
◆ THE DERBY CITY NSCIA NEWSLETTER ◆

OCTOBER 2004

The Derby City Chapter of the National Spinal Cord Injury Association Network- Serving Kentuckiana.

Message From the President

Dear Members & Friends-

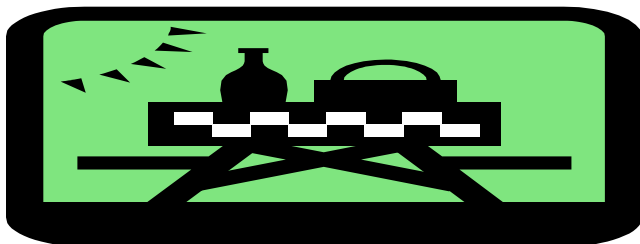
This month's meeting will not have a speaker. Instead, we will watch a video and have pizza and soft drinks. The video will talk about life after a spinal cord injury. Subjects include transferring, relationships, adapting, family viewpoints, and other areas of interest. Please come out and join us for what should be an informative evening.

November's meeting will be held at Frazier Rehab, 4th floor dining room. Social hour: 6:30; speaker at

7:00 p.m. Refreshments provided.

I would like to thank everyone for their support and attendance at this year's picnic. It was a wonderful turnout, as well as a beautiful day, and I believe a good time was had by all. I would particularly like to thank Tom and Cheryl Stokes for all their hard work in preparing the wonderful meal, and helping to decorate the dining hall. Their continued support and loyalty is what helps make our chapter a success. I would also like to thank Betty Mudd and her family for all their help in securing our door prizes and raising money for the picnic, and their general support of the chapter. Lastly, I would like to thank Betty Perry and Michael Feger for working the table at the door and taking the money for the food as well as the chances on the raffle. Thanks for your continuing efforts in fundraising for the chapter.

- David Allgood



The following article is from SCI Update Newsletter (online), Winter 2004. —ed

TREATING SCI PAIN WITH RELAXATION AND HYPNOSIS: A UW STUDY

Chronic pain is a serious, debilitating problem for many persons with a spinal cord injury. It can interfere significantly with daily life and is often unresponsive to conventional pain treatments. Mark Jensen, PhD, professor in the Department of Rehabilitation Medicine at the University of Washington and an expert in the field of pain and disability, is conducting a five-year study, funded by the National Institutes of Health, to test the effectiveness of two different relaxation treatments for SCI pain.

“We really want to expand the treatment options for persons with SCI-related pain because we know the treatments we have available now are not very effective,” Jensen said. “Medications are not always helpful and often have adverse or intolerable side effects.”

“In contrast, hypnosis and relaxation techniques are a way to get pain relief that has only positive side effects, such as improved sleep, lowered blood pressure, and decreased anxiety.”

The two treatments under investigation in this study both contain hypnosis and relaxation training components. One focuses on direct verbal suggestions

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Derby City Area Chapter
of the
National Spinal Cord Injury
Association

ABOUT THE ORGANIZATION

The Derby City Area Chapter of the N.S.C.I.A. is a membership organization for individuals with spinal cord injuries, their families, and health professionals. Founded in 1984 as a Charter Member of the N.S.C.I.A., it was incorporated under IRS Section 501 (c) 3 as a not for profit organization. The Board of Directors consists of the Officers, Past President and the Board Members At Large.

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NSCIA
DERBY CITY CHAPTER
NEWSLETTER

Editor- Barbara Davis

Contributor- David Allgood

TREATING SCI PAIN (Continued From Page One)

relaxation; the other uses biofeedback-assisted relaxation. “Patients report they feel better after both treatments, and each has shown to be effective for chronic pain in other populations,” Jensen said.

Jensen explains the effect of deep relaxation by comparing the brain to a television set: “You can only listen to one or two channels at a time. Yet there are potentially thousands of channels of information available to our brains. We can’t process all the possible input that our brain receives. In a deeply relaxed state, the mind simply has more control over how we process information. Also, it’s hard not to hurt so much when you’re deeply relaxed.”

