcomes after a spinal cord injury (SCI). On Sept. 30, 2016 the current five-year cycle of SCIMS, a U.S. Department of Health and Human Services grant program (NIDILRR) will come to an end. Also on that date, the next cycle, 2016-2021, will begin. As I write this, current SCIMS staff members are hard at work writing the Shepherd Center application for the next cycle, with the hope that the unbroken record of funding that began in 1982 will continue.

There are some key changes involved in the next cycle, however, that will affect the application in process. David Apple, Jr., M.D., founding medical director of Shepherd Center and I, who have served as the project co-directors for the Shepherd Center program, will both retire from Shepherd Center this year. Our 40 years at Shepherd have been rewarding and wonderful, and our long-term participation in the SCIMS program is one of the hallmarks of our careers in spinal cord injury medicine. In addition, Patricia Duncan, who has been the data coordinator for the Shepherd SCIMS grant for 26 years, will be leaving Shepherd Center in the near future. I look forward to writing one last article for AXIS later this year, at which time I hope Shepherd Center will have once again been successful in its application to be included in this prestigious program.

So, what have we learned from all these years of collecting and analyzing data? What do we know from creating and implementing innovative patient programs designed to improve their chances for recovery and provide them with the skills to successfully

participate in meaningful lives after injury? The answers to those questions are complex, but here are some highlights. This information comes from the latest annual report of the National Spinal Cord Injury Statistical Center (NSCISC), located at the University of Alabama-Birmingham. This is where data from the 14 grantees in the SCIMS program is sent to be compiled and analyzed. The annual report is an update of valuable information on traumatic spinal cord injury in the United States. To view the report, visit: <http://bit.ly/ITDUDFq>

A few highlights include (from data reported Sept. 1, 2015):

- SCIMS has entered data on 31,255 individuals since it began.
- SCIMS has entered 158,624 follow-up forms on patients who have been injured from one to 40 years.
- Survival of individuals entered into this database rises steadily from the first year post-discharge through the 20th year and then declines very gradually through the 40th year.
- Eighty percent of subjects entered into the system are male.
- Auto accidents continue to be the most frequent cause of injury in most SCIMS centers, followed by falls, gunshot wounds and diving.
- Individuals who are injured are getting older on average: Twenty years ago the average age was 24, and now it is close to 30. As a result, many of the SCIMS locations have initiated rehabilitation programs to provide the best services for older adults.
- The largest group of individuals in the database consists of high school graduates, followed by individuals with some high school and then college graduates.
- Thirty-two percent have returned to work after injury, with 15 percent returned to school.
- The overwhelming majority are discharged from initial hospitalization to a private/home location, with just over 1 percent living in professional facilities.
- The majority of subjects interviewed has indicated satisfaction with life.
- Many have embraced numerous aspects of technology designed to make their lives easier.

In all programs, at every SCIMS location, there has been a greater emphasis on wellness after discharge. These hospitals endeavor to train their patients to remain in good health, avoid complications of injury and, in general, take the initiative for their own wellbeing and life satisfaction. This has been one of the many significant trends observed since the SCIMS program began in the early 1970s.

It has been my great privilege to have been associated with the Shepherd Center SCIMS program since 1982. Together, we have achieved so much, and the outcomes for individuals entered into the national database over the years have improved steadily. Researchers and clinicians alike have used this information to conduct hundreds of research projects and initiate many patient services that have improved life expectancy, reduced secondary conditions and, in general, enhanced the lifestyle options for individuals who have sustained traumatic spinal cord injury.



FDA Clears Indego® Assisted Walking Device For Some People with Paralysis

State-of-the-art device tested at Shepherd Center allows people with spinal cord injury to stand and walk.

Parker Hannifin Corporation, the global leader in motion and control technologies, recently announced that the U.S. Food and Drug Administration (FDA) has given clearance to market and sell the Indego® exoskeleton for clinical and personal use in the United States. The company intends to commercially launch the device in the United States in coming months. Indego is already commercially available in Europe, having received the CE Mark in November 2015.

