



PARAVIEW

September 2007

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Be Inspired!

Value in exercise and education.

In 1982, before Greg Hayden sustained a spinal cord injury he was working as a plan operator for a civil engineering company, operating machinery in suburban estates and railway shunting yards in Brisbane. Greg had a motor cycle accident on the way home from work on the Friday, 30th June, 1982, which is not only a date he will never forget because of his accident, but it was also (& always will be), the end of the financial year.

Greg lost approximately 15 kilograms of muscle while in hospital after the accident and so decided he must do something about his fitness. In the following months he took up swimming at Chandler Swimming pool and began training. He started with swimming one lap at a time, but slowly increased that to swimming 30 laps x 2. Greg says the he has swum a maximum of 64 laps – what a significant achievement!

Swimming for exercise increased Greg's upper body strength and general physical fitness. In addition, Greg says his mental strength also improved substantially and he was positive, active and above all, focused. Greg was intent on getting back to work.

In the first year after his accident Greg returned to the education system, went back to school and completed grades 10-12 combined. In the following year he took on odd jobs and completed TAFE courses to increase his ability to undertake office work. Greg continued to study at TAFE, studying 2 nights a week, while also working fulltime. Further education has paid off well for Greg; he has completed a diploma in business Admin. And has almost completed an Advanced Diploma in Accounting. Exercise and swimming have been so good that he continues to keep fit by swimming 2-3 times a week throughout summer and in winter he handcycles near where he lives.

Greg is studying fulltime to become a primary school teacher and plans to graduate at end of 2008. Greg says 'education has been a challenge in my life, when I am in a teaching position I believe I still have 14 or more good years to work and give back to the community'. He said 'having contact with people with a disability at a young age will help children to understand that we have a lot to offer the community and workforce.

In summary, Greg has found that keeping physically fit also keeps you mentally fit to focus on the challenges in life. He says 'To enjoy life, a person must have personal short and long term goals and challenges. It keeps the weight off your body and as well, your life is much more enjoyable, not only to you, but to the people around you who love you.'

(Editor's note: how true this last paragraph is!!)

Courtesy: Imprint July – August 2007 – written by Marion Webb



Editorial

Hi Readers,

'Hip, hip hooray'!! Are the Editorial Team happy? You bet we are!! We now have a 'new beaut' printer which we are experimenting with and we are now like kids with a new toy!

The format of the Newsletter has been 'revamped' and we hope you think it looks more professional and slick. Many members have commented that the content has improved considerably during the past twelve months and the Editorial team are always on the lookout for interesting articles. If you have something you would like printed then just let us know or if you have a question to put to readers we will be happy to include it also!

We will continue to seek improvements and are looking at changes that will bring the Newsletter to a more professional level. Last Newsletter we were willing to give a \$50 voucher for some input – no one came forward other than to say they liked what they see – so we decided to put on our 'thinking caps' and come up with a new name. The 'prize' for the new name, Paraview' goes to Chris Bosworth, EO (so no prize has to be given). We decided to have an inspirational story on the front page from now on as we hope this will make all readers read from front to back and be inspired also. If you know someone whose story is inspirational then we would like to invite them to submit their story. There are so many people in the community who have risen above adversity and are showing us that they can contribute so much to the world by their participation.

Regards,

Harold, Louise and Jenny

Coming Events

***ParaQuad Association of Tas. Inc. (ParaQuad Tas.)
is holding its***

17th Annual General Meeting

On Friday 5th October, 2007—12 noon at

ParaQuad Tas. Inc. Office, 26-28 Tolosa Street, Glenorchy

(Members must be financial if they wish to attend and vote)

Please RSVP before 28th September, 2007 (Numbers required for catering purposes)

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SpineSafe Week—10th—17th November, 2007

Opening of ParaQuad Tas. Units

Wheelchair Sports Dinner

Launch: 'Ways To Work' Report

Wheelie Good Guide

Stayin' Alive Website

(Further information: on dates etc. please contact ParaQuad Tas. Office

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Chairperson's Report

The ParaQuad Tas. Board has been working hard these past few months to address some of the governance issues that have required refining and to also work towards a more professional Board that has a sound Strategic Plan that moves the Association forward to ensure that we are able to assist all people with spinal cord injuries across Tasmania with support when required. It is a huge task to undertake with little available resources but this is our aim.

I am very pleased to report that the opening of the 'Glenn Moore' units will be held on 10th November, 2007 at 2.30 pm at 26-28 Tolosa Street, Glenorchy. It has taken a very dedicated team of ParaQuad members headed by Glenn Moore over the past 17 years, who have all worked tirelessly for many years, to raise the necessary funds to realise their dream. The dream when the Association was reformed in 1990 was to raise funds to build fully accessible respite units for people with spinal cord injury. The units project and planning was begun in 2000 and although it has been a slow process we believe it has proven most worthwhile.

The two units will be available for short term respite only and will be available to anyone who is dependent on a wheelchair. ParaQuad Tas. will not be providing support staff at this stage.

SpineSafe Week is being held from 10th – 17th November and we will be launching the 'Wheelie Good Guide', the 'Ways to Work' Report and 'Stayin' Alive' Website (as well as opening the units) – so it will be a very busy week. Wheelchair Sports is holding a Dinner on the 10th November to fundraise for their organisation. (See details under 'More Coming Events'.)

The 'Ways to Work' Project has given ParaQuad Tas. plenty of tasks to undertake over the next twelve months! The ParaQuad Board will be working through the strategies so that the Association will be much stronger and able to provide more support to people with spinal cord injury and their families in the future. The Report will be available after SpineSafe Week and it is only through the honesty (as stated in the last newsletter), of the participants, that the Report is so detailed. Robyn Wolstenholme, who carried out the research, was overwhelmed by the contribution of these participants.

ParaQuad Tas. is pleased to advise that there will be upgrades and establishment of several fishing venues, across Tasmania, for people with disabilities so that they can have a safe, accessible venue to fish when they want to catch a fish (or two) in the future. (ParaQuad Tas. will be involved in the accessible design on a couple of these venues so I will advise you in next Newsletter how the upgrades are progressing.)