Jensen and his colleagues are recruiting up to 134 participants who have SCI at any level and who experience bothersome chronic pain. Participants can have neuropathic pain—caused by abnormal processing of sensory input due to the nervous system—or musculoskeletal pain—due to overuse of non-paralyzed muscles, as in wheelchair propulsion. Most people with SCI have a combination of both types of pain, says Jensen. “One of our research questions is whether these treatments are effective for different kinds and combinations of pain.”

Participation involves an initial interview; a physical exam by the study physician (Dr. Diana Cardenas); a two-month “baseline” period (before beginning treatment) of daily pain ratings; random assignment to one of two relaxation treatment groups; 10 free one-hour relaxation training sessions over a two-to-four week period; and monthly follow-up phone interviews for one year after treatment. Patients will receive free parking, free treatment sessions with a research psychologist (which normally costs \$120 per session), and compensation for follow-up interviews.

Participants in the study so far report significant benefit from the relaxation training, Jensen says. Because relaxation is something people can learn themselves, it can give them a sense of control over pain. Many participants have been surprised at the effectiveness of the techniques—for some, this was the first time in years they had felt pain-free. Some said the procedures eliminated their pain; others that it helped make their pain more tolerable. A number of participants commented that it was a good way to decrease anxiety and get through tough times. It also improved sleep for many.

“These techniques don’t relieve pain for everybody, but some people get significant pain relief, and most people report at least a little,” Jensen noted. Furthermore, “relaxation is a good stress management skill.” Finally, many research participants like knowing they are contributing to research that will help others in the future.

Refrigerator Calendar

***2004**

OCTOBER

4th - Elderly & Disabled Advisory Council Meeting

Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

18th - NSCIA Derby City Area Chapter meeting; 6:30 p.m., Frazier Rehab.

Mon 4th floor dining hall; speaker to be announced.

16th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.

Sat Speaker to be announced; if questions, contact Terri Leasor at 589-6620 or at mdclouky.org

19th - Louisville Metro Sweep for Access

Tues Crescent Hill Library; 2762 Frankfort Avenue

NOVEMBER

1st - Elderly & Disabled Advisory Council Meeting

Mon 1:00-2:30 p.m.; TARC; 1000 W. Broadway; Board Room.

15th - NSCIA Derby City Area Chapter meeting, 6:30 p.m., Frazier Rehab.

Mon 4th floor dining hall; speaker to be announced.

20th - Metro disAbility Coalition Meeting; 1 p.m. – 3 p.m.; PVA Office on Goss Avenue.

Sat Speaker to be announced; if questions contact Terri Leasor at 589-6620 or mdclouky.org

16th - Louisville Metro Sweep for Access

Tues Crescent Hill Library; 2762 Frankfort Avenue

For More Information Call
David Allgood, 502-589-6620

BACK PAIN, WHEELCHAIR SEATING, AND POSTURE

Are back pain and shoulder pain an inevitable consequence of using a wheelchair for people with spinal cord injuries? Jennifer Hastings doesn't think so, and she's on a crusade to change the way patients, providers and manufacturers think about wheelchair seating.

Hastings is a physical therapist who specialized in SCI rehabilitation for 13 years. She established the wheelchair seating clinics at both the VA and Harborview medical centers. She has lectured and published widely on the subject and is recognized as a national expert.

The reason pain is so common among wheelchair users with SCI, Hastings believes, is that "we've forgotten the skeleton and deal with all the neurological patients—stroke, SCI, Parkinson's—as if they are only a nervous system." She thinks close attention to the skeleton and proper postural alignment can alleviate or avoid many of the typical musculoskeletal pain problems in this population.

The obvious purpose of a wheelchair for people with SCI is to provide mobility, but a less recognized need is to provide stabilization of and substitution for weak or absent trunk muscles during sitting and functional activities. "If you don't have use of your trunk muscles (abdominals and back extensors), as in a cervical injury", Hastings said, "you don't have an anchor to your wheelchair."

To feel more stable, people slump back and slide the buttocks forward in the seat. "That's very stable," said Hastings, "but you can't sit that way all day without eventually developing posture-related pain problems."

The traditional 90/90 wheelchair (seat parallel to the floor; high seatback at a 90 degree angle to the seat) sets people up for this kind of posture problem from day one, Hastings claimed. "Some facilities are still prescribing these for people with SCI, and it should not be allowed."

One way to increase stability in a wheelchair is to recline the backrest or tilt the chair in space. While this allows the lower back to stay against the seat, it also thrusts the neck forward, which quickly becomes fatiguing and painful for the neck muscles.

