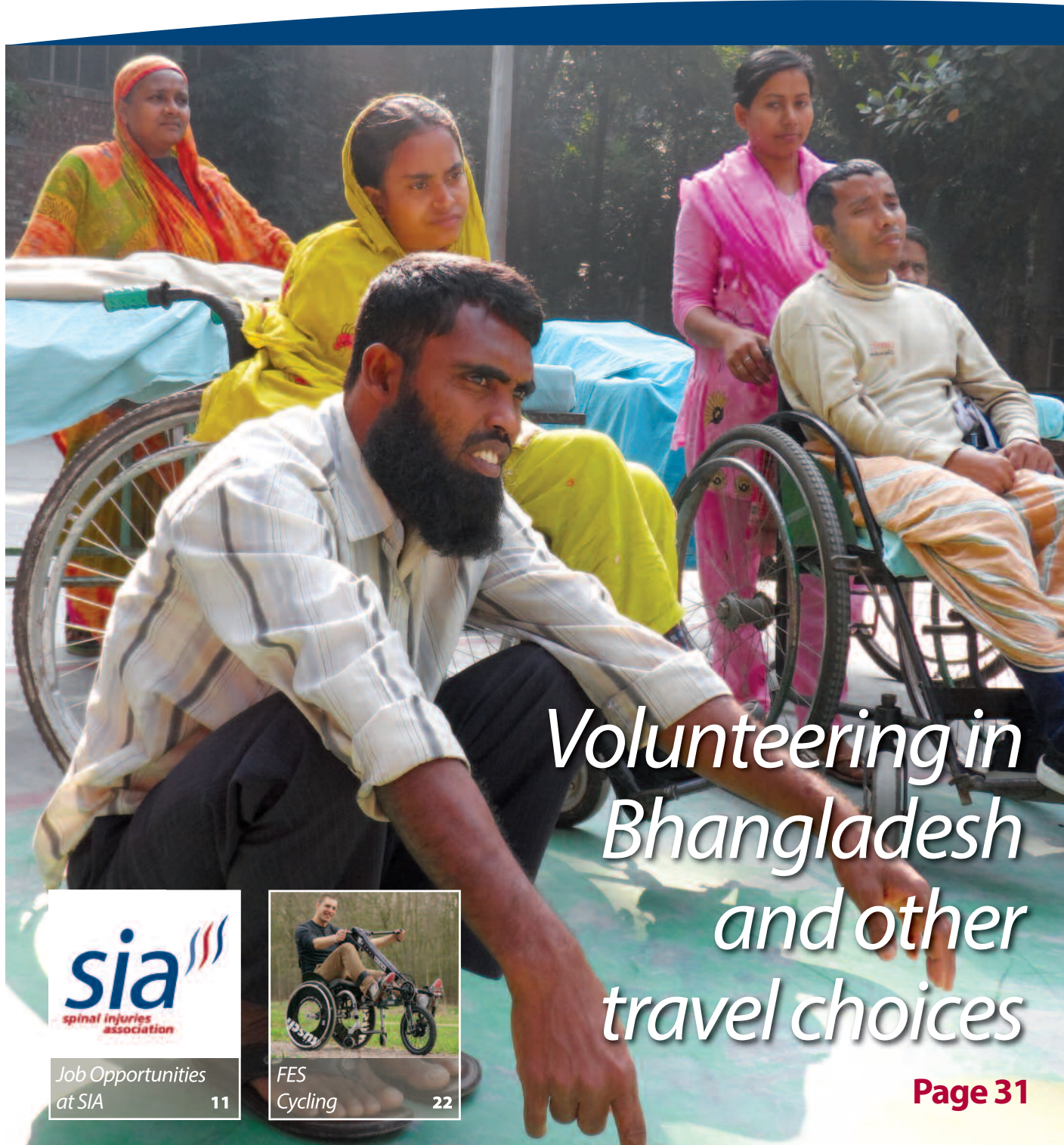


debate | information | real life
forward
for *thinking* people with spinal cord injury



Volunteering in Bangladesh and other travel choices

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FEBRUARY 2013
ISSUE 113

forward message

In our house tradition dictates that as the Christmas decorations come down, holiday brochures are collected and scattered around the living room. The pictures of palm trees, sun and sand seem to brighten the gloomy January days.

Everybody looks forward to their summer holiday, but I am still left frustrated by the lack of truly accessible holiday accommodation. Opportunities for those of us with an SCI to travel and see the world have developed over the past few years and rightly so. I always enjoy reading the holiday experiences of others and I hope you will find inspiration in the pages that follow for your own holiday this year.

I was very sad to learn of four past SIA Trustees who passed away late last year. Liz Martin, Liz Pook, Carl Ford and Mike Tennison were valued members of the SIA family and will all be greatly missed.

Finally, now is the time of year that we appeal to you as an SIA member to consider standing for election as an SIA Trustee. SIA Trustees determine the direction and monitor the progress of the Association. It is an important role and affords you the opportunity to play a part in SIA's future. New Trustees and the fresh ideas they bring are always welcome, so why not!

Jonathan Fogerty, SIA Chair C5/6

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Find out more about us at www.spinal.co.uk

forward is available to download from the member profile area on the SIA website.

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Concern about waste and cost of continence products

I have used Peristeen for some years. I have no complaints about the actual product, I could not manage without it. However, I have a major problem with the apparent waste generated by Coloplast products and, no doubt, by many other continence equipment suppliers. It is their insistence on selling their products in particular combinations that makes wastage, in my opinion, inevitable. For example, if you order what they call their 'system' this is what you get: one control unit, which includes one bag for water and two tubes (this is essential), two single-use rectal catheters (why would I only want two when the rest of the equipment is meant to last for months?), two straps (I have never used these) and a grey canvas sponge bag to store the products. The bag is perfectly useful and I don't mind the look. It is certainly needed the first time you order, but on subsequent occasions? The company advises change of their 'system' at approx six monthly intervals. I have not needed to renew the sponge bag every six months, have you? So why do I have to receive something I don't need and then have the potential problem of getting rid of it?

I contacted Coloplast when I first started to use their products and complained about this. They said they would look into my concerns and would consider selling items individually, not as a package. Several years on, no change in their selling policy has taken place.

In the long term we all pay for this wastage. We are a captive audience: we need the products, so the NHS pays for the wastage each time. This makes me

angry as we don't seem to have a choice.

I am also critical of the over-packaging of continence products. For example, let's say you need a supply of rectal catheters which are single-use. Let's say you need 40 of them (this seems to be the upper limit I can order each time). These catheters are packaged in batches of 10 in large, rectangular boxes. So that makes four boxes with each order. Why does it need a massive box to pack 10 catheters (not exactly breakable, because they are encased in individual plastic anyway)? My order of 40 catheters would comfortably fit into ONE box, never mind four. I have tried it. On top of that, the whole order is then put into yet another massive box for distribution; as you can guess, most of this box is actually empty. So you have an overkill of packaging material each time you order. I need someone to help me open these boxes and dispose of them in my recycling bin, I can't do it by myself. Is this something we should accept?