"For individuals who sustain spinal cord injuries, this is a milestone that could have a meaningful impact on their lives," said Tom Williams, chairman and CEO of Parker Hannifin. "In a relatively short amount of time, we have taken what was a prototype device and readied it for full commercial launch. We are excited about the future for this new growth opportunity."

The FDA's clearance came after the completion of the largest exoskeleton clinical trial conducted to date in the United States.

"In sponsoring such a comprehensive and landmark study, Parker demonstrated the safety and performance of the Indego

technology," said Gary Ulicny, Ph.D., president and CEO of Shepherd Center, Parker's lead clinical partner. "Over the course of more than 1,200 individual sessions, study participants were able to use Indego to safely walk on a variety of indoor and outdoor surfaces and settings with no serious adverse events."

"This is an exciting development that will allow Indego to be more widely available," added Achilles Dorotheou, head of the human motion and control business unit for Parker. "With the regulatory barriers addressed, we look forward to a full commercial launch of the device and further studies that will provide evidence of the economic and health benefits of exoskeleton technology."

In October 2015, Parker announced that it would supply Indego devices for a four-year U.S. Department of Defense-funded study of the tangible economic and rehabilitation benefits of exoskeletons at three of the nation's top rehabilitation centers, including the James Haley Veteran's Hospital in Tampa, the first VA center in the country to use Indego.

Indego is a robotic exoskeleton or powered orthotic device that allows users to stand and walk, and holds great promise for affording people with paraplegia a new level of independence.

For more information on Indego, visit indego.com.



Wade Hoag, 19, of Ohio completed rehabilitation for a spinal cord injury at Shepherd Center. He recently returned to try out the Indego exoskeleton.

Shepherd Center, Duke University and Northeastern University Awarded \$4.625 Million for New Center on Technologies for People with Disabilities

Shepherd Center, Duke University Medical Center and Northeastern University are launching a partnership to conduct research and develop new technology solutions to promote independent living and community participation by people with disabilities.

The partnership received a \$4.625 million, five-year grant from the National Institute on Disability, Independent Living and Rehabilitation Research to fund the LiveWell Rehabilitation Engineering Research Center for Community Living, Health and Function (LiveWell RERC).

The LiveWell partnership has two primary goals: to promote access to existing and emerging information and communication technologies for all people regardless of ability and age and to develop and validate information and communication

technology applications to enhance independent living and community participation.

"It's about helping information and communication technology developers recognize the market opportunities among their potential customers waiting to be served," said Mike Jones, Ph.D., vice president of research and technology at Shepherd Center, and co-director of the LiveWell initiative. "And challenging developers to shape future information and communication technologies for people of all ages and abilities through universal design."

One project is built around the Safe@Home research project already underway at Shepherd Center under the direction of Ron Seel, Ph.D., director of brain injury research at Shepherd Center. He is collaborating with researchers Misha

Pavel, Ph.D., and Holly Jimison, Ph.D., at Northeastern University's Bouvé College of Health Sciences and College of Computer and Information Science to develop in-home passive sensing systems that identify and minimize risks to individuals living with the effects of brain injury.

"People living with brain injury face considerable risk because of decreased judgment and inhibition, and sometimes limited balance, coordination and vision," Dr. Seel said.

Other projects will focus on wearable platforms such as smartwatches and other trackers, and will rely on biometric sensing to provide feedback to the user.



Shepherd Step Program Gives Hope to People with Mobility Impairments

When Wayne Flanagan of Dunwoody, Ga., left Shepherd Center after a several month stay, he knew he wanted to come back – he had more work to do. That’s how he became part of Shepherd Step, an intensive walking program coupling Body Weight Supported Locomotor Training (BWSLT) over a treadmill with over-ground activities to assist participants in achieving the most functional level of walking possible.

While walking again after an illness had left him paralyzed was certainly a dream of his, Wayne set realistic and incremental goals in his rehabilitation.

“I went into Shepherd Step in a wheelchair, saying that if continuing to work hard helped me even be able to stand at the kitchen counter to do something as simple as get my own glass, it would be worth it,” Wayne says. “I was afraid to hope that I would walk again, but I knew that at the very least, I would be stronger than I was before.”