Whether standing or sitting, proper postural alignment places the ears over the shoulders over the hips while maintaining normal spinal curves. This alignment is optimal because "it takes the least muscular work to maintain," Hastings explained. Less muscular work means less fatigue and pain and more

Frequently the lowered backrest height meets with resistance from other clinicians. "I've had many arguments with doctors who say, "You can't have a backrest that low—they're jelly above that!" Hastings recounted. "But it's jelly that I want to align this way to allow the person to use the strength they have." In case after case she has found that maintaining a normal thoracic curve and providing lumbar support do provide stability without compromising alignment.

She has the same goals for newly injured patients trying out their first wheelchair while still in the hospital. "I start with the backrest a little higher and more reclined than I would go (with a long-time injured person)," Hastings said. "But by discharge the backrest height should be lowered and the angle more acute."

The concept is the same for power wheelchair users. While you need to use a higher backrest for a power wheelchair due to the need for power recline and often driving from a chair "you can still set it up to allow the normal thoracic curve," she said. The key is to support the lumbar spine and have the backrest fall (rearward) at the thoracic area to allow for the normal spinal curves.

Hastings and many of her patients have noticed that improving posture results in better overall appearance. In one case, a woman went home after Hastings adjusted her power wheelchair to a more normal upright alignment, and her family immediately noticed the difference. "Her kids said she looked taller, and her husband thought she looked thinner," Hastings recalled. "Posture is also about vanity."

Hastings also cautions patients against forming bad postural habits that occur while performing routine activities.

Computer users, for example, position the keyboard too far away; as a result, they have to slump down to avoid pitching forward. "The keyboard should be positioned close to you so that you aren't reaching out," Hastings said. "If you're an all-day keyboard user, I recommend using a strap to give you a little support." Crossing the legs while typing twists the torso and cuts off the blood circulation if maintained for too long. "You should adjust your posture to different tasks throughout the day," Hastings continued. "It's good to shift your position around frequently."

A seat cushion that's too long is a common mistake in wheelchair configuration. Recently the standard length of the seat cushion was increased to 18 inches (too long for all but the tallest people) because a longer seat was thought to distribute seat pressure over a larger area and reduce the risk of skin problems. The longer seat can also make transfers easier. But Hastings believes that a seat that is too long makes good upright posture impossible. "Unless you're really tall, it makes you sit with your buttocks forward and your pelvis tilted posteriorly." The seat should not be any longer than the distance between the small of the back and the bend in the

(Continued on Page Five)

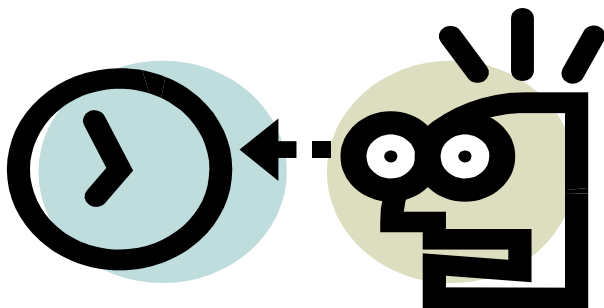
BACK PAIN, CONT'D

knees. You can learn a new transfer technique or buy a seat cushion designed to reduce pressure, Hastings said, but good posture should not be compromised. Poor posture causes pain.

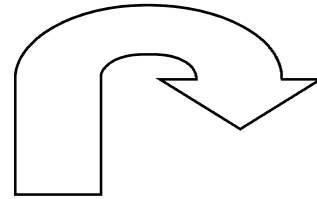
Pain develops when muscles are asked to do a job they aren't designed for and to "stand in" for muscles that are paralyzed, Hastings explained. There are two types of muscles: tonic, for holding (the postural muscles); and phasic, for mobility (the task-oriented muscles). "They are union workers," she said. "They don't do things not in their job description. With paralysis, there are fewer muscles to work, and the remaining muscles are asked to do work they weren't designed for physiologically. Asking phasic muscles to hold and tonic muscles to move results in pain and fatigue." In addition, if these muscles are doing a different job, they are not available to do their own job. The situation compromises functionality.