The coming year we will be gearing up to have our volunteers more involved with the community and one of the tasks will be to have trained peer support volunteers who will be able to be 'matched' to the person requiring support. We have also invited schools to take advantage of our SpineSafe Education Program which has proved most successful but we are always looking for more educators to visit the schools – so if you are interested in being trained to become an educator we would be pleased to hear from you.

Notice of ParaQuad Tas. 17th AGM is listed in 'Coming Events' opposite page – it will be held on 5th October, 2007 at 12 noon at the office. How about coming along to learn what your Association is about and how you can contribute – meet the Board and maybe consider becoming more involved.

Scott Shaw, Chairperson

Pain and Spinal Cord Injury

Pain is a frequent problem for many individuals with spinal cord injury (SCI) and can interfere significantly with daily life. A person with SCI is likely to experience many types of pain that can be troublesome to categorize. Location, type, duration and severity of pain can vary a great deal and are key to understanding its cause and choosing the right treatment.

If you have chronic (long-standing) pain, it is important that you talk to your doctor about what type of pain you have since the treatments differ.

Neuropathic pain

This is the most common type of chronic pain in the SCI population and the hardest to treat. Neuropathic pain is usually felt at or below the level of the injury. It is caused by abnormal signals from the nerves that were damaged by your SCI, and this is why a person can feel neuropathic pain in an area that otherwise has no sensation.

It is often difficult to identify a specific stimulus or cause of neuropathic pain. Your doctor may ask you to undergo an x-ray or MRI (magnetic resonance imaging) scan of the spine to make sure there is no bone or spinal cord abnormality such as a syrinx (a cavity that develops in the spinal cord of about 2% of the SCI population). If your doctor does not find a specific abnormality, then your pain is considered to be caused by the abnormal signals of your SCI.

Many different medications are used for neuropathic pain, including antidepressants at low doses, anticonvulsants, nonsteroidal anti-inflammatory drugs such as ibuprofen, and others. Sometimes combinations of drugs work better than a single drug. In some cases, treating spasticity helps reduce the pain.

Types of neuropathic pain:

- Transitional zone pain (also called segmental pain) is usually felt at the level of injury in a band-like pattern

around the trunk, or it may involve the arms. Transitional zone pain is treated with medications and sometimes with a surgical procedure called DREZ (dorsal root entry zone lesion).

- Radicular pain can be felt at any level and is caused by nerve root damage from broken pieces of bone, dislocated disc material or inflammation. Radicular pain is usually located on one side only. It can be worse with rest and is often improved with activity. This type of pain can begin within days to weeks after injury and may be hard to distinguish from pain caused by the injury itself. Radicular pain often improves with nonsteroidal antiinflammatory medications (NSAIDs) such as ibuprofen.
- SCI pain (also called central pain, dysesthetic pain, or diffuse pain) is the term used for neuropathic pain that occurs below the level of injury. This kind of pain is usually felt all over the body rather than in a specific area. It can get worse if you are fatigued or stressed; smoke tobacco; or have bowel or bladder problems, pressure sores, or spasticity.

SCI pain usually starts a few weeks or months after injury. If it starts years after injury or gets worse, it might be caused by a syrinx or a problem with the vertebrae (the bones of the spine) and should be evaluated by a physician.

SCI pain is very hard to treat and individuals with SCI pain have found relief from a combination of drugs, or from drugs in combination with physical therapy or other treatments. Some treatments, like implanted morphine pumps, work well but only temporarily. Often a holistic approach that includes a combination of exercise, medication, stress reduction, or complementary medicine (such as acupuncture), can help relieve SCI pain.

Musculoskeletal pain

Musculoskeletal pain comes from problems in the muscles or skeleton and is common in the population as a whole, especially as people get older. In the SCI population, musculoskeletal pain can be produced by injury at the time of SCI, injury following SCI, overuse or strain, arthritic changes, or wear and tear of the joints, often from wheelchair use. Treatments usually involve medications, physical therapy, equipment changes, or all three.

- Shoulder pain in people who use a manual wheelchair may be helped by changing the posture in the wheelchair and doing specific physical therapy exercises. Propelling a wheelchair can lead to an imbalance of the shoulder muscles, such that the muscles in back are weak compared to those in front. A physical therapist can teach you exercises that strengthen the muscles in back and stretch the muscles in front to help reduce shoulder pain.
- Back pain is a common problem in people with paraplegia. If there has been a fusion, the spine is more rigid at the levels of the fusion. Increased motion is likely to occur just above and just below the fusion, and this can lead to back pain. A different back rest that provides more support can help, although this may reduce upper back mobility. Low back rests allow more motion but do not provide as much b a c k s u p p o r t . People with tetraplegia (quadriplegia) may also have back pain, especially if they are able to walk but still have weakness. Even patients with complete tetraplegia can have upper back and neck pain.
- Musculoskeletal pain at or below the level of injury is usually confined to one specific area. It often worsens with activity, gets better with rest and an ice pack, and responds well to nonsteroidal antiinflammatory drugs (NSAIDs) such as ibuprofen.

Visceral pain

Visceral pain is located in the stomach and digestive area and can be caused by undiagnosed gastrointestinal complications such as ulcers, constipation, or appendicitis. Since a person with SCI may not have the usual symptoms associated with these medical conditions, a physician with limited experience caring for SCI patients may have difficulty making the correct diagnosis and prescribing the right treatment.

Visceral pain can also exist even if there is no medical problem. In that case, it would be a neuropathic pain that is caused by abnormal nerve signals but felt in the abdomen.

Alternative treatments

In addition to the treatments mentioned under each type of pain in this brochure, there are many other treatments for pain. People have gotten some relief with massage, aerobic exercise, acupuncture, stress reduction techniques, hypnosis and psychotherapy. Your physician can discuss these alternatives with you.

Prevention and self-care

Overall health can have a big impact on pain. Pain can get worse and be harder to treat if you are rundown, stressed, suffering repeated urinary infections, or not getting enough sleep. For this reason it is very important to pay attention to your health and lifestyle habits, and to get prompt treatment for medical problems.