My local council has (at long last) started to recycle hard plastics. With this in mind, I recently contacted Coloplast and asked which of their materials would qualify for recycling. Not one single plastic part, not even the hard plastic screw top, nor the plastic control unit, nor any of the plastic tubes. I was appalled. For how many hundreds of years will these materials sit there without degrading?

I think we, as the consumers and regular users of these products, should be concerned about the issues outlined above, including the cost to the NHS and the wastage of items not needed each time.

All of us together should have enough clout to force this company (and other continence product suppliers) to sell and package their products responsibly. I would like SIA to pass on our comments and requests to this company. It would also be good to see Coloplast's comments published in *forward*. So let's make this a mass protest! Happy complaining!

Maria Parnell T5

Coloplast's response to the letter from Maria



Dear Maria

Thank you for sharing your thoughts on Peristeen and its packaging. It is a core value for us to listen to our customers, so we appreciate that you've taken the time to look at our product and provide us with such detailed feedback.

Peristeen is a unique product, helping a lot of people with bowel issues and it's great to hear that you do not have any complaints about the product and you find it useful – this is very important feedback for us.

Peristeen is used by patients with many different conditions, all with differing needs who irrigate according to their individual needs – and we do everything we possibly can to fulfill these different needs for all our Customers.

For some people, dealing with bladder and bowel issues can be very emotional and a daily challenge, especially as this is often a difficult subject so we like to do our very best to make sure that all items are readily available. The two catheters supplied in the Peristeen System kit are there to ensure we make it as easy as possible for

Editorial & Advertising Lynne Punchard | Tel 020 8361 6971 | Email lynnepunchard@btconnect.com |
Next copy date 1 March 2013 | **Published by** Spinal Injuries Association, SIA House, 2 Trueman Place, Oldbrook, Milton Keynes MK6 2HH | Tel 0845 678 6633 | Fax 0845 070 6911 | Email sia@spinal.co.uk | Freephone Advice Line 0800 980 0501 Mon-Fri 9.30am to 4.30pm | Text messaging Text SIA and your enquiry to 81025 messages will be charged at your standard network rate | Registered Charity No 1054097 **Chief Executive Officer** Paul Smith | **Design & print** TU ink www.tuink.co.uk

people who order and use the product, and also for healthcare professionals when training people to use Peristeen. Reducing the complexity and the number of prescription line items reduces the risk of errors and makes ordering as smooth as possible – and a lot of our customers really appreciate the items included. The additional two catheters also help to avoid people ending up without a catheter if they order a kit, but by mistake do not order catheters.

We constantly work to improve both our products and packaging and appreciate your comment about the canvas sponge bag/toilet bag and the straps. Whilst we consider all the needs of people who benefit from using Peristeen, we also take our environmental responsibilities very seriously and have taken several key initiatives to reduce our carbon footprint. We have made the catheter more environmentally friendly by changing from PVC as raw material to a polymer material without chlorine, which means that the catheter is now less harmful to the environment when it is disposed of, especially via waste incineration.

Peristeen's ability to be disposed as recycled plastic is very difficult as the product consists of so many different materials, each optimized for the specific function they fulfill. This in itself makes it a challenge to recycle the system; therefore, we do not generally recommend disposing of the system as recycled plastic. Similar to other medical

devices used for intimate healthcare, appropriate disposal is required. On the other hand, we highly recommend recycling the cardboard box packaging.

Other improvements which we have made include sourcing our retail and packaging boxes from 40 – 50% recycled paper. Furthermore, we have changed the box colours to white, which reduces the amount of dyes used and we won't stop there.

We actively seek and encourage people to provide us with feedback so we can continuously improve our products and we very much welcome any specific ideas for improvements. You can do this through joining our existing online *InnovationbyYou* group, which consists of people who have a passion for making a difference to products and services as they share their experiences and opinions with us through a variety of ways. You can find all the details for this group online and should register at www.innovationbyyou.com.

We hope you recognise that there are many concerns we need to consider when producing and selling a medical device. We need to make sure the performance and quality meets all standards, and, once that is achieved, we do everything we can to ensure minimal environmental footprint. Once again, we thank you for your input – your feedback will be taken into account in the further development of the Peristeen System.

Søren Hvidberg Nielsen
Marketing Director
Coloplast, UK

Dancing on wheels

I am writing on behalf of the Wheelchair Dance Sport Association (UK), We are the National Governing Body for recreational wheelchair dance and wheelchair dance sport within the UK as well as the International Paralympic Committee and British Paralympic Association representative for the sport.

Wheelchair Dance Sport is an up-and-coming sport that is open to all areas of the community and we are looking to build and grow the work the WDSA (UK) has done so far by working with organisations to develop and promote the sport to the local community and enable more individuals young or old to be involved or set up a local group or club within their area.

The WDSA (UK) offers a wealth of support and training which we can only offer by working with other groups to help train and develop individuals to become Instructors. We offer a wide range of training which can be aimed at children to enable them to be more involved in the sport within the school or community environment, via workshops or regional or local competitions. The WDSA (UK) also offer a membership service which enables those individuals who want to compete or just want to >

The views and opinions expressed in forward are not necessarily those of the Spinal Injuries Association. We reserve the right to edit letters sent for publication. The deadline for receiving contributions for the April 2013 issue is 1 March 2013.



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Patrick McGeough
Business Development Director
Wheelchair Dance Sport Association (UK)
Email patrick@wdsauk.co.uk
Main Line 0300 111 30 45
Website www.wdsauk.co.uk

Lack of support for AGM

Thank you to Paul Smith, SIA's CEO, for taking the time to call me at home on a Sunday afternoon to advise me that I was one of only four people who had confirmed their attendance at the SIA AGM, (how bad is that!!!) We had some further dialogue which included apathy and the good work being done by SIA and how I had very much enjoyed attending the Equality Master Class a while ago.

I decided not to come to the AGM but will continue to watch the website, read *forward* and support SIA. As a member who has never been to, or been referred to, a Spinal Centre I have gleaned valuable information over my 26 years as a C5/6 incomplete.

Elizabeth Dixon

House swap holidays

I have been reading your magazine since 2010 when my partner had a spinal injury (C6/7 complete). We are often looking for places to go on holiday that are practical and affordable (in the absence of an insurance payout or a team of friendly marines!).

