

Other useful tips

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1. Spinal Injuries

All care agencies in the UK are regulated by the Commission for Social Care Inspection - www.csci.org.uk.

Spinal Injury Association's Moving Forward CD/folder is a useful source of information and their Helpline on 0800 980 0501 and their website www.spinal.co.uk are invaluable.

SIA also organises the Spinal Cord Injury Lifetime Learning Scheme which is a comprehensive self-management training program for those with a spinal injury. Find out more from SIA.

This site has been set up to be a portal for all types of information relating to spinal injuries - www.spinalnet.co.uk.

This British Government site is a good, comprehensive guide to disability related issues and support - www.direct.gov.uk/Audiences/DisabledPeople/fs/en.

There is a UK-based organisation which aims to combine the knowledge of the various medical and clinical professionals working with people with a spinal injury and which can be a useful specialist source of information and advice - www.mascip.co.uk.

These other sites are also useful:

www.healthopedia.com/spinal-cord-injury/
<http://calder.med.miami.edu/pointis/handbook.html/>
www.sci-info-pages.com/
www.spinalcord.uab.edu/
www.spinalcord.org/html/resources/

2. Bathroom/Toileting/Catheters

* Dark coloured rye bread, like pumpernickel, is a great source of roughage. Eaten regularly, one slice a day, it has extremely beneficial effects on keeping the digestive system moving well. Agreed, it looks like carpet tile but smothering it with butter and jam makes it tasty as does using it as a base for an open sandwich, this is the original smorgasbord, with just about anything on it. Rye bread can be found at most supermarkets and speciality bakers. The best ones contain lots of sunflower seeds etc.

* Perhaps it is too obvious to mention but diet affects how the whole body works - and notably digestion and bowel management. Experience has shown that consumption of spicy food (Indian, Thai, Chili) can be useful to reduce constipation and consumption of eggs can help with diarrhea. NB - take care not to overdo it...

* Many people use suppositories to aid toileting. Obviously, these can be inserted digitally but another means is to use a suppository inserter. Two options are available on this website - www.wisdomking.com/line.asp?cc=2&swords=suppository

* The issue of people with a spinal injury and the potential need for manual evacuation of the bowel causes much confusion and not a few problems. Recently further guidance for nurses has become available which you may find helpful:

http://81.144.177.110/site/media/documents/704_patientbriefing_spinal_injury_bowel_care.pdf

* Using a good barrier cream is advisable to reduce or prevent skin inflammation/irritation around the bottom which can be caused by toileting - Cavilon is used in spinal units - <http://cms.3m.com/cms/GB/en/2-137/kzxziFY/view.jhtml>

* Coloplast makes various ranges of urine bags. The Conveen range in particular is popular. The 800ml leg bag, stock number 5175 using NDC connectors, has a good capacity and the tube has a good wide bore for fast drainage. The night bag, stock number 5062, has a 1500ml capacity.

Contact Coloplast on 0800 220622.

* If you need a large capacity leg bag, try adapting a night bag by cutting the tube to the right length and re-attaching the connector.

* To avoid a filled up a night bag during the night and being called to empty it simply attach the night bag to the tube of your day bag rather than substituting the night bag for the day bag.

* A simple tip with obvious benefits - put a washing-up bowl under your night bag, this saves a lot of cleaning up if the tap gets left open or the bag leaks.

* Many of us guys use drainage sheaths and many of them leak, come off or otherwise cause problems. The P-sure range from Manfred Sauer UK works well and does not leak. Take care to ensure you get the right size. They can be contacted on 0191 291 0166.

* Some people have a problem with drainage sheets chaffing the skin at its base/catching on clothing. A simple fix is to stick a single-sided foam strip around the outside of the sticky edge at the base of the unrolled sheath, i.e. partly over the top of the edge of the sheath and partly on the skin. Single-sided self-adhesive foam strips, 15mm x 15cm stock number 1004, which work perfectly are available from: Payne Healthcare on 0161 367 8561.

* There are several thousand wheelchair accessible public lavatories around the country. These are administered/kept clean by RADAR and are kept locked to ensure only disabled people use them. To obtain a key visit: <http://there.is/cgi-bin/radr/e-shop/cgi>

* Electric bag emptier - not being able to empty one's leg bag independently is a frustration to us all of us. A client has recently let me know about this ingenious little device that does the job for you - and apparently very effectively too. It is an American product and information can be found on the websites.

www.wheelchairs.com or www.rdequipment.com

3. Cars/Vehicles

* Keep a toileting bottle in the car at all times for obvious reasons.