Distraction can be a useful way to cope with chronic pain. Even though severe or constant pain may sometimes overwhelm everything else in life, making an effort to distract yourself can actually help reduce pain and can make you feel like you have some control over your life. A counsellor or psychotherapist can help you learn psychological strategies such as distraction and relaxation techniques.

Courtesy: Paralyzed Veterans, USA



Independent Living Centre News

Back on Track (Lower Back Injury)

When a person is diagnosed with a lower back injury, the usual advice is to avoid unnecessary daily tasks. If the injury extends into weeks or months, the person will feel an increasing need and desire to be independent and resume household and recreational tasks. Tasks can be made easier and pain/discomfort reduced, using some of the suggestions below.

Self Care

Reaching can be difficult and painful. Sitting on a chair or stool to shower can help a person reach their legs and feet.

Long handled toe washers and sponges can make it easier to reach legs, feet and back. Other items to consider include a long handled pumice stone for foot care, an extension razor holder suitable for an electric or disposable razor and a long handled applicator for creams or ointments.

A flannel strip with handles at both ends may help someone wash and dry their back by reducing twisting and reaching.

Because back movement is limited, it can be hard to reach a piece of soap dropped in the shower or bath. A wash mitten or soap on a rope is useful in this situation.

Cutting toenails can be difficult. Long handled toenail scissors can assist or you may need to visit a podiatrist for regular foot care.

Dressing

A long handled shoehorn may help with pulling on shoes.

Putting socks on may be easier with a sock aid. A double style for pantyhose is also available.

Dressing stick reduces bending / reaching with lower garments. Folding model also available.

Cleaning

One big weekly clean may no longer be possible, so a change in routine may be required. Consider being selective and prioritising jobs. In a large or two storey home keep more than one set of supplies around the house to save carrying heavy objects over long distances.

Reduce your need to reach by using a feather duster with handle extension.

A range of long handled brushes featuring sponge and scrub surfaces are available for cleaning baths, shower screens, toilets and mirrors.

Buckets on castors require less lifting/carrying and come with a range of wringing systems. They can also be used as a bin that can be moved easily from place to place when tidying.

Swivel mops reduce twisting while mopping and can be purchased with a selection of pads.

A long handled broom and pan can be indispensable for small spills.

When choosing a vacuum cleaner consider the overall weight of the cleaner, and features such as self propulsion or a swivel mounted hose attachment for improved manoeuvrability.

How easy it is to change the dust bag or attach/remove the accessories? You may wish to consider a central vacuum system that has a motor built into the house and several inlet wall valves throughout the house. A number of robotic vacuum cleaners that vacuum independently are also available.

Picking Up

A reacher tool (with a magnet attached) helps to pick up objects such as clothes & toys from the floor. Models range from 340mm to 900mm in length. Folding reachers available also.

Making the Bed

Making the bed is easier if you use a fitted sheet and a quilt instead of blankets and flat sheets that need to be tucked in.

Reduce lifting by using a lightweight quilt that is waterproof and doesn't require laundering. If

you use blankets, look for lightweight styles that have a high warmth to weight ratio that can be machine washed and tumble-dried.

In the Kitchen

Avoid bending by using the top rack of the dishwasher only. Consider a bench top or drawer style dishwasher that can be mounted at the height that is most comfortable for you.

Frequently used items should be stored between hip and shoulder level. A wire carousel can be installed in corner cupboards to allow easier access to items. A shelf that sits under the microwave and pulls out to provide a convenient surface for stirring and food preparation is also available.

A trolley or traymobile can be helpful when moving heavy items.

A kitchen stool can be used to perch at the counter but be careful not to hurt your back by over reaching or swivelling from a sitting position.

A long handled oven cleaner may help you reach the back of the oven without bending or reaching.

Laundry

A washing machine plinth will bring a front-loading washing machine up to a convenient height. Use a reacher to remove items from inside the machine.

A laundry trolley on wheels will help you to move clothes out to the line or around the house.

A freestanding clothesline will reduce reaching and can be folded flat for storage. Wall mounted clotheslines can be mounted at a height to suit the user and come in a range of sizes. A wall-mounted clothesline that hangs at a 45 degree angle and eliminates reaching up is also available.

Carrying and erecting an ironing board can be difficult. A pull out or wall mounted ironing board is convenient if space permits. Small bench or counter top boards can be set up at a comfortable height.

Shopping

If you can drive or have access to transport, small frequent shopping trips may be easier for you to manage than one large trip.

Place shopping items in the top basket of the trolley so you don't have to reach down too far to retrieve them at the checkout.

Ask a shop assistant if they can take shopping out to the car for you.

If you have a deep car boot, it may be easier to put small amounts of shopping onto the front passenger seat. (Be aware that unsecured items may become a hazard if you are in an accident or have to stop suddenly.)

Home delivery and internet shopping may also be available in your area.

Gardening

Raised planter boxes and tubs will bring flowers and vegetables up to a comfortable height.

A range of lightweight, long handled tools with attachments are available to suit most jobs around the garden, such as:

a pot lifter, which is a long handled device that can assist in lifting and moving pot plants without bending; a seedling planter, which is designed to reduce the need to bend. The point of the seedling planter digs a small hole in the soil. The seedling can then be slid down the tube of the planter. Soil can then be firmed around the seedling with the tip of the planter. trolley can be used to move items about in the garden and a work surface at a suitable height for propagation and other tasks is essential. Consider a traymobile or table that can be adjusted to a suitable height.

For further information or to make an appointment please contact the Independent Living Centre, Launceston. The Independent Living Centre offers free advice on equipment and techniques to help you with everyday tasks.

Courtesy: ILC SA: Information Sheet: April 2007: Lower Back Injury
Email: ilcsa@ilc.asn.au

The good, the bad and the ugly

The Human Rights and Equal Opportunity Commission has produced a new CD aimed at designers, builders, building certifiers, access consultants and access advocates.

The good the bad and the ugly looks at thirteen examples of common mistakes made in applying today's Building Code of Australia (BCA) in areas such as handrails on stairs, use of Tactile Ground Surface Indicators, signage, visual indicators on glazing and kerb rails on ramps.

The purpose of this resource is to explain why precise application of the BCA and its referenced Australian Standards is necessary by describing how people with disability benefit from good design and construction.