I have seen the holiday homes advertised in the back of your magazine that are designed for people with spinal injuries and

it got me thinking that a house swap system for adapted houses could work well. Not everyone can afford a holiday home but generally we live in houses or flats that are adapted. If we could link up with others with adapted houses and swap for a holiday we could stay in different parts of the country, or even abroad for little cost. It may even be possible to make arrangements to swap carers for the holiday as, however good your carers are, you don't always want to take them on holiday with you.

I wondered if SIA might set up a specialist property swap section as part of the SIA website or persuade one of the existing property swap agencies to open a dedicated section for properties with disabled facilities. We would be most interested in one that focused on properties adapted for SCI people rather than general disabilities because, in my limited experience, places that say they are wheelchair accessible are thinking of small manual chairs not large electric ones. Even the adapted rooms at Premier Inns that people told us were usable aren't for us. I spent over two hours (after an eight-hour drive) re-arranging the room and putting the bed up on blocks. I had to sleep on the floor myself.

I would like to start the ball rolling by offering our house (which will be ready by early summer 2013). It is an extension on a listed cottage in mid Wales with beautiful views and designed for a wheelchair user requiring a hoist to transfer. It will sleep 6+. If you are interested in a swap please get in touch – we would like to stay in London, Devon, Cornwall or anywhere really and need somewhere with one or two bedrooms.

Hannah Scrase

Email hannahs@gn.apc.org

Travelodge

This letter is to remind *forward* readers about the Travelodge Hotel chain's booking policy.

Twice this year I visited Wales and

booked in at Cardiff Airport Travelodge as I am unable to stay with my relatives. This lodge is only a mile from their house.

You can imagine my dismay at discovering on arrival that on both occasions they had given my 'disabled' room away, despite me having made the booking through the internet and ringing the hotel direct to tell them of my arrival time and to confirm they had the room available.

I was completely and utterly disgusted and told them so in no uncertain terms. The first time I thought it was a mistake and it was rectified when the person who had been given my room heard of my plight and did an immediate swap.

The second time was not a mistake. I was told it was their policy to deal with whoever turns up on the day on a first come basis. So, to cut a very long story short and several letters later, I have had a letter from Jessica Riley, Customer Services Senior Advisor who says, and I quote:

"Can I kindly ask that if you make a reservation, let me know at once you have done so and I will contact the hotel directly. I will do all that I can do to make sure your reservation is secure and that you have a pleasant stay with us."

I assured them that I would





- local restaurants, no fish and chips and pints of bitter
- shopping
- promenade and/or marina.

If any *forward* readers have experiences of destinations that come near to these criteria, we would be interested to hear from you. Either via the magazine or at trevjean@talktalk.net
Trevor Grantham T10

Editor's note: The holidays and travel forum on the SIA website is a good way of exchanging information about travelling.

Well travelled

I am happy to offer advice to any member who wants to visit one of the many places my wife and I have visited together. I am 66 years old and have an SCI at T9.

We have been to Barcelona, Berlin, bit of Jordan, bit of Thailand, Botswana, Brazil, Brugge, Burma, Cambodia, Canada, China, Cyprus, Egypt, France, Holland, Hong Kong, India, Italy, Jersey, Jerusalem and Eilat, Marrakech, Mexico, North America, Paris, Peru, Prague, Rome, Russia, South Africa, Switzerland, The Gambia, Tobago, Tunisia, Vietnam, Zimbabwe.

Please contact me by email.

Peter Bailey

Email peterbailey1@btconnect.com

Manx holiday

I have recently returned from a short holiday in the Isle of Man and I would like to give a short account of the accommodation we stayed in.

The Joey Dunlop Foundation accessible house is fairly new, but in terms of facilities provided, location and price, I found it great value.

The house is located on the outskirts of Douglas and consists of a number of self-contained accessible units. Ours comprised two double bedrooms, each with twin beds, with one room being larger than the other. The beds are adjustable. There is also a door in this room with access to a large decked area.

The bathroom is very large with a roll-in shower and an all-singing-all-dancing loo. It washes and dries you. The living room/dining/kitchen area is a very good size with an adjustable sink unit and all you need to make meals and serve six people. The sofa is another double bed so, these units can easily accommodate a family. Round the side of the property there is a utility room with washer and dryer and it is free to use. The unit is light and airy and there is plenty of room to get around. Although there was no ceiling hoist in our unit, there was a portable hoist available.

We thoroughly enjoyed our stay as there is much more access now, even the buses are becoming accessible. Personally, I think it's the best of the 'UK Islands' with such a variety of scenery, including moors and mountains. It's not as expensive as it used to be either so it's great for those not wanting to travel too far.

Prices vary with the seasons and, of course, as it is a 'bikers' Foundation, disabled bikers get preference for TT week. The cheapest way of getting your car over is by ferry from Heysham. It only takes about 30 minutes longer than the Liverpool Cat, and they do a special price from Monday to Friday; and two kids go free.

Visit the [Joey Dunlop Foundation website](http://TheJoeyDunlopFoundation.com) or contact the manager direct for prices and availability.
kevinquirk@hotmail.com
www.joeydunlopfoundation.hometownstead.com

Anne Peskey T4/5

be writing a letter to *forward* and to the other SCI charities to inform them of this good news.

Hopefully, there will be no more incidents of this nature. If any member needs to book a Travelodge or has any complaints about the accessible accommodation please telephone or write to Jessica Riley. If you don't get the result you want, continue until you do. It's the only way we will be treated better.

Alison Lyon, SIA Trustee

Jessica Riley's number is
01844 358500

The address is Travelodge,
 Sleepy Hollow, Aylesbury Road,
 Thame, Oxon OX9 3AT

Holiday advice

I have just taken my first flying holiday since being in a wheelchair and fortunately found everything worked very well. We went to Maspolamas on Gran Canaria. We are now looking for other destinations, and wondered if other readers had any opinions?

The perfect destination, if one exists, would be:

- no more than 5 hours flying time
- reasonably quiet, no drunken louts
- reasonably flat



Q I am getting a car on the Motability Lease Scheme. Can you advise me what adaptations are available and how much it will cost me?

A Not all cars are suitable for adapting, so it is important to consider the adaptations you need before you choose your vehicle.

Motability currently has around 400 different adaptations available through their Motability Managed Adaptations Programme. For information on the different types, please visit www.motability.co.uk/cars-and-wavs then follow the links through adaptations and adjustments, types of adaptation and adaptation prices. Some adaptations are free but for others there is a contribution to pay. There is a guide to pricing on the website.

Q I have a Blue Badge, am I entitled to concessions on toll crossings?

A Not all toll crossings offer concessions to Blue Badge holders. Disabled people using the toll bridges and tunnels listed in the website below should be entitled to concessions, provided they meet the criteria which has been set by the operators or owners. This tends to be that the vehicle is exempt from Road Tax. For more information and for details of the criteria visit www.gov.uk/driving-if-disabled/toll-concessions

Please note: toll concessions can change so check before you travel.