* A sheepskin or a Jay cushion gel pad placed on top of the car seat helps reduce red marks from pressure on the skin.

* If your vehicle is through Motability, an excellent way of getting a vehicle, be sure to tell them you have numerous carers and they will provide 'any driver' insurance for a nominal additional charge. For more information see - www.motability.co.uk

* Many people need insurance for drivers aged 21-25 but find the cost of getting such cover prohibitively expensive. The brokers Heath Lambert Insurance (tel. 01603 828392) are recommended by the Disabled Drivers Association and they should be able to help. Also, you may wish to consider having an over 25 policy but putting any younger drivers on as needed for odd weeks for a relatively small additional sum.

* Hand controls - these can be very expensive but funding is available from two sources. The first to try is Motability; please note that these grants are means tested. The second is the Access to Work scheme through Jobcentre Plus which is not means tested. If you are employed and will use the vehicle to get to work, you can apply for a grant toward the cost of hand controls. For more information, see - www.jobcentreplus.gov.uk

* If you have not already got one, a Blue Badge gives disabled people a wide range of parking concessions:

www.dft.gov.uk/stellent/groups/dft_mobility/documents/page/dft_mobility_028957.hscp

4. General

* Types of spinal injury. Most people will have come across these terms but please bear with us if this is the case as we hear of confusion from time to time. Most notably this took the form of a Social Service department potentially providing services to quadriplegics but not tetraplegics as they thought the former condition was inherently more severe...

The medical terms for the condition resulting from a cervical spinal injury (as a result of a broken neck) are either **tetraplegia** or **quadriplegia**. Both mean exactly the same thing, i.e. that all four limbs are affected by the injury; it is just the choice of language used that is different. Tetra is 'four' in Greek and Quadra is 'four' in Latin. Tetraplegia is the term used in **Europe** with **Quadriplegia** being common in the USA and elsewhere.

The term used for the condition resulting from thoracic and sacral spinal injuries (as a result of a broken back) is **Paraplegia** with para from the word for 'two' in Greek to reflect that just two limbs are affected.

* It is often difficult to find trousers, or even get ones made, that fit someone in a wheelchair properly. Experience has shown that Rolli-Moden in Germany can do the job. They can be contacted on 0049 6226 960200. While their products/work is not cheap, it is of good quality and good value.

* You may find that the rear seam in trousers irritates the skin causing redness or lines from creases. We have found that stretch, seamless boxer shorts/underwear work well to prevent this problem. The best styles we have found are the ASICS transitive seamless boxer TGM139 - www.roadrunnersports.com These are only available in the USA and are widely available from companies such as Roadrunner Sports on 001 800 743 3206.

* To reduce dizziness in the morning, try raising the head of the bed by a few centimeters by placing blocks under the bed 'legs'.

* Many of us use straws for drinking. To keep them together and avoid them getting broken/crushed and/or covered in fluff, try keeping them in a travel toothbrush case (available from chemists etc.) in your bag/wheelchair pouch.

* We are all aware just how expensive new disability equipment can be...The classified pages of the SIA publication Forward often contain ads for secondhand equipment to buy or for donation. Also a wide range of secondhand equipment is available at The Disability Equipment Register website - www.disabreg.pwp.blueyonder.co.uk.

* **BT** has a useful option relating to Directory Enquiries. The **195 Directory Enquiry service is free for disabled people** AND the operators will put you through to the number you want so you do not have to write the number down and then dial it. Ring 195 to register.

* Have you ever found that you need an adaption individually made to help your chair, car, TV or whatever work for you but been unable to find an engineer to make it? If so, for help contact - www.remap.org.uk.

5. Health

* Autonomic Dysreflexia - this potentially serious condition, which is characterised by a thumping headache/sweating, can affect people with a cervical spinal injury (and sometimes other levels). It is most frequently caused/treated by:

NB - IF NECESSARY, FIRST RING 999 AND CALL AN AMBULANCE

CAUSE	TREATMENT
1 blocked catheter	Medical professional to put in new catheter
2 bladder infection	Treat with antibiotics
3 full/blocked bowel	Empty bowel
4 pressure sore	Remove pressure

Ask your doctor for some nifedipine to keep at home (this drug will reduce the affects of dysreflexia until the appropriate treatment has been carried out) in case you get dysreflexia.