It does not try to replicate all the access provisions of the BCA or Australian Standards in words and pictures, and it does not seek to define access requirements under the Disability Discrimination Act. It simply draws attention to the fact that the technical specifications are there for a reason and failure to apply them has serious consequences.

The good the bad and the ugly could be used as a self learning tool or as an in-house continuing education program for building certifiers, designers, builders, building managers, fit-out specialists, access consultants or advocates interested in access issues.

The CD also contains the photographs used in *The good the bad and the ugly* which can be used to develop your own presentations by copying them into programs such as PowerPoint.

A copy of the Commission's *Guidelines on access to buildings and services* is also included on the CD. The guidelines are aimed at businesses, service providers, Government agencies, property managers and anyone involved in the purchasing, leasing or assessment of property. The aim

of the guideline is to assist in identifying possible barriers to buildings and services and direct people to resources and expertise to address those barriers.

All these resources have been developed in consultation with people with a disability and others in the building, design and access fields, however, once the material is more widely circulated no doubt there will be many good suggestions for editorial changes and additional material, including photographs. Ideas and comments should be sent to **disabdis@humanrights.gov.au**

To order a free copy of this CD please contact **publications@humanrights.gov.au** or telephone 1300 369 711

The material is also available on the Commission's website and will be updated from time to time so check this website for updates.

http://www.humanrights.gov.au/disability_rights/buildings/good.htm

Many people with SCI tell us that the first year after discharge from rehabilitation is very difficult because they have so many questions and new problems to solve but don't always know where to find the information they need. To address this, ParaQuad Tas. is upgrading our SCI Kit and if you have any suggestions or hints for the Kit then please forward them to Kerrie Chilcott or phone her on 6272 8816. If you or someone you know requires peer support, for spinal cord injury, Kerrie can put you in contact, by phone, with a peer support volunteer. If you have a medical complication then it is very important that you contact your sci support health professional.

Taking Charge of One's Life

Todd Stabelfeldt is the consummate example of someone who has taken charge of his life under the most challenging of circumstances and has done it with humor and style. At the age of eight, Stabelfeldt was shot in the chin while he and his cousin were playing with guns, resulting in C4 tetraplegia (quadriplegia). That was 20 years ago; now he is a full-time professional, living on his own, financially independent and active in the community.

"I've had a 20-year course in C4 quadriplegia," Stabelfeldt said recently to a class of occupational therapy (OT) graduate students. "It's been a difficult course and I wish I could drop out, but I can't. I am paralyzed, and it's rough, and I wouldn't wish it on anybody. But I've learned a ton and feel I can share it with you with the hope that it can help others gain quality in life."

Stabelfeldt has been a regular presenter in this assistive technology class taught by Brian Dudgeon, associate professor of rehabilitation medicine. "I'm a big fan of learning from consumers," Dudgeon says. "Todd tells his story of injury and emergence with a huge reliance on assistive technology and environmental design to enable his employment, self-managed living status and other community engagements. He has been very resourceful in tracking down the technology systems that work for him."

A self-proclaimed geek with a keen sense of humor about himself and life, Stabelfeldt has gained his hard-won independence through sheer grit and moxie, searching out equipment for assistive technology (AT) in unorthodox places, including the maritime and RV industries, and developing creative solutions to accessibility problems. "We live in a really cool time for technology that's available for AT," he says.

Stabelfeldt's entire home is networked so he can independently access and operate his phone, email, photos, CDs, movies and books. A computer screen is positioned at his bedside. "At night I wear a headset. I can turn the fan on via computer interface. If a

client calls me at 4 am, I can answer, bring up a screen, and deal with the problem from bed. So much industry today can be applied to my disability and give me independence."

It wasn't always that way. "Growing up in the '80s, the AT was awful," Stabelfeldt recalls. "Childhood for me was not fun, not accessible at all." For years after the injury, "I felt I wasn't in charge of my life, like an infant. I decided at some point to work on my brain. If the vessel is broken, what's inside is not." He obtained computer training and at age 18 landed a programming job with a medical software company. He worked his way up and is now the director of operations.

Stabelfeldt lives by himself in an apartment, with personal care assistance in the morning and evening. He works at home remotely, and periodically comes into the office, commuting alone by ferry. Paralyzed from the shoulders down, Stabelfeldt operates his motorized wheelchair—tricked out with his own setup of fiber optic buttons and voice-controlled communication system—using a chin-control device.

In addition to functionality, Stabelfeldt strives for a certain elegant simplicity in his AT solutions. He avoids overly complicated technology when low-tech works fine, such as hooking up a granola bar to a flexible arm attached to his workstation, so he can bite some off "like a gerbil" when he's hungry.

Stabelfeldt prefers his wheelchair streamlined and aesthetically pleasing, so "when people see me, they focus on the user, not the chair." He designed a custom denim cover for his urine bag, to achieve a less medical look, and because, "I believe you would prefer to see a denim bag than my urine." The bag is attached to his wheelchair with not one, but two hooks. "Who would have thought that urine bag hooks would matter?" he muses. But it does matter, and it's one of those many details he learned about the hard way. "Have I dragged my urine bag behind me for half a mile? Have I run over it? Have I done both these things

on a first date? The answer is yes.”

He dealt with that awkward moment as he always does, with humor. “Humor for me is huge, a heal-all,” he says.

“So I said something funny to dispel the tension. But I never did have a second date with her. So the take-home lesson is: The two-hook style urine bag will get you the second date.”

Stabelfeldt’s sense of style is evident also in his personal appearance. He is usually well turned out in custom-tailored attire; a smart cap, tie and vest; hair and beard impeccably groomed. “I like to smell good and wear nice clothes,” he admits. “It’s important to me.”

He is a fan of Nordstrom, which tailors clothes to work with his body and chair, and where he is always treated with respect and professionalism. “I’m treated like a regular customer at Nordstrom,” he says. “I wheel in there, and I feel great.”

Relying so heavily on AT to maintain his independence, Stabelfeldt is meticulous about safety and emergency preparedness. A backup system of individual batteries linked together and charged by regular electricity can keep all his equipment running in case of a power outage. “I’m a redundancy guy,” he admits. “I do everything by Internet, and don’t want to lose connectivity if there’s a power outage. I want backup on everything. I have done three-day outages successfully.”