Muscles also have a length they like to operate in, and if they are stretched or shortened due to poor posture they become weak. "Poor posture sets up and exacerbates muscle imbalances," Hastings said.

The key, then, is to make sure the wheelchair is configured properly to give adequate trunk support and stability so the non-paralyzed muscles do not become fatigued and painful from doing too much or doing the wrong job. Pay attention to the skeleton so the muscles can do their job, Hastings said. "That's the take-home message."

IT'S THAT TIME AGAIN!!

**SET YOUR CLOCKS BACK
ON HALLOWEEN NIGHT
OCTOBER 31!!**

FOR SALE!!!!**

***1985 Komfort Koach van;**v-8 engine; power fold-up wheelchair lift; power window and door locks; wheelchair safety strap/hooks; almost new tires; AC/front and rear vents; cruise control; AM/FM radio, tape deck, CB radio; game table and window shades; trailer hitch; \$135,000 mi.; good cond.; \$2750.00 (502) 425-0314.

***Chair Topper & Hand Control;** price negotiable; Call Greg @ 968-4630.

***2003 Ford F-250 lift-equipped green/gray van;** leather seats, TV, DVD player. Playstation hookup, am-fm radio. Rick Miller, 937-2245.

Shower Chair; 2 yrs old, negotiable; 2 RoHo cushions; low profile; \$150 each; Invacare 900 Action Power Chair; 4 yrs. Old; \$600. Call 448-5296.

***RoHo High Profile 16x16 cushions; \$160; 589-6620.**

***2002 Dodge Caravan "Entervan" (Braun modification);** app 18,000 mi; remote operated oil recently changed; mechanic confirms excellent condition; used only a little more than 2 mos.; \$34,000. Call 859-492-7971.

***Ford 1997 Econoline Van;** 100,140 mi; \$16,000. Hunter Green-gray; new tires & brakes; "loaded"; call 270-786-4547; ask for Dale.

***Heavy Duty Scooter; used less than 50 hours/2 new batteries;** \$1200. Call (502) 348-9305.

***Liberty Stairlift/Set for 13 steps;** \$1500 soft; 937-9492

***Video tapes for sale.** Various topics related to spinal cord injuries. Call David Allgood or Buddy Lawson.

****If assistance is needed to pay for any of the above items, contact Kentucky Assistive Technology Loan Corporation at for information on loans at 5% interest to qualified candidates.*

HAPPY HALLOWEEN!!

You are cordially invited to join us!

The Derby City Chapter of the National Spinal Cord Injury Association consists of people with spinal cord injuries and similar physical conditions, their family members, friends, and professionals or other interested parties.

We meet:

WHEN- Third Monday of every month from 6:30 to 9:00 PM

*WHERE- Frazier Rehab Center, 4th floor Dining Room
220 Abraham Flexner Way*

If you wish to be a member, donor, and/or be on the mailing list of the Derby City Chapter of the National Spinal Cord Injury Association please complete and mail the following form to the address below

National Spinal Cord Injury Association
Derby City Chapter

Membership & Organization Sponsorship Form

Name: Mr./Mrs./Ms./Dr. _____ Date _____
 Address: _____ Apt.# _____
 City/State/Zip: _____
 Business (if any): _____
 Home Phone: () _____ Work Phone: () _____
 Date of Birth _____
 Para: _____ Quad _____ Hemiplegic: _____
 Level of Disability _____ Other Disability _____
 Able-Bodied(yes/no): _____
 New Member: _____ Renewal _____ Newsletter Subscription
 (only \$12): _____
 Special Interests /Hobbies/Sports: _____

Membership is open to all individuals and sponsorship to all organizations interested in spinal cord injury.

Mark Type of TAX DEDUCTIBLE Individual Membership or Organization Donor Category Desired***

- | | |
|------------------------------------|--|
| _____ Regular-\$12 | _____ Bronze Organization-\$100-249 |
| _____ Sponsor-\$25 | _____ Silver Organization-\$250-499 |
| _____ Patron \$50 | _____ Gold Organization- \$500-999 |
| _____ Benefactor-\$100 | _____ Platinum Organization-\$1000-2499 |
| _____ Permanent- \$1000/lifetime** | _____ Diamond Organization-\$2500 Or Over. |

Please make checks payable to: **NSCIA Derby City Chapter**
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