Q I have seen something called ServiceCall when putting petrol in my car. What is ServiceCall?

A ServiceCall is a way for a disabled driver or wheelchair/scooter user to call for service at premises where access or use of the service being provided is difficult or impossible. It works by aiming or pressing the button on a small infra-red ServiceCall transmitter. The transmitter activates the ServiceCall receiver in the petrol station, bank or supermarket and attended

Q I loved gardening before my accident and now I am in a wheelchair I would like to start gardening again. Where can I find help and advice?

A There are some excellent websites that will give you advice and guidance on returning to gardening as well as equipment and tools that will help.
Carry on Gardening
www.drcbeds.org.uk/advice/information
Thrive www.thrive.org.uk
Gardening for Disabled Trust
www.gardeningfordisabledtrust.org.uk



service will be provided by the outlet.

For more information please visit their website on: www.service-call.net

Q I have booked a holiday in Florida and will be hiring a car. Can I use my Blue Badge for parking?

A The answer is no. Blue Disabled parking permits are no longer recognised in Florida and you may incur stiff penalties if you are found parking in a disabled bay without displaying the proper locally-recognised permit. However, you can apply for a temporary visitors' parking permit to use whilst on your holiday.

British visitors can apply in advance, by post for the temporary disabled parking permit (HSMV 83039). You must send a US cheque or money order for \$15 or provide your credit card details (please provide the name on the credit card, credit card number, and expiration date). There is an additional \$2 fee for applicants using their credit cards. You also need to send a copy (both sides) of your UK Blue Badge, and

a copy of your personal details from your passport (the last pages). Once you have done that, send them all in an envelope, with a covering letter, to one of the Driving Licence and Motor Vehicle Service Centres (DLMVSC) offices.

For more information please visit: www.flhsmv.gov/dmv/disabled_pkg.html

Q I would like to know if I can claim back the VAT on the repairs and servicing done on my second-hand adapted car?

A This was a question we answered in the October edition of *forward* but we didn't give quite enough information. The answer should be:

Unfortunately no, unless the car was exempt from VAT when it was bought new due to the adaptations fitted *and* you have the original receipt from when the car was first purchased. This will prove it was exempt from VAT then. If you have this, then yes, the repairs and servicing are exempt from VAT.

Employment and Support Allowance

Have you applied for Employment and Support Allowance?

Are you moving from Incapacity Benefit onto Employment and Support Allowance?

If you need help in completing the Limited Capability for Work questionnaire, please call Ray Cross on the Advice Line 0800 890 0501.

Time to share our breaking news



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Ashleigh Bailey

Administration Assistant

I am very pleased that I have officially joined the SIA team as Administration Assistant to the Executive Management and Outreach Services team. My new role is split between the two teams – ensuring that I will be a very busy bee for 2013! Last year I was on a temporary contract working on SIA's Study Days for healthcare professionals. In 2013 we will

be holding specific Study Days for Moving and Handling and Bowel and Bladder management. We are hoping that with more specific Study Days there will be a bigger impact on the newly-injured community, ensuring better care is given to them. This is something I have a strong passion for as my background is on a stroke ward in an NHS hospital.

I am originally from South Africa and I look forward to finding my feet in this new role and working hard to get our Outreach Services to more of the SCI community and to increasing awareness within the NHS and private care community. You can email me at a.bailey@spinal.co.uk



Gary Dawson

**Community Peer Support
– NW England**

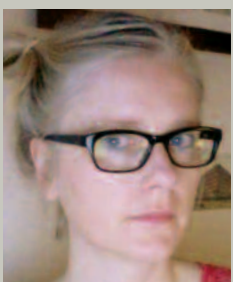
After falling off my motorbike in 2003, when I was 19, I was left paralysed at T6 complete. I was sent to a BUPA hospital for a fixation operation but before I had the op I suffered some complications and I was rushed back to Hope Hospital in Manchester where I suffered complete organ failure. I was ventilated and put on dialysis as I had a blood clot lodged between my heart and lungs. I deteriorated so fast that they sent my family in to say goodbye. Lady Luck was on my side and I survived.

Having gone through this terrible near death experience I did my best to crack on with life with the same enthusiasm as before. After being discharged I went back to live at my mum's house, staying in the dining room and only going out when someone could drive me. My priority became getting my own place and learning to drive. Once I accomplished this, my life really turned around. I became completely independent, and started making plans to travel round Australia and play basketball.

My role as CPSO-NW is challenging but so rewarding.



I'm glad I can help people going through a tough time post injury and hopefully show them the light at the end of the tunnel. Contact me at g.dawson@spinal.co.uk



Michelle Kopczyk

Trusts Manager

For the past 10 years, I have worked with public and private funders, universities, community organisations, business and disabled people to secure, maintain and grow funding to deliver stellar initiatives. As the Managing Director for the Canadian cultural magazine *Fuse* I secured funding to deliver a quarterly publication and programmes that

focused on social justice. Before this, in a similar role, at *Gallery Gachet* I ensured this user-led organisation and its programmes supported Gachet's mission to demystify and challenge issues related to mental health, trauma and addiction.

In addition to securing trust and government funding for SIA, I will be a contributor to the magazine *forward*, the e-bulletin *eclips*, and the SIA website. Drawing on my experience I look forward to serving SIA members and helping to achieve the organisation's objectives.

In my personal life, I am a practising visual artist and writer, equal rights activist and vegetarian. You can contact me at m.kopczyk@spinal.co.uk

SIA website

Recent visitors to the SIA website will have noticed a few changes.

We have freshened and updated the design of the site and stored the content in a way in which we hope will make things easier to locate.

If you haven't done so already please visit www.spinal.co.uk and let us know what you think.

We look forward to hearing from you.

Governing Council Elections 2013

Enclosed with this issue is a nomination form for those SCI members wishing to put themselves forward for election to the Association's Board of Trustees, known as the Governing Council. The nomination process commences from the beginning of February, with the closing date for the receipt of nominations being 26th April 2013. Should a ballot be necessary (ie should the number of nominations received exceed the number of Trustee places available) then ballot papers will be circulated to eligible members during the month of May, with voting closing at the end of June. The nomination form is also available to download from the SIA website by following the relevant link from the Home page.