And while batteries are expensive, cumbersome and have an unpredictable lifecycle, “you can’t put a price on independence and security,” he says. “I use Bi-PAP (a ventilator device) at night, so battery back-up is a lifesaver.”

Financially independent, receiving no government support or benefits, Stabelfeldt is unusual for someone with his disability, according to Dudgeon. “I know of no other men with such high level SCI who are as successful as Todd in employment, living status, and community involvement. The independent and resourceful manner in which Todd developed these skills is unique.”

Stabelfeldt is eager to share his experiences

and lessons with a wide audience so others can benefit. In addition to his full time job, he is a motivational speaker who delivers compelling and humorous speeches to high school and youth groups. At the UW’s Northwest Regional Spinal Cord Injury System, he is an SCI peer mentor, member of the Consumer Advisory Board, and a frequent SCI Forum participant. He wants to spread the word, not only about the wonders of AT solutions for people with disabilities, but also about the personal rewards of overcoming adversity of all kinds.

“Todd’s desire to influence young people is impressive,” Dudgeon adds. “He uses his heartfelt story and humor to provide a very frank and open presentation of a life that dealt with this enormous challenge, but is nevertheless a life everyone can learn from.”

Courtesy: United Spinal, USA

Here are a few things to think about that you probably have never thought about

Can you cry under water?

How important does a person have to be before they are considered assassinated instead of just murdered?

Why do you have to “put your two cents in”... but it’s only a “penny for your thoughts”? Where’s that extra penny going to?

How is it that we put man on the moon before we figured out it would be a good idea to put wheels on luggage?

Why is it that people say they “slept like a baby” when babies wake up like every two hours?

Why do doctors leave the room while you change? They’re going to see you naked anyway.

Why do toasters always have a setting that burns the toast to a horrible crisp, which no decent human being would eat?

What's in a name?

Knowing the active ingredients of your medicines can help prevent medicine mishaps. This is true for all medicines, including those bought without a prescription from pharmacies and supermarkets. The brand names of these medicines don't always give you a clear picture of what's in them, so reading the label is essential.

Common medicines may come in many brands.

Panadol, Disprin and Nurofen are three common brands of painkillers available at pharmacies and supermarkets. However, many people don't realise that their active ingredients — paracetamol, aspirin and ibuprofen respectively — are sold under many other brand names. Knowing this is important if you are allergic to one of these ingredients, or if you should not take the ingredient. It can also prevent you taking a double dose by mistake.

Common medicines may come in many brands
Some paracetamol brands
Panadol Dymadon Dymadon P* Lemsip Panamax* Tylenol Chemists' Own Paracetamol
Some aspirin brands
Disprin Aspro Clear Solprin*
Some ibuprofen brands
Nurofen Advil Brufen* Herron Blue Ibuprofen Rafen* Triprofen
* Medicine is available on prescription under the Pharmaceutical Benefits Scheme.

Common brands that contain paracetamol <i>and</i> other ingredients
Chemists Own Pain Tablets Codral Day and Night Codalgin Demazin Cold and Flu Di-gesic Dimetapp Day and Night Cold, Cough and Flu Liquid Caps Dymadon Co Mersyndol Panadeine Panadeine Forte Panalgesic Sudafed PE Sinus Allergy and Pain Tablets



Don't double the dose.

As well as medicines that contain only paracetamol, there are more than 50 medicines that contain paracetamol in combination with other active ingredients. This means that it is quite easy to accidentally take a double dose of paracetamol if you take two medicines containing paracetamol for different purposes. Be especially careful with cough, cold and flu medicines, as many of these contain paracetamol.

Similar brand names may have different ingredients

Just because two medicines have similar brand names and packaging, this does not mean that they contain the same ingredients. Often, they do not.

Similar brand names may have different ingredients	Active ingredient
Some Codral brands	
Codral Cold and Flu tablets	Paracetamol, codeine, phenylephrine
Codral Forte tablets	Aspirin, Codeine
Codral Pain Relief tablets	Paracetamol, codeine
Some Lemsip brands	
Lemsip Max Cold & Flu sachets	Paracetamol, phenylephrine
Lemsip Flu 12 hour capsules	Ibuprofen, pseudoephedrine
Some Visine brands	
Visine Advanced Relief eye drops	Tetrahydrozoline
Visine Allergy eye drops	Naphazoline, pheniramine

Tips

- Don't rely on the look of the packaging to tell you what's in a medicine.
- Check the label of all your medicines for the names of the active ingredients and their strengths. If unsure, ask a pharmacist for advice.
- Be careful not to take two medicines that contain the same active ingredient.

Quick quiz

Are the following statements true or false?

People with osteoarthritis may find that paracetamol is not strong enough for them.

Learning about 'self-management' helps people with long-term health problems.

Medicines bought from overseas websites may not be good quality.

Nurofen and Advil are different medicines.

Answers

Sometimes true. However, many people who find that paracetamol 'does not work' have not been taking enough.

True. We can all benefit from learning to manage our health, but self-management skills can be particularly helpful for people with chronic health problems.

True. Medicines from overseas may not be as good quality as those bought in Australia, and may not even contain the same ingredients.

False. Nurofen and Advil contain the same active ingredient: ibuprofen.

MedicinesTalk 2007



Conquer your Computer

Viruses, Spam and Hoaxes Fact Sheet

Mega's Top Tips for Safe Email

- * **NEVER** reply to spam
- * Install a spam filter
- * Install anti virus software
- * Keep it updated
- * Check for hoaxes

Spam, Viruses and Hoaxes:

Spam

We are inundated with emails that offer us things for body parts we don't have, or miracle solutions for the ones we do! How can we stop it?!

Why me? Spam marketers use sophisticated computer programs to guess email addresses and to trawl the internet looking for them on web sites.