Shepherd Step offers interventions at a high level of intensity designed to meet specific walking goals. After an evaluation, the expert clinician will make recommendations regarding the number of sessions and the length of stay, using current evidence for best practices. If you are unable to participate at the recommended level, other programs may be suggested. The program is customized for each client, so additional modalities and treatments are utilized per the clinical judgment of the treating physical therapist and doctor.

“When I first started, I could hardly bear any weight, but as I progressed, I got better at moving my own feet and bearing weight,” Wayne says.

By the time Wayne left the program, he was standing with a walker with wheels. He continued to work out at Shepherd Center’s gym, moving to a walker without wheels and eventually, to just a cane.

“All of my therapists believed in me, at times, even more than I believed in myself,” Wayne says. “It was truly a team effort.”

Potential Outcomes

- Improved quality of walking
- Increased walking speed
- Increased walking endurance
- Decreased use of assistive devices

Criteria for Admission to Shepherd Step

Individuals selected for Shepherd Step must meet the following guidelines:

- Have a motor incomplete spinal cord injury (ASIA impairment scale of C or D)
- Must safely tolerate upright position and weight-bearing
- Have defined and realistic functional ambulation goals
- Must have prescription from physician
- Cannot be dependent on a ventilator

The Following Diagnostics Groups May Be Included

- Traumatic spinal cord injury
- Acquired Brain Injury
- Stroke
- Transverse myelitis
- Spinal cord infarct
- Surgically decompressed primary tumor (excluding radiation and chemotherapy)

For more information on Shepherd Step, contact Velma Moore at 404-350-3102 or visit www.shepherd.org/patient-programs/shepherd-step

Shepherd Center Launches New, User-Driven Patient Portal

Online program gives people with spinal cord injury easy access to essential injury-related information.

By Amanda Crowe, MPH

Shepherd Center is launching its new Engagement Portal this month. This virtual resource allows patients with spinal cord injury (SCI) to conveniently view, manage and download certain medical records and other critical information related to their injury – something clinicians hope will help patients feel more confident in managing their care post-discharge and facilitate a more seamless transition to their community-based providers.

The portal, accessible through a secured link – <http://shepherd.org/myportal> – on Shepherd Center’s homepage can be customized to include a patient’s medical/surgical history—baseline blood pressure, allergies, and current and past medications—to facilitate efficient medication management. It also houses detailed information about equipment and supplies, including prompts to flag when it’s time to reorder something, as well as a list of suppliers and other useful resources.

“The portal gives patients a central repository to manage important injury-related medical information,” says Julie Gassaway, RN, MS, director of health and wellness research at Shepherd Center. “While it seems like a simple concept, it’s not something they’ve had before. Instead, patients often find themselves juggling multiple files and papers.”

Because spinal cord injuries are complex, having a central place to keep this information is key to helping patients stay organized and take an active role in care. The portal also includes important education, guidance and tips for managing medical issues common to SCI, which helps to reinforce the hands-on learning they and their caregivers received at Shepherd Center.

“This effort is in response to patients’ requests for greater use of technology, and it comes at a time when acute care hospitals have been mandated to have a patient portal,” Gassaway says. “However, portals mandated by the Affordable Care Act have not been well adopted; uptake is only between 5 and 15 percent, so we wanted to take a different approach.”

For this reason and because there was no off-the-shelf product available that would fully meet patients’ needs, Gassaway and her team

embarked on building a portal from the ground up. They wanted the portal to be practical, and “owned” and updated by the user to give individuals control over what is included and how they might use it. As a result, the types of information and resources housed on the portal – a joint initiative with Craig Hospital in Englewood, Colo. – was shaped, in part, by input from individuals with SCI, some newly injured and some more than 20 years post-injury.

Their feedback has been vital to the portal’s development, Gassaway says. For example, it was patients who requested inclusion of information necessary for wheelchair repair such as serial numbers, repair history and supplier contact information. They also suggested adding fields to plug in information such as last blood transfusions, blood type, implants and other information that is frequently requested on intake forms in doctor’s offices.

J.D. Frazier of Marietta, Ga., who sustained a C-4 complete injury more than 30 years ago after falling 17 feet from a ladder, recalls the flurry of information that often comes at discharge.