What is autonomic dysreflexia? www.medfriendly.com/autonomicdysreflexia.html#whatisit
Medical treatments for dysreflexia -
www.guideline.gov/summary/summary.aspx?doc_id=2964&nbr=2190&ss=6&x1=999

* To keep tablets in order and to avoid taking the wrong dose, get one of the plastic boxes with compartments for daily doses marked out. You can get these from your GP.

* Root/nerve/phantom pain - at last, it appears that there is a treatment for this notoriously painful, debilitating and hard to treat condition. It is a drug called Lyrica from Pfizer Pharmaceuticals - see links below:

www.prnewswire.co.uk/cgi/news/release?id=179349
www.drugdevelopment-technology.com/projects/pregabalin/

* Cranberries contain a substance which is very good at reducing bladder infections (<http://news.bbc.co.uk/1/hi/health/1412586.stm>). Numerous cranberry products are widely available but one of the best is **FSC Cranberry Concentrate tablets**. At 1200mg per tablet, they are apparently the strongest available and work well when combined with drinking the recommended 2-3 litres of water a day. They are available from Kan Wholefoods in Kendal on 01539 721190 and probably from other good healthfood shops. We have also heard that a brand of tablets called Cranactin work well.

You may be able to get cranberry tablets on prescription from your GP.

Cranberry extract powder is also helpful as it can be used to mix with water to make a sugar free juice.

*** CAUTION - we have recently heard that cranberry pills/extract and warfarin, which is commonly prescribed to reduce the risk of blood clots, can react strangely with each other

(<http://news.bbc.co.uk/1/hi/health/3120206.stm>) We suggest consulting your doctor before taking cranberry if using warfarin ***

* We have all been advised to drink around 3 litres of non-alcoholic fluids each day to reduce the chance of getting bladder infections. While this is undoubtedly sound advice, we have become aware of a potentially VERY SERIOUS side effect namely, low blood salt as a result of the flushing effect of the high fluid intake. We advise you to ask your GP about testing salt levels if they are not already doing so.

* In order to reduce the incidence of chest infections, it is worthwhile having a flu' jab every Autumn. Additionally, there is a different injection to prevent pneumonia which is required only once (see this webpage for more information <http://www.scotland.gov.uk/library5/health/pv65-00.asp>). Both are available via GP's surgeries - mention to the surgery that you have no cough reflex and are in an 'at risk' group or the surgery may say they're only available to the over 70s - which is not the case.

* Apart from the obvious benefits of avoiding bladder and chest infections, this article explains the increased risk of stroke and heart attack caused by these infections - <http://news.bbc.co.uk/1/hi/health/4095033.stm>. Particularly when combined with the autonomic dyreflexia commonly experienced by someone with a cervical spinal injury who has an infection, these could be serious and give even more reason to guard against these common infections.

* Those with a spinal injury not uncommonly have issues with bowel management/toileting. Sometimes, constipation is the problem, then it's diarrhea, or gas or indigestion or acid...These may be 'just one of those things' but a potential cause of these, and some other rather more serious problems like ulcers, is a nasty stomach infection called helicobacter pylori. This is easy to diagnose and treat and getting rid of it can bring major benefits. Find out more from your GP or at - www.besttreatments.co.uk/btuk/conditions/9708.html.

* Use of a good anti-bacterial soap or shower gel such as Carex can help to reduce cross-infection.

* Every area in the UK has a dentist who has hoists and slings in place to accommodate dental patients with special needs.

* Overheating in summer is a problem for all tetraplegics. A hat and water spray from a small spray bottle - like those used for houseplants - provides welcome and effective cooling.

* Conversely, severe low temperature in winter can cause problems. Hypothermia is a serious condition and can strike tetraplegics when least expected. Monitoring the temperature in the house/room and taking care to maintain body temperature of around 37C can improve one's general health substantially.

* Much has been written about the importance of good skin care to avoid pressure sores and we do not propose to redo it. However, a couple of small tips that anecdotal evidence indicates help. The first is to maintain a good diet of freshly prepared food - skin is, of course, made from the materials we consume and the better the materials we eat and drink, the better our body will work and skin it will make - a car runs better on good fuel...Another tip relates to the Mycil or Daktarin you may already use to treat inflamed skin, a fungal infection, in the groin area. For some reason, using the same spray on a pink

mark where the skin is not broken, like the kind caused by sitting on a crease, seems to help the mark go away much faster and reduces the likelihood of it reappearing - but don't ask us why! Finally, a good moisturiser helps keeps skin in good condition - Bio-Oil works well.