- NEVER reply to a SPAM message. If you do, you are simply telling the sender that they got your email address right, and they'll keep using it and may even sell it on to other spammers.
- set up RULES in your email program - if you use Hotmail, utilize the 'Junk Mail filter'. If you use Microsoft Outlook or Outlook Express, use the Rules Wizard and create rules that automatically send suspicious mail to your Deleted Items folder.
- test out and decide on a spam filter that works for you. There are a couple of popular ones:

Mailwasher which is a program that downloads only the subject line of each email, allowing you to 'bounce' it back which tells the sender that they got the wrong address - hopefully encouraging them to take you off their database. It is free and Spamtrap which I prefer - because with Mailwasher you have to process each email one by one. With Spamtrap - you change a setting in your email program, sending your mail through the Spamtrap server first - which cleans out any suspicious emails and only sends valid ones through to your account. I have received only 2 spam messages in the past 5 months this way... previously it would be around 100 a day! It is free for 30 days, then \$33 p/year. Governments all around the world are now passing legislation to prosecute spammers, so we may see an end to this in the future.

Viruses

A virus is a small computer program which attaches to a computer file. It can be spread via email, downloading from the internet or file transfer via floppy or CD-Rom.

- * Do not open attachments you were not expecting
- * Install and maintain anti-virus software
- * Use the software's features to automatically update it
- * Back up your files regularly

Hoaxes and Scams

The biggest nuisance recently has been a thing called 'phishing' - someone creates a website or email to look like it is from a legitimate business, like a bank or auction site, and entices the reader to provide their personal login details including user name and password. The best way not to be caught by these scams is to be vigilant - if you receive an email asking for your details or an update to your details, go to the original website (not by clicking the link in the email) and provide the details that way. There is no Nicaraguan business man who has tens of thousands of dollars and needs your help to get it out of the country. There is no way Bill Gates will send you money for forwarding on an email. There is no boy with cancer waiting for your postcard. There is no virus on your computer with a teddy bear icon. Email hoaxes are just like the chain letters we all received as a kid. A nuisance! Try not to forward them on to your entire address book - they just clog up the Internet for valid email. You can check if a message you've received is a hoax by searching for information about it on the Internet.

A good place to start is Symantec's Hoax List (www.symantec.com/avcenter/hoax.html)

Another helpful fact sheet from www.conquyourcomputer.com.au

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Disability and Ageing

Many of us have negative stereotypes about ageing, said Dr. Steven Stiens, UW associate professor of rehabilitation medicine. “The myth is that getting older means being ill. But this isn’t necessarily the case.” Although ageing does present certain inevitable challenges, we now know there are steps we can take to maintain a high level of health and function in the advancing years, even with SCI.

A recent study in Great Britain followed 834 people with SCI for more than 25 years.

The researchers found that—regardless of age, length of time since injury, and injury severity—perceptions of overall health were quite high (over 70%) and actually improved over time, until subjects reached the 40-years-post-injury milestone, at which point people reported a decline in perceived overall health. “So there is some evidence that when you get to the 40-year mark there are some points of deterioration that you need to watch out for,” Stiens said.

Cardiovascular Health and Metabolic Syndrome.

“We are particularly concerned about the risk of heart disease in people with SCI,” Stiens continued. “Metabolic syndrome—a condition associated with high risk of heart attack, stroke and other complications—is especially common in the SCI population,” and consists of four major characteristics:

1. Obesity. “In this country we have an epidemic of obesity; this is also true for the SCI population, mainly because it doesn’t take a lot of energy to push a wheelchair or run a power wheelchair. Not infrequently we overeat for our size and the amount of energy we expend.”

2. Insulin resistance and diabetes. “By insulin resistance, I mean the insulin is there, but unsuccessful in bringing glucose to cells. And cells, because of inactivity and other factors such as obesity, are less efficient at using insulin. As a result, the fasting blood sugars tend to be a little higher in people with SCI and the ability to manage large glucose loads is worse.”

3. Poor cholesterol profile. “Specifically, this means low levels of the ‘good’ cholesterol (high density lipoprotein, or HDL), which goes around mopping up the bad cholesterol off vessel walls,” Stiens explained. “Exercise contributes to a rise in HDL, and people with SCI tend to have lower HDL than others their age because of lack of exercise.” HDL can be improved with exercise, as well as drinking one or two drinks (especially red wine) per day—“But no more than that, or you blow the whole thing!” Stiens warned.

4. High blood pressure. Even though there is a tendency to have lower blood pressure with SCI, obesity tends to bring it up and it becomes a concern.

All of these symptoms tend to increase with age in the general population, and perhaps at a slightly younger age in persons with SCI, Stiens added.

How can you turn this syndrome around and improve your cardiovascular health?

1. Keep your weight down.
2. Change your diet—decrease sugars and simple carbohydrates, reduce fat and cholesterol.
3. Keep moving; increase the total activity in your day.
4. Talk with your doctor about whether or not you need medications for cardiovascular health. “We’re finding more and more that some of the medications originally designed to lower heart rate or cholesterol can improve risk for heart disease and directly prevent heart attacks,” Stiens said.

Bowel and Bladder Changes

Urinary tract infections (UTIs) are more common as people age with SCI, perhaps due to drinking less fluid or to a weakened immune system. There is also an increased risk of bladder stones, which can block the ureters (tubes that carry urine from the kidneys to the bladder) and cause urine to back up into the kidneys, a serious condition. For this reason, Stiens recommends having

an annual medical evaluation that includes an ultrasound of the kidneys and urinary collection system. If stones are found, they can be eliminated using lithotripsy, which sends sound waves through the body, causing stones to break up.

It is important to pay attention to UTI symptoms because UTI leading to sepsis is a common cause of death in people with SCI, Stiens warned. (In people with quadriplegia (tetraplegia), pulmonary problems such as pneumonia are the most common cause of death; see the section on “Pulmonary Problems,” below.) “If you have UTI associated with fever and chills, you need to get to the hospital and get on antibiotics,” he added.

Bowel care is a very significant quality of life issue. “For some people, their bowel program runs their life,” Stiens observed. “Ideally, you want a bowel program that doesn’t take too much time and that gives you confidence that you won’t have a problem when you’re away from home.”