“It can be overwhelming. It’s nice to know such critical information will be in one place, readily accessible to patients,” says Frazier, who operates The Specialty Nurse Company and holds a number of volunteer positions and a Master of Science in Conflict Management. “Shepherd Center has always been on the cutting edge of coordinating resources and making them available to patients. This portal will help ensure a smoother transition and ongoing effective management of the injury rehabilitation process.”

To that end, a share feature integrated into the portal allows patients to invite medical providers and share their medical information with caregivers. They can give their doctors and therapists access to view – even edit and update – their health profile to help ensure continuity of care.

Patients are introduced to the portal during their inpatient stay, when they are ready. Demographic information flows to the portal from Shepherd Center’s electronic medical record. Clinicians help patients register for the secure portal and add additional information, such as exercise plans, dietary guidelines, etc. Ultimately, each patient is responsible for maintaining their portal and keeping the information up to date.

Gassaway and her team are tracking how often patients log onto the portal and which sections are – or are not – being used, to continue to make improvements and determine future phases. Future plans may include adding two-way communications for scheduling appointments or medication refills and adapting the portal for use by people with traumatic brain injury.

“We don’t want to make any assumptions, so we are rolling out a very basic version so we can collect and consider user feedback to further refine the portal,” she says.

This program reflects Shepherd Center’s ongoing commitment to be responsive to patient requests and leverage available technology to provide patients with enhanced access to, and ownership of, their personal healthcare information, Gassaway explained.

“Our patients now have a way to organize their injury information, which is what they’ve told us they desperately need,” she says.

This project is part of the larger Patient Centered Outcomes Research Institute grant that has also helped Shepherd Center revamp its education and peer support programs. For more information, contact Julie Gassaway at Julie_gassaway@shepherd.org.

The portal gives patients access to medical records and other critical information related to their injury.

The screenshot displays the Shepherd Center Patient Portal. At the top, the logo for Shepherd Center is visible, along with 'Emergency Info' and 'Log Out' buttons. Below the header, there are six main navigation categories: Allergies & Medications, Equipment & Supplies, Documents & Education, Resources, Profile, and Contacts. Underneath these, a 'Quick Resources' section is provided, featuring links to 'Peers Facebook' (with the URL <https://www.facebook.com/shepherd.peers>) and 'My Shepherd Connection' (with the URL <http://www.myshepherdconnection.org/>).

Shepherd Center Harnesses the Power of Social Media to Promote Diving Injury Awareness

According to the National Spinal Cord Injury Statistical Center, diving is the fourth leading cause of spinal cord injury for men and the fifth for women in the United States. Each summer at Shepherd Center, there are several patients admitted because of diving-related injuries – often severe cervical injuries resulting in tetraplegia. Diving injuries occur in pools, rivers, lakes, creeks, swimming holes and oceans.

Fortunately, these injuries are largely preventable. Shepherd Center's Injury Prevention Program has traditionally used mass media to bring awareness to the general public and to reduce these highly preventable, yet catastrophic injuries. To reach a broader audience, the injury prevention program launched a Google Ad Words campaign last summer aimed at preventing diving injuries.

"We identified three target audiences using Shepherd Center admissions data – teenagers and young men ages 14 to 32, educators, or influencers and parents," says Emma Harrington, MSPS, Ed.M., director of injury prevention and education at Shepherd Center. "We then created separate banner ads, and videos were created to appeal to each disparate audience."