JOB ADVERTISEMENTS



COMMUNITY PEER SUPPORT OFFICER – YORKSHIRE REGION

SIA is seeking to appoint a further Community Peer Support Officer to join our Outreach Services team, specifically to provide support within the Yorkshire region (including East Yorkshire). The role of the CPSO is to address the needs of newly injured people not receiving treatment in a specialist Spinal Cord Injuries Centre, undertaking visits to District General Hospitals and other non-specialist centres within the region so as to offer support to them and their families. The post also involves building relationships with key staff working at these locations and at SCI Centres serving the Yorkshire area. The post is part-time (21 hours per week) and includes visits to SIA House in Milton Keynes when required, therefore a willingness to travel is essential. Due to the nature of the work, we anticipate that the postholder will themselves be spinal cord injured and will require them to undergo relevant checks with the Disclosure & Barring Service.

The post is offered on a three-year fixed-term contract (with the possibility of renewal) at a salary of £14,134 per annum, plus 28 days leave (pro rata) and access to group life assurance and pension schemes.

For a Job Information Pack, please email c.pinches@spinal.co.uk or visit www.spinal.co.uk

Closing date for applications is Friday 22 February 2013

Interviews will be held at the SIA Office on Tuesday 15 March 2013

OUTREACH SERVICES MANAGER (2 POSTS)

Due to rapid expansion of our Outreach Services team, SIA seeks to recruit two regional Outreach Services Managers to be responsible for management of SIA staff working at various outreach locations across England, Wales and Northern Ireland. Reporting to the Head of Outreach Services, the postholders will provide regular one-to-one support to the Outreach staff team, and on occasion will also provide direct peer support to newly injured people and their families in the absence of usual staff. They will monitor and evaluate progress of the team against agreed objectives, and ensure provision of ongoing training and personal development initiatives through delivery of quarterly training sessions, national and regional development days, and annual performance review. Strong

leadership, interpersonal and organisational skills are essential, as is a proven background in people management, including budget handling. The posts are full-time (35 hours per week) and will involve extensive travel nationally (including occasional overnight stays) therefore the use of own vehicle for business purposes is essential. The specific areas to be covered will be dependent upon the location of our successful candidates. Due to the nature of the work, we anticipate that the postholders will themselves be spinal cord injured and will require them to undergo relevant checks with the Disclosure & Barring Service.

In return we offer an annual salary of £28,747 plus 28 days annual leave and access to group life assurance and pension schemes.

For a Job Information Pack, please email c.pinches@spinal.co.uk or visit www.spinal.co.uk Closing date for applications is Friday 22 February 2013 Interviews will be held at the SIA Office on Thursday 7 March 2013

forward Survey

In the October 2012 edition of *forward* we included a survey for readers to complete to provide feedback regarding the magazine, its content and format. The survey was also available for completion online.

A very big thank you to everyone who took the time to fill in the survey, we really value your comments and feedback. Sadly, a lot of people did not take part in the survey and so although the results are helpful they do not necessarily reflect the majority opinion of *forward* readers. For this reason we would be happy for any further feedback that you may feel inspired to provide after reading this article.

Some of you may also have received a call from us with a request to answer three questions about *forward*. Thank you to those people who have kindly helped us in this way. The outcome of the telephone survey will be used, in combination with the results detailed below, to help inform our future development of *forward*.

What the survey told us about the readers who completed it

Over 50% of respondents to the survey were over 45 years of age and male. A very small percentage – 5.3% were not SCI or disabled in any way. The majority of the respondents were complete injuries at the thoracic level who have been injured over 20 years.

Feedback regarding *forward* content

In terms of content the features were rated most highly – these are the items that relate to the theme of each issue eg holidays, motoring, ageing etc. *forward matters*, which includes our regular articles on topics such as walking and parenting was rated second, whilst *forward thinking*, which covers the letters' page and Q&A was rated third most popular.

When people were asked about the past six issues, issue 108 from April was chosen by the highest number of people. The main theme of this issue was spinal cord injury in the older person and if we consider the age group who completed the survey, this is not a surprising result.

Some people provided further comments about the content. The majority of these comments were extremely positive, a few of these are listed below:

"Can't recall all but the one ticked stands out in my head. To be honest all are enjoyed and appreciated!"

"I look forward to this magazine which is important to me as an incomplete C5/6"

"Interesting to read about members living daily lives, recommendations and tips for dealing with differing daily situations"

However, there was also a request for more content about fighting discrimination, less on continence issues and more for SCI people who are on low incomes.

In general, people would like to see the magazine include more information about ageing issues, disability equipment, benefits, technology for disabled people and lifestyle articles.

We were pleased to find that the majority of people thought the number and type of advertisements was 'about right' although some people felt there was a need for more variety with regard to advertisements. When asked what they would like to see advertised people listed a range of different products the most popular of these

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were wheelchairs, clothing, vehicles and motoring equipment, holidays and second-hand or 'sale' items.

Alternative versions of forward

We are currently considering what is the best format for *forward* and have considered various options. These have included, improving the online version that we currently upload to the website and producing the magazine as a smart phone app. Feedback from the survey showed that over 50% of respondents had never downloaded forward from the website whilst the majority of the remaining respondents 'occasionally' downloaded it and just 6% 'always' downloaded it.

When asked to comment further on the online copy some people said that they were unaware of it or did not have access to a computer. Easier, more obvious access to the online copy is something that will be addressed when the new navigation is installed on the website.

Many people fed back comments on why they preferred a paper copy:

"I prefer a paper magazine that I keep to hand and frequently refer back to"

"I prefer the magazine both for reading and if I want to show something in the mag to somebody else"

"Although I use technology I am old fashioned on this one – I like the printed magazine"

When asked about an App over 70% of respondents answered that they were 'not at all likely' to download it. Of the remaining respondents who answered this question, just under 20% were 'quite likely' to download it with the remainder saying they would 'most definitely' download it.

Looking ahead

We were pleased to read a lot of positive comments regarding *forward* generally and its content and have

gained a useful insight into the kinds of things that are of particular interest to readers and which topics we may have been missing.

There is obviously some interest in a downloadable version of *forward* but it would appear that the majority of people prefer a hard copy or only look at the online version occasionally. Ease of access and better navigation on the website to the online version may increase its popularity but certainly with the survey respondents there is strong support for the paper version.

This is an on-going process and one in which we really need your involvement as members. The survey is now closed but if you have any comments on any of the issues raised we would like to hear them, just contact Julie by email j.braithwaite@spinal.co.uk or by phone on 0845 678 6633 ext 202



Congratulations to Andrew Horrocks whose name was drawn from the survey respondents as the winner of the Apple iPod Touch kindly donated by Coloplast.

Campaigning for Change

SIA Manifesto
2013-15

Enclosed with this edition of forward is a copy of SIA's new manifesto which focuses on five areas of work for the Public Affairs and Campaigning team over the next three years.