“But the truth is, when people age, gut transit can go down,” Stiens continued. If bowel care is very prolonged and doesn’t respond to treatment, a colostomy may be a good choice. (A colostomy involves surgically connecting the colon to the abdominal wall, and collecting stool through an opening called a *stoma*.)

“People who’ve had colostomies after SCI are usually pretty happy because they are free of the bane of bowel care,” Stiens said. Studies show that among people with problems such as incontinence and/or excessively long bowel care times, the amount of time devoted to bowel care can be significantly reduced after colostomy, in some cases down to 1.3 hours per week from a whopping 13.4 hours per week! “Don’t be afraid of a colostomy, because not infrequently it becomes the solution later in life,” he added.

It’s best to have a bowel movement every day, but it can be every other day if you aren’t eating too much fibre. “If you are waiting too long between bowel movements, you can overfill and distend (stretch out) the bowel, and as a result the bowel may not perform as well as it should,” Stiens explained. “So the message is: eat a diet with

enough fibre to have good stool consistency; drink enough fluids to keep stools soft, but formed; do bowel care on regular schedule; and empty the bowel adequately. You will probably stay out of trouble.”

Pulmonary Health

“With age, risk of pneumonia increases, lung capacity generally decreases, and risk of sleep apnea increases,” Stiens said. People with cervical injuries have a high risk for respiratory infections due to a weakened respiratory system and an inability to cough deeply enough to clear the lungs. “The higher the injury level, the higher the risk for pneumonia.”

There are cough assistance devices that can help clear the lungs, such as the mechanical insufflator-exsufflator (MIE), that blows air into the lungs and then pulls air and mucous out. “I’m a T-2 and don’t have full use of my chest muscles,” Stiens said. “So as I get older, I may keep an MIE machine around the house to improve my quality of cough during an upper respiratory infection.”

Sleep apnea—pauses in breathing while sleeping—“affects the quality of your sleep and puts you at risk for daytime sleepiness and even sudden death,” Stiens said. If you have symptoms such as loud snoring and excessive daytime sleepiness, you should talk to your physician about being evaluated for sleep apnea. Recommendations for maintaining pulmonary health while aging:

§ Stop smoking.

§ Get a flu shot yearly and a pneumovax vaccine (to prevent pneumonia) every five to seven years.

§ Exercise and keep weight down.

§ Take deep breaths to keep the chest expanded.

§ Treat sleep apnea if appropriate.

Skin Health

“Pressure ulcers are a source of decreased quality of life and there’s a higher risk of pressure ulcers as time goes on,” Stiens reported. “One study we did on people living with SCI in the community found that 25% have skin breakdown. So this is an extreme risk and something you have to watch for very carefully.”

How to avoid pressure ulcers:

- § Perform daily skin checks, using a mirror or with the help of a caregiver.
- § Review seating regularly (once or twice a year) with a physical therapist. Make sure a pressure mapping assessment is done for each of your seating surfaces.
- § Keep your weight down.
- § Modify your diet to get adequate protein, vitamin C and zinc.
- § Protect yourself from sun exposure (to avoid skin cancer).

Mobility and Ageing

Years of pushing a wheelchair can take a toll on the shoulders. “If you’re beginning to get shoulder pain, it might be a good time to look into getting an assist wheel or power chair,” Stiens said. “The trick is to get into power mobility before you have trouble with your shoulders so you don’t develop trouble with transfers.”

Increased fatigue, weight gain, loss of muscle mass and medical complications can impact mobility. “Developing a program of regular physical activity early on is one way to fight against that,” he added. “Keep in mind that people with a loss of mobility over time are less satisfied with their lives.”

How to protect your mobility and your shoulders as you age:

- § Keep your shoulders strong and make sure your wheelchair propulsion technique is safe and efficient.
- § Transition to power mobility early, but keep exercising.
- § Keep weight down.
- § Avoid overhead reaching.
- § Avoid sleeping on your shoulder.
- § Stretch front shoulder muscles and strengthen back shoulder muscles.
- § Sit upright with shoulders pulled back.

Life Satisfaction While Ageing

- § Cultivate your passions. (Renoir continued painting into his eighties—from a wheelchair—despite arthritis.)
- § Choose fun activities that keep you flexible and fit.
- § Plan activities so you always have something to look forward to.
- § Cultivate enriching long term relationships.
- § Look at your environment and don’t let it trap you if you have a change in function. It might require redesigning your current dwelling or moving to a house on a flatter surface.

“Many of the risks non-disabled people face (obesity, hypertension, diabetes) are equally if not more important for SCI survivors,” Stiens said. “The lifespan of the SCI individual is continually extending, so that many people with SCI now die of the same things the average American dies of.”

“Certain conditions are associated more with age (diabetes, cardiovascular), others with time since injury (shoulder and skin problems),” he added. “And, thankfully, life satisfaction does not necessarily correlate with age.”

Courtesy: Janna Friedly, MD, in the UW Department of Rehabilitation Medicine, USA



Landmark Study of Depression in SCI

The Northwest Regional SCI System (NWRSCIS) was awarded a five-year, \$5.8 million grant from NIDRR to lead a multi-site study of the effectiveness and tolerability of the antidepressant venlafaxine XR (Effexor XR) for the treatment of major depressive disorder (MDD) in people with SCI who are one or more years post injury. Chuck Bombardier, PhD, in the Department of Rehabilitation Medicine, and Jesse Fann, MD, MPH, in the Department of Psychiatry and Behavioral Sciences, will co-lead this study, which includes three other sites in addition to the University of Washington : Northwestern University/Rehabilitation Institute of Chicago, University of Michigan , and University of Alabama-Birmingham.

This is the first controlled study of depression in the SCI population, Bombardier says. "Depression is a common disabling problem in SCI. About 22% of this population report significant symptoms of depression, including 15% who report thoughts of death or suicide." Rates of depression in SCI are two-to-six times higher than the general population. People with SCI are generally treated for depression the same as everyone else, even though there is no research indicating whether the treatment works or is well-tolerated in SCI patients.

"We wouldn't be doing this trial if we were sure antidepressants worked among most depressed people with SCI," Bombardier says. "Unfortunately, there is a reasonable chance that the standard antidepressant treatment everyone gets now isn't always very effective. The severity of psychosocial stresses-losing one's independence, source of income, and the activities that brought enjoyment-may make depression harder to treat in this group. If standard treatment doesn't really work for certain people, we need to know that so we can come up with better ways to treat depression in this population."