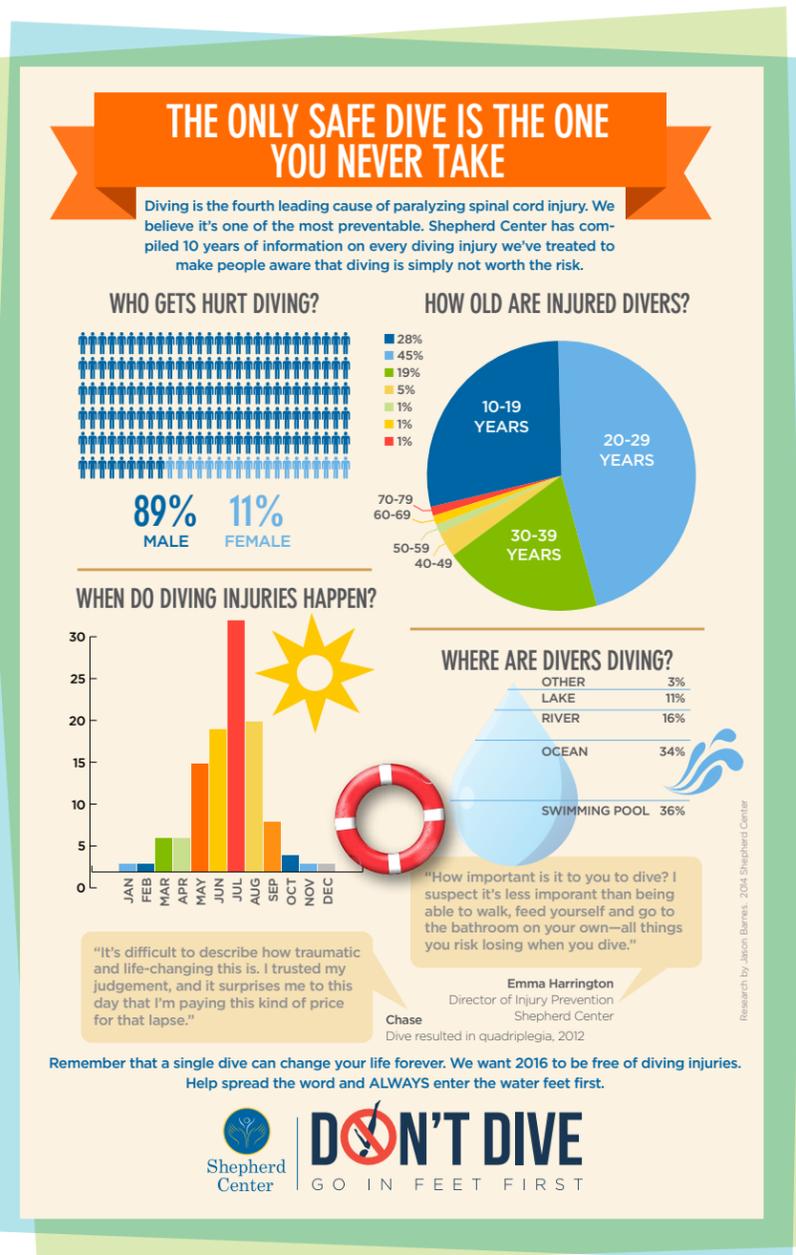
The videos contained footage from previous diving injury prevention campaigns, featuring two former Shepherd Center patients and their stories. All three banner ads were slightly different to appeal to the different target groups, yet the message remained the same: "Feet first every time."

The campaign also used several key search terms that each audience might use, such as swimming classes, summer break and beach vacations. The campaign was targeted to the metro Atlanta area, and the users were then followed with our banner ads and videos as they continued browsing. Campaign success was measured by the number of impressions, click-through rates and the number of times people watched the videos in part and in their entirety.

The campaign ran from July 2015 to September 2015 and was rolled out on desktop computers, smart phones and tablets to maximize reach to appropriate audiences.

As the campaign ran, far more people viewed the banner ads and videos on their tablet as opposed to desktop computers. In total, the campaign generated 1,073,083 impressions and 1,611 total clicks with a click-through rate of .15 percent. When people clicked on the ads, they were directed to the diving injury prevention page on the Shepherd Center website. Analysis revealed that 169,825 people started to watch the videos, and 121,187 people watched them in their entirety.

"This campaign used best practices in both peer-to-peer messaging and mass media campaigns," Harrington says. "Peer-to-peer messaging is essential in planting the seeds of behavioral change. We look forward to analyzing the data obtained during this campaign further so we can enhance future campaigns."



Groundbreaking Program Effectively Prevents and Manages Condition that Can Impede Rehabilitation

Integrated program to treat lymphedema enhances Shepherd Center's standard of care.