If you don't receive a copy with the magazine and would like one, please contact c.stribling@spinal.co.uk 0845 678 6633 ext 206



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OBITUARIES

It is with the greatest sadness that we have to report on the deaths of three past SIA Trustees, all of whom contributed to the development of the Association. In their own very different ways, each made a significant impact on the lives of SCI people:

Carl Ford 1954 – 2012

In any discussion about the origins and development of the independent living movement, Carl's name will come up. He was one of the movement's pioneers and, as was said at his funeral, 'he transformed others' lives'.

Carl became SCI as a result of a hang-gliding accident in Oman in 1980 and, after hospitalisation, was living in a Leonard Cheshire Home. This setting was anathema to Carl, and he set about seeking ways in which he could 'escape' and build his own life, lived according to his own wishes and aspirations. Crucially, he keyed into the thinking which lay behind the establishment of the first Centre for Independent Living in Hampshire and the group of disabled people who were advocating self-determination and choice. As a result, Carl left the confines of the Cheshire Home to live independently. He took on his local authority, fighting for suitable housing and funding, as well as demanding the right to choose his Personal Assistants, all of which battles he won.

His political awareness and interest in disability politics led Carl to sit on the British Council of Organisations of Disabled People (now UKDPC – United Kingdom Disabled People's Council) which spearheaded the campaign for Direct Payments. Carl's focus was always on independence and how disabled people could live independently if they so wished. His knowledge and experience proved invaluable in what was becoming an important issue in the disability world.

Alongside his political interests, Carl was also an entrepreneur, setting up his own company to manufacture aids for disabled people, all of which, of course, were aimed at assisting severely disabled people on the path to independence.

Carl was a highly respected Trustee of SIA, passionate about his subject and determined to fight for those who sought independence whatever the severity of their injury.

Liz Pook 1943 – 2012

Prior to her spinal cord injury, Liz had been a highly accomplished sportswoman, making her name in the highly competitive world of women's golf by reaching the final of the English Women's Amateur Championship in 1963. She was a member of the GB Team, playing for her country in the 1966 World Cup and at the 1967 Commonwealth Tournament. Liz was one of the few players to win the British title two years in a row when she beat Mary Everard in the 1967 final at Harlech.

After retiring from golf to raise her family, Liz underwent unsuccessful surgery which left her paralysed with an incomplete SCI. As a wheelchair user and a walker, Liz had to get to grips with living her life with a disability. She often joked that her much-referred-to copy of *The Disability Rights Handbook*, though handy, was 'worse than the rules of golf'.

Liz used her enthusiasm for life and living by giving talks and making her mark as a member of SIA's Fundraising Committee. Fundraising was a great passion and, until shortly before her death in December, she was still raising funds for SIA despite claiming that she couldn't quite comprehend why she gave talks, as they made her so nervous.

Liz's attitude to life was relentlessly upbeat. She was a great believer in the power of positive thinking and often referred to a card sent to her while she was in hospital inscribed with the words 'Misfortune is an occasion to demonstrate character'.

Liz had bags of character and her enthusiasm, kindness and concern for others will be greatly missed.

December was a sad month for SIA on hearing of the deaths of our three past Trustees. We would like to send our sincere condolences to Carl's wife, Val and family, Liz's husband, Tony and family, and Mike's wife, Liz and family.

Michael Tennison MBE 1945 – 2012

Mike was one of the longest-serving SIA Trustees, also serving for many years as the Association's Vice Chair.

Despite a high cervical injury received in his early twenties, Mike lived his life to the full and was particularly active with local disability groups. He worked for the NHS for many years and brought his experience of that background and of living with SCI to all that he did. He was Chairman of the Hull Council for Disabled People and helped establish their Dial-A-Ride Service. This involvement led to him chairing a new organisation known as 'IN' which aimed to promote the social needs of disabled people as seen by them, and not as perceived by professionals.

Following retirement from the NHS, Mike's involvement in local activities became even greater; for example, he became Chair of the East Riding Social Service Users Committee, acting as their representative on a combined group of voluntary organisations and professionals for the Hull and East Riding North Bank Forum. He was also involved in Shopmobility in Hull and co-ordinated the journeys of volunteer drivers who provided the daily Dial-A-Ride service.

Alongside this, Mike served as an SIA Trustee and Vice Chair for many years. His particular interest and skill was in fundraising and he was responsible for single-handedly raising many thousands of pounds for SIA. He often said he was proud to represent SIA members living north of the Wash and he had close connections with the Middlesbrough SCI Centre, always concerned to ensure that SCI people were being best served.

His frequent re-election by SIA members to the Trustee Board was a demonstration of the regard in which he was held by all: members, Trustees and staff and, for his services to disabled people, he was awarded the MBE by HM The Queen.

The All Party Parliamentary Group on Spinal Cord Injury

The All Party Parliamentary Group on Spinal Cord Injury met on Wednesday 28 November in the House of Lords.

The subject of this meeting was the issue of SCI people living in care homes following their discharge from hospital.

The meeting heard from Dr Brett Smith from Loughborough University who presented a research report carried out by ASPIRE on *Understanding the health and wellbeing of spinal cord injured people in care homes*.

The report highlighted a number of growing concerns including a reduced quality of life, damage to physical health and damage to psychological wellbeing.

Following the findings of this report, Roger Hearne gave an honest

and moving account of his experience of living in a care home. Roger was injured five years ago and following his discharge from an SCI Centre was sent to live in a care home without having any say in the matter. Roger still lives in the same care home today.

Roger described the difficulties his family has faced in trying to find appropriate housing and the emotional stress this has put on his family. He said that there should be specialist training for those working in care homes as well as specialist facilities for SCI people.

The Chair of the APPG, Ian Lucas MP, said that the group needed to put pressure on the Government on this

matter. The group has written to the Housing Minister requesting a meeting to discuss the issue.



NHS Continuing Healthcare to be available as a '**Direct Payment**' from April 2014

Personal Health Budgets are designed to give people the freedom to design their own NHS care. It is an amount of money paid to the individual which gives them more choice and control over the nature of the care and support they receive.

Personal Health Budgets can be delivered in a number of ways:

- A notional budget held by the Health Authority Commissioner (eg a number of hours of care that the service user can draw down at their discretion).
- A budget managed on the individual's behalf by a third party (eg an Independent User Trust)
- As a cash payment to the individual (the same as the Direct Payment/Individual Budget method used by social services).

This announcement is of particular interest to people who are currently receiving social services funded care packages as a Direct Payment/Individual Budget and managing their own care who are facing the prospect of moving over to NHS Continuing Healthcare. It means that from 2014 they will be able

to continue organising their care in exactly the same way as they currently are under the Direct Payment/Individual Budget.

The Government has been running a number of pilot schemes around the country where Personal Health Budgets have been available. These areas will remain authorised to continue providing people with Personal Health Budgets and from April 2014 they will become available throughout England.