Furthermore, part of the depression seen in the SCI population may actually be normal feelings of loss or grief, which "doesn't respond well to antidepressants," Bombardier explains. "In this study, we will try to separate grief from depression," in order ensure that the treatment fits the diagnosis.

Since depression is known to increase the risk for pain, pressure sores and other medical complications in the SCI population, Bombardier anticipates that successfully treating depression will result in better overall health and quality of life. Ultimately, he and his colleagues hope this study will lead to more aggressive identification and better treatment of depression in SCI, both regionally and nationally.

The antidepressant venlafaxine XR (Effexor® extended release) was chosen for this study because it generally has fewer side effects, less tendency to interact with other drugs, and more pain-relieving properties than other antidepressants-all important considerations for people with SCI, who often take several medications and have complex pain problems related to nerve damage.

Subject recruitment for this study is scheduled to begin in spring 2007. Individuals may be eligible if they are at least one year post injury. Once they enter the study, participants will be randomly assigned to receive a 12-week course of either venlafaxine XR or placebo (an inactive substance, sometimes called a "sugar pill"). Participation will include careful monitoring of symptom changes and any side effects, and participants will be paid for their time. Participants who receive the placebo and remain depressed at the end of the trial will be offered free treatment with venlafaxine XR.

Depression is a common illness that can affect anyone. About 1 in 20 Americans (over 11 million people) get depressed every year. Depression is even more common in the spinal cord injury (SCI) population-about 1 in 5 people. Estimated rates of depression among people with SCI range from 11% to 37%.

Courtesy: Spinal Cord Injury Assoc., USA

WHATS ON AT WHEELCHAIR SPORTS

BASKETBALL

HOBART

Every 2nd Sunday 3:00pm - 5:00pm

MOONAH Basketball Stadium

Gormanston Rd

MOONAH

Contact Kevin for details PH 62782120

LAUNCESTON

Every Thursday 6:00pm - 7:00pm

Queechy High School

Elphin Rd

NEWSTEAD

Contact Malcolm for details PH 63349757

TABLE TENNIS

Friday 6:00pm - 7:00 pm

YMCA

Constance Ave

GLENORCHY

Contact Roger Massie for statewide details

PH 62664287

Judith Blades is moving to PRIVATE PRACTICE in September 2007.

Judith specializes in **Disability Discrimination** law and has a lifetime background in disability.

She provides free initial legal information and advice on any area of disability and law such as wills, enduring guardianship, powers of attorney and more.

Judith also runs workshops and education sessions on Disability Law in such subjects as Discrimination in the Workplace Disclosure and Your Rights to Privacy Duty of Care

She also runs a consulting business for organizations needing information and advice about discrimination and disability related subjects.

Contact Details:

judith.blades@bigpond.com.au

ph/fax 03) 6244 8459

PO Box 203 LINDISFARNE 7015

More Coming Events

Physical Disability Council of Australia Ltd. Conference

on

Monday 22nd October, 2007

10.30 am—3.30 pm

Hotel Grand Chancellor, Hobart

(Free to people with disabilities)

Further information: pdca@pdca.org.au

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Wheelchair Sports Tas. Dinner

Being held at Wrest Point, Sandy Bay

on Saturday 10th November, 2007 - 7.30 pm

Fundraising event—auction etc.

Cost: \$1200 for table of ten

Guest Speaker: Mark Inglis

Sportsperson 'extraordinaire'

Mark is a double amputee and he challenged himself to climb Mt Everest—he succeeded in

May, 2006!

Further info: Bevan Williams, 0416 280 280

Email: b.williams@salamancare.com.au

—————o000o—————

Tasmanians with Disabilities Inc.

(Southern Branch)

is holding its

'Arts & Crafts Exhibition'

From 3rd—7th December, 2007

to celebrate

International Day of Disabilities

If you have a disability and you are hand in the area of arts and craft you are cordially invited to submit articles into this year's Disabilities Arts and Crafts Exhibition.

Articles to be exhibited must be accepted at TWD Office 20 Creek Road, LENA VALLEY by 20th November.

Certificates and Awards will be made at the presentation reception on 3rd December at 11 am at the office.

Further Info: 6278 8023 or

Email: taswdis@southcom.com.au

Accessible Accommodation and Recreation

~ Accommodation ~

BAYSIDE INN

Phone 03 6376 1466 **Facsimile** 03 6376 1653
Star Rating 4
Address 2 Cecilia St, ST HELENS TAS 7216
Area East Coast



Description 1 fully accessible unit. Reception area accessible. Car space outside unit.

Bathroom Bathroom has wheel-in shower recess, rails for shower, hand held shower spray, no lowered hand basin or mirror. Plastic shower chair available. Bathroom may not accommodate hoist.

Toilet Height 410mm (floor to seat), AS1428 standards for rails.

Bedroom Door width is 850mm, 1 double & 1 single bed, bed height adjusters available. Bedside controls - radio & light switches. No TV remote.

Facilities No Kitchen facilities & room service is available.

Approved ParaQuad Tas; Nican.

~ Attractions ~

Name: FREYCINET NATIONAL PARK
Phone: 03 6257 0107
Region: East
Address: COLES BAY
Description: For those who enjoy camping, the unique Freycinet peninsula provides facilities suitable for disabled people including toilets and campsites. Wood barbecues are located within the campsite, while electric barbecues are available nearby at the Ranger Creek day use area. For those less adventurous the Freycinet Lodge offers two cabins that are wheelchair accessible, while spectacular views of the coastline can be seen from the many vantage points accessible by vehicle.
Toilet: Toilet is accessible

For a complete copy of the *Wheelie Good Guide* please contact Kerrie Chilcott at the office on 62728816 Wednesday and Thursday's

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If undeliverable return to:
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May be opened for Postal Inspection

The deadline for the next edition of this Newsletter is October 15 2007. As mentioned in the Editorial, news items and letters to the Editor are most welcome.

For further enquiries, contact:

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