By Amanda Crowe, MPH

Shepherd Center has recently implemented an innovative program to treat lymphedema, an unhealthy buildup of excess fluid beneath the skin that can impede rehabilitation in patients with spinal cord injury.

"The earlier and faster we can address swelling, the better," said Rebecca Hammad, MHS, therapy manager for the Spinal Cord Injury Post-Acute Program, who leads the lymphedema program at Shepherd Center. "There are huge functional benefits to getting the fluid out. But traditional approaches don't seem to work well in our patients, and many providers won't offer these interventions to people who cannot feel or who have limited movement."

Lymphedema occurs when the lymphatic system – a sophisticated network of vessels and nodes that help the body get rid of extra fluid and waste – does not work properly. What results is a noticeable buildup of fluid, most often in the arms or legs.

Lymphedema can present serious problems for many patients with SCI, whose weakened muscles are no longer able to help push the fluid through the body.

"My leg would balloon up," said Harley Smith, 57 of Decatur, Ga, who sustained a C-5 to -6 SCI while jumping on a trampoline. "My leg was so big, I had to take my shoelaces off to have any hope of getting my foot in my shoe."

The goal for Harley was to get his swollen right leg – twice the size of his other leg -- back to the same size. After three weeks of massage and daily wrapping, the swelling went down.

"Once it is under control, it can be life changing. I have found sometimes patients are so swollen and stiff that when we remove the fluid, their leg or arm is lighter, their joints more supple and I've seen flickers of movement in toes and fingers and biceps," Hammad said.

Spinal cord injury patients must sometimes undergo treatment for a complication called lymphedema, which can impede rehabilitation.



Shepherd Center has 12 lymphedema-certified therapists working across its inpatient and day programs thanks to a five-day intensive course held in partnership with Shepherd Center partner Kindred Healthcare.

A Four-Step Process

Lymphedema treatment – or complete decongestive therapy, as it is referred to medically – involves four steps:

- 1. Skin care:** Therapists focus on keeping the skin intact, which guards against infection.
- 2. Manual lymph therapy or drainage:** Unlike retrograde or deep massage, therapists apply a light-touch technique that is done at the surface level of the skin to help stimulate the lymphatic system and promote the flow of fluid. When therapists push down to the muscle level, they can actually squish closed the more superficial (skin-level) lymphatic pathways.

- 3. Compression through bandaging and/or garments:** Wrapping helps soften the thick fluid and provide the right pressure to reduce the size of the limb; garments help to maintain these gains.

- 4. Specialized exercise program:** Exercises are incorporated into what patients are already doing in therapy. The main difference is that therapists will reverse the order of exercise to start closer to the body and then work outward to the extremities.

"Lymphedema has presented a problem for patients with SCI and traumatic brain injury for years, and no one really knew what to do with it," said Shari McDowell, PT, DPT, SCI Program Director, who supported Hammad in this endeavor. "But we now have the expertise and evidence to know that these interventions work."

AXIS

AXIS covers news and information about research, medical treatments, healthy living and events for people who have experienced spinal cord injury, brain injury or a related neurological condition.

It is published twice a year.
Questions? Call 404-367-1306

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Supported in part by a grant from the National Institute on Disability, Independent Living, and Rehabilitation Research. U.S. Department of Health and Human Services, Washington, D.C., for the Southeastern Regional Spinal Cord Injury Model System at Shepherd Center in Atlanta, Georgia. Grant #90SI5002-01-00.

If you would like to make a gift to support the work you have read about, please contact the Shepherd Center Foundation at 404-350-7305 or visit shepherd.org.



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The Shepherd Center Recreation Therapy Program encourages all former patients and their families to participate in its upcoming events in 2016.

We hope you'll join us!

What: Overnight Bird Watching Retreat

When: Friday, Sept. 9 – Saturday, Sept. 10

Where: Unicoi State Park and Lodge
1788 Highway 356
Helen, GA 30545

For more information:

Contact Wendy Battaglia at Wendy_Battaglia@shepherd.org

What: Scuba trip

When: September

Where: Bonaire, located in southern Caribbean

For more information:

Contact Kelly Edens at Kelly_Edens@shepherd.org



For more information about recreation therapy services, call 404-350-7375