(Personal Health Budgets will not be available in Wales and NHS Continuing Healthcare operates differently in Scotland and Northern Ireland).



More details of what the Care and Support Minister said can be found on the NHS Continuing Healthcare pages of the SIA website.

For more information contact SIA's NHS Continuing Healthcare Adviser, Brian O'Shea, on 0845 678 6633 ext 204

Personal Independence Payments Update

In December 2012, the Department of Work and Pensions announced their plans for the delivery of Personal Independence Payments (PIP), which will begin in April 2013. Throughout the process of introducing PIP, the Government has been keen to consult with disabled people and with a large number of disability organisations, including SIA.

This consultation has brought some limited successes for disabled people, with a number of changes being made to the assessment criteria as a direct result. One of the key concerns highlighted by disabled people's organisations in the final PIP consultation was the speed of the reassessment process. Following the consultation the Government will now adopt a significantly slower reassessment process which will mean that the peak period of

reassessment will now be approximately two years later than originally planned.

From October 2015, anybody who is in receipt of an indefinite award for Disability Living Allowance, or is on a fixed term award, will be randomly selected and notified about how to make a claim for PIP. Priority will be given to recipients who are 65 after 8 April 2013. Remember, PIP is a new benefit and the Government will not assume that you wish to claim it, even if you have a lifetime award for DLA.

A surprise to many disabled people is the Department of Work and Pensions' announcement that the rates of PIP will be the same as for DLA. The 'enhanced' rate of 'Daily Living' component of PIP will be the same as the higher rate 'Care' component of DLA and, perhaps more surprisingly, the standard rate

of the daily living component will be set at the same as the middle rate for the DLA 'Care' component. The rates for the 'Mobility' component of PIP will remain the same as those of DLA.

The weekly rates of PIP are:

Daily Living Enhanced Rate = £79.15

Daily Living Standard Rate = £53.00

Mobility Enhanced Rate = £55.25

Mobility Standard Rate = £21.00



These rates will remain provisional until the legislative process is completed in early 2013, but will remain protected within the uprating measures announced in the Chancellor's Autumn statement and will continue to be uprated by inflation.
Dan Burden

Calling all SCI people in Manchester and Cornwall!

In 2012, SIA joined forces with our sister organisations ASPIRE and Back Up to audit the experiences of SCI people as part of a programme to improve local health services for people with paralysis, supported by Neurological Commissioning Support (NCS).

NCS works with the voluntary sector to provide support in getting involved with commissioning in a more productive way. As part of this project the three SCI charities will be focusing their work on two specific areas of the UK: Manchester and Cornwall.

The three charities have now launched a survey to understand the needs and experiences of SCI people living in these parts of the country and we would like you to spread the word.

The survey will be sent out to all of the contacts known to the three

organisations who live in these areas of the country, and is also available on the Campaigning pages of SIA's website. Most will receive this via email but paper copies are available from SIA House for anyone who does not have an email address. We would like as many people as possible in these areas to complete the survey, particularly those who may have fallen through the gap and are unknown to SIA and the other charities. Please pass on the word to other SCI people you may know in the area and through any groups or networks you may be a part of, so

that we can get the best picture of SCI people's lives as we possibly can.

The results gathered from this survey will provide us with a better understanding of the experiences of SCI people using health services in Cornwall and Manchester. The information will enable us to inform NHS Commissioners and work towards improving services for people living with SCI.



In the meantime if you would like to volunteer to get word of our survey out to the community then please contact

Catherine on 0845 678 6633 or on c.stribling@spinal.co.uk



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The Midlands Centre for Spinal Injuries, Oswestry and The Yorkshire Regional Spinal Injuries Unit, Pinderfields are currently running a clinical study on male patients with a Spinal Cord Injury, under regular follow up at these Centres, to evaluate a new product intended to prevent return of bacteria in the urine after treatment of UTI.

If interested, please contact for further information:

Mr. J Roy Chowdhury *(Consultant)*
Study Nurses: **Lynn Edwards / Julie Ferguson**
Midlands Centre for Spinal Injuries
Robert Jones & Agnes Hunt Orthopaedic Hospital
NHS Foundation Trust
Oswestry, SY10 7AG
Phone: 01691 404643

Mr. Wajid Raza *(Consultant)*
Study Nurses: **Beverley Taylor / Barbara Burlace**
Clinical Research Team
Pinderfields Hospital
The Mid Yorkshire Trust
West Yorkshire, WF1 4DG
Phone: 01924 543775/543762

Canine Partners – dogs that help people with spinal cord injury



Ex-Royal Navy man Barry O'Connell (66) had been very active and fit until 2005 when he had an accident. He fell from a ladder breaking his back in three places and his life turned upside down. He came across the charity Canine Partners and eventually was paired with a flatcoat retriever called Guy, who is trained to assist Barry around the home and out and about.

Barry and Guy



"When we set out on our new life together, my whole world utterly changed," he says. "It became summer in my life. Guy pulls me up in the morning, then he will get anything I ask, like socks and underwear. His favourite task is taking clothes out of the washing machine. He also takes the card and receipt out of a cash machine, and the money too. He enjoys the supermarket and getting items for me and paying. At meal times he will bring me his bowl. At night he will undress me and that is the time of day when we have lots of cuddles and fuss."

Canine Partners trains around 55 dogs a year to help people like Barry lead a more independent life. There is a waiting list of two years as more disabled people apply for one of these very special canine carers. The charity receives no Government funding, and relies on the generosity of individuals, organisations and businesses to support their work. It takes between 18 months and

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two years to train a canine partner.

The dogs are trained to perform a variety of tasks which a disabled person would find difficult, painful or impossible, including loading and unloading the washing machine; opening and closing doors and drawers; pressing buttons; undressing; retrieving dropped items; handing a purse over to the cashier in a shop and fetching help in an emergency.

"The dogs are trained to perform a variety of tasks which a disabled person would find difficult, painful or impossible"

Steve Brookes (33) also had a promising career in the Royal Navy until an RTA in 2008, when a car knocked him off his motorbike and he suffered irreparable damage to his spinal cord leaving him paralysed from the shoulders down. As a young man with a very young family he was devastated to

learn he would not be able to walk, stand or move his arms which meant he could not hold his daughters again. Understandably he suffered from anxiety, breathing difficulties and depression... until canine partner Kizzie came into his life.

He says, "When I need her she is there. When we go out and about she helps by getting those difficult lift buttons that are just out of my reach. In a shop, she grabs my wallet and passes it to the cashier. Independence-wise she has given me a new lease of life. I don't have to take a carer when I go out. If I get into trouble I don't have to worry about dropping the phone, because automatically Kizzie will pick it up.