* When you are in a chair, it is easy to put on weight but very hard/slow to lose it. The benefits of a good balanced diet are numerous but consider also that drinking 5 cups of tea a day, each with 2 sugars, to flush out the kidneys/bladder really piles on the calories (70 teaspoons of sugar a week...) - even if you have a good diet.

* Often the places red marks are most likely to appear are on bony areas that are hard for you, the client, to see. A good way to 'see' these areas is to get your carer to take a picture of them with a mobile phone or digital camera so they can be considered as you feel is necessary.

* It concerns us that, despite the advice we all get in hospital, such a significant number of people with a spinal injury still get pressure sores and end up spending weeks, months or even years in bed as a result. We all get the odd red mark but experience has shown these two issues as being involved in pressure sores developing:

1. New equipment or changes to existing equipment.

We advise being exceptionally careful when using new equipment or if something has changed, e.g. with shoes, wheelchairs, cushions/padding, hoist slings etc, and checking your skin all over, even under toes and more than usual, when using new equipment until time proves it can be used safely.

2. Continuing to put pressure on a red mark.

We advise never continuing to apply pressure to a red mark or an area of skin-off, e.g. by sitting on it and thinking it will be OK for a bit. It ALWAYS gets worse. A quick day or so in bed at the outset is often all it takes to put it right.

Consider what happened to Christopher Reeve/Superman as the result of a pressure sore which started off as a pink mark: he died.

Please take note of these links which have much useful information on pressure sores and how to avoid them:

www.epuap.org

www.epuap.org/puclas/index.html

6. Moving and handling

* Sliding boards have become increasingly widespread and with good reason as their correct use lessens the effort required in a transfer for both the carer and the client although the board can require training to use properly. To reduce the potential for bruising/damage to the sitting bones, padding the board helps. A layer of foam rubber clad in vinyl or leather works well. To help the movement slide properly, a sliding sheet put on top of the board is invaluable. These sheets, the boards themselves and training in their use are available at no charge via local Community Occupational Therapists. You can also buy the boards from most mobility centres or from a manufacturer such as Onward Design on 01773 852077. Sheets are available from, among many others - www.phil-e-slide-uk.com/prodrange.html. We have found that, for some reason, sliding sheets seem to work better if you turn them inside out...

* Try using silk or polyester sheets rather than cotton to ease sliding/moving/handling whilst in bed.

* Moving up the bed for a tetra. Place the sliding sheet under the hips and buttocks, remove pillows from under the head [this move also works if you leave the pillows in situ], then the carer stands at the bottom of the bed and push client up the bed by holding the ankles. A very high lesion may need two slide and glide sheets.

* If a carer is very tall, it is worth considering that they use a kneeling position when working at bed height. Adopting a kneeling position can reduce the need for a tall carer to bend to work at bed height, improve their posture and reduce the risk of overstrain when they are carrying out toileting, washing, dressing and even sliding board transfer activities.

* Having one's bed/easychair at the same height as one's wheelchair aids transfers and makes your carers life much easier. These bed raisers are good and having a wide top makes them much more useable than others as they can be used on a wide variety of beds/easychairs. They also stack and are light enough to take on holiday.

www.westonshealth.co.uk/acatalog/Westons_Health_Elephants_Feet_114.html

* Moving and handling equipment is widely available to buy from local suppliers which you can find in your Yellow Pages. Westholme on 01422 260011 - www.westholme.co.uk - also supply a range of this equipment.

7. Travel/holiday with clients

* When traveling, planning is the key to success and an enjoyable trip. A detailed packing list that can be amended in the light of experience is very helpful. We suggest you 'hope for the best but plan for the worst' - just in case.

* When arranging a holiday, check early if the PA/carers needs a visa to travel and arrange any necessary visas early. NB - Non-Europeans and South Africans in particular need visas to travel and these can take weeks or even months to organise...

* If you are planning to hire a car for which you will pay but which the PA/carer will drive, ensure that:
either

1 you are the named driver and then add your PA/carer is added as an extra driver. NB - you will need a valid driving licence and credit card.

or

2 as the main driver, your PA/carer has a valid CREDIT CARD to cover any collision damage waiver - even if you will pay for this. NB - THERE IS A CHANCE THAT IF THEY DO NOT HAVE A CREDIT CARD, YOU'LL HAVE TO USE THE OPTION ABOVE OR TAKE A TAXI AS THEY WON'T GIVE YOU A CAR...

* For those people who use hoists to transfer, traveling away from home can be rendered nigh on impossible by the difficulties in taking heavy equipment with you or finding a supplier nearby. A real innovation is the invention by Carl Ford (C5/6) of the Highlite portable hoist which makes easily taking a universal lifting method wherever you go a reality. Find out more from Huntleigh Technology on 0121 607 0556 - www.huntleigh-highlite.com. NB - Highlite hoists and other equipment can also be rented from Huntleigh for short or long periods - they'll even deliver/collect at the airport if you need equipment for a holiday.

* For those of us who toilet using a shower chair, a folding/dismantleable version is needed to facilitate transportation. To find out about the Chair-in-a-bag, call Accessatlast on 01772 814555 or visit www.accessatlast.com/accessibility-products/travel-accessories. It costs around £300 and looks good.

* A useful website for a wide range of specialist disability travel and other equipment is - www.borringia.com.

* 'This transportable hoist really works; I advise taping the hand control during transit though!' - www.molift.co.uk/smart.html.

* An easily transportable transportable ripple mattress - for use to prevent pressure problems when in bed away from home - is the Alphabed from Huntleigh Healthcare. The pump is about the size of a shoebox and the mattress folds up like a li-lo but works on any flat surface short of a hard floor; all normal beds are fine. They can be contacted on 01582 745777. Make sure to get the heavy duty OPB3 bubble pad as it is much longer lasting than the others. Equipment can also be rented from Huntleigh for short or long periods - they'll even deliver/collect at the airport if you need equipment for a holiday.

* Take simple things to help you fix problems yourselves, e.g. sewing kit, screwdrivers, tape, superglue, other tools if needed, fuses, batteries, extension lead, a spare cushion cover etc. If an important piece of equipment doesn't work on arrival (as DOES happen), being able to fix it yourself can be essential.

* When booking your air tickets, confirm the airline is OK if your baggage is going to weigh over 15kg. Recently, they have become much less flexible and we advise getting written exemptions to their limits as you are carrying medical equipment.

* How to ease getting into/out of aircraft seats.

Any disabled person who has flown knows how much 'fun' it is being transferred into/out of an aircraft seat and, sadly, this may put some people off flying. One particular client had a lifting sling of this type - www.samarit.ch (go into Nursing Aids and see the Pull-Up)- which is used very successfully by the airport moving/handling teams when transferring him. Its use avoids causing him the problem and pain of being picked up by the shoulders and knees and simplifies the whole process.

* When booking seats, take care to get a bulkhead seat as access is easier and there is more legroom.

* During the flight, ask the cabin staff in the aircraft to radio ahead to ensure your chair is by the aircraft door on landing - if not, it will often end up on a carousel in baggage reclaim going round with the suitcases...

* No-one wants to get ill at any time but particularly when on holiday. This is a good site for advice and specific local information - www.fitfortravel.scot.nhs.uk

* For free access to health services elsewhere in Europe, register for a European Health Insurance Card - www.ehic.org.uk - but also continue to get travel insurance as well!

8. Wheelchairs/cushions

* Wheelchairs, cushions and other mobility items are available at no charge from the local Mobility Services department which can be contacted via Social Services.

* Many people with a spinal injury struggle to find and maintain a comfortable sitting position in a wheelchair. It sometimes seems that a wheelchair setup that maintains rearward and sideways balance in the early days later causes the top half of the body to tip forward which then means the hips slide forward or we hook onto the push handles to prevent nose-diving out forwards. This website has some interesting comments on the subject:

<http://depts.washington.edu/rehab/sci/posture.html>

A client has reduced his manual wheelchair back height 2.5cm. This reduced the tipping forward problem significantly, made sitting more comfortable and he has noticed an improvement in his ability to take deep breaths too. There has been no corresponding loss of balance. Such has been the impact that he is considering a further 2.5cm reduction in back height. He concluded that 'just because my chair had been OK for years did not mean it was right from now on'.