At home, the moment I drop something like my phone, remote or keys she instantly picks them up and returns them to my lap. But the real reward I have from Kizzie is the life she has helped me get back, in particular the close relationship with my children. They love throwing



Steve & Kizzie

the ball for her so walks are not so boring with daddy now."

Barry sums up life with a canine partner: "I was a human being who was becoming every day more depressed trying to deal with life in general, then enter one very special dog and life becomes the most wonderful thing to enjoy each and every day. I have gone from winter to summer, thanks to this magic dog."

If you think you might benefit from having a canine partner, then please call 01730 716043 or visit www.caninepartners.org.uk



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London 2012 Paralympics

London 2012 has been talked about for the past seven years, since the bid to host was announced... but I do not think anyone was prepared for the actual enormity of the event.

Paralympic sport has never been given the full exposure that it deserves in the past.

When Channel 4 were given the television coverage rights for London 2012 Paralympics they were determined that every sport would be available to be viewed. They were also determined that Paralympians would become household names... and that they have achieved!

For the past four years I have been working as the Nurse for GB Wheelchair Rugby (aka Murderball!). The team is sponsored by Coloplast. Early on in my time with the squad, the then Team Manager, Ross Hall, said to me, "Bev, you must commit to at least a whole four-year cycle." Well four years have passed and I am going nowhere! I have had the most fantastic four years working with some incredible people... both athletes and staff.

As a squad we entered 'the Village' on 27 August. A couple of days before the Opening Ceremony and nine days before our competition began.

The Opening Ceremony is a memory I will treasure forever. One of my friends captured me on TV looking totally bewildered... I was waving my Union Jack trying to take it all in!

We trained at an off-site venue for a few days so that removed us from the hype that was building around our sport. Anyone who left the Village was soon mobbed for photographs and autographs!

Our first game was against the USA... the then current Paralympian Gold Medalists. The Basketball arena was full to capacity. Standing in



the tunnel waiting to enter the field of play was a 'goose-bumpy' moment! The noise and the atmosphere were incredible. GB played a close contest but the score did not reflect that. GB 44 : USA 56. Our next game was against France. A game GB won 57 : France 50.

On Friday, the Japanese were our next opponents... a must-win game for GB if we were to progress to the medal games. The final score was GB 39 : Japan 51. GB were defeated and gutted. The changing room was a lonely place for us all.

On Saturday we had to pick ourselves up and brush ourselves down to finish in the best possible

position. GB 54 : Belgium 49; GB 59 : Sweden 47.

The results meant that GB had regained its position of first in Europe... small consolation when everyone was hurting badly. The support from family, friends and people who have found and now love the sport has been incredible.

The Team watched Australia win the Gold medal beating Canada in the Final. USA had to settle for a bronze medal after they beat Japan in the 3rd /4th playoff.

That evening we attended the Closing Ceremony – a wonderful showcase and spectacle.

For many the journey was over. Life-changing experiences and life-long memories. The London episode had finished, but the Management Team had to prepare for the the next cycle. Two major presentations to UK Sport and Sport England to hopefully secure funding for Rio 2016.

We are currently waiting for our funding bid results... if we are successful we can then start our next four-year cycle!

Bev Everton
Head of Support Services
Great Britain Wheelchair Rugby



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Peddalling your way to **fitness** with **FES** cycling

Eva Sobonova, FES Cycling
Physiotherapy Specialist and
Jon Graham, FES Dropfoot
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Whether it was a New Year resolution, or your personal legacy of the amazing London 2012 Olympic and Paralympic Games, have you been inspired to get fitter in 2013?



Berkel Bike
Fitness

The fitness challenge for individuals with a spinal cord injury is the loss, whether partial or complete, of movement in the lower limbs, and upper limbs, depending on the level of your injury. You may be asking: "Is there a way of getting a beneficial workout that will improve the health of my heart and lungs, rebuild my muscles, help with weight management and even reduce my spasticity"? The answer for you may lie in Functional Electrical Stimulation (FES) cycling.

What is FES Cycling?

FES involves delivering a small electrical current to a nerve via sticky pads placed on the skin. The stimulated nerve in turn activates the muscles that it supplies. When this is coupled with a power-assisted static bike, coordinated muscle

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- Increased muscle strength and bulk, which can help with prevention of pressure sores
- Maintenance of muscle length and joint mobility
- Relaxation of muscle spasms
- Increased local blood circulation
- Improved bladder and bowel function
- Improved mood and well-being

This is due to coupling the FES with the assisted functional activity of pedalling.

The benefits are not limited to leg muscles. FES can also stimulate the back muscles, stomach muscles and arm muscles. By stimulating the back and stomach muscles, you can improve your posture and potentially your ability to cough more effectively.

To acquire and maintain these benefits you need to commit to FES cycling as a leisure activity in its own right.

Following assessment and setting of the various stimulation parameters, you need to build up your exercise tolerance gradually until you can do 45-minutes to one-hour daily. You should aim to cycle from a minimum of three times per week up to six times per week to achieve optimum results.

Who can benefit from it?

You can use it if you have one of the following conditions:

- Spinal cord injury: complete or incomplete above T12
- Brain Injury
- Stroke
- Multiple sclerosis
- Parkinson's Disease
- Cerebral Palsy

You should avoid using it if:

- You have a cardiac pacemaker
- You have unhealed fractures
- You are pregnant

You will also need a sufficient range of movement in upper or lower limbs to accommodate the cycling motion. Your skin must be intact without open wounds or pressure sores in the areas where the electrode pads will be placed.

In injuries below T12 (ie Cauda Equina), the nerves supplying the leg muscles will have been adversely affected and are unlikely to respond to FES stimulation. That said, if you have an injury just below T12, it is still worth having an assessment. It just may work for you.

Are these available for home use?

There are three FES cycle product ranges available in the UK.

- 1 Restorative Therapies RT300 from £11,995 to £17,995
- 2 RehaMove from £8,768-£9,985
- 3 BerkelBike from £6,650-£8,995



Restorative Therapies RT300

The RT300 range allows you to cycle indoors using stimulation for lower limbs or to exercise your upper limbs. There are six channels to deliver stimulation and the option of an additional four wireless channels (ie you can stimulate up to 10 muscle groups in one session). The in-built SAGE controller ensures that the motor speed, resistance and torque (how hard the motor turns) are all automatically responsive to your performance and your phase of therapy – whether you are in the warm-up, active or cool-down phase. SAGE also connects your cycle to the internet enabling your FES Cycling specialist clinician to remotely monitor your progress and fine-tune your training programme.

RehaMove 2

The RehaMove 2, pictured in the advertisement, is a combination of a MOTomed Viva 2 and an FES stimulation unit (Hasomed). Again, you can cycle using stimulation for lower limbs or upper limbs. Stimulation is limited to eight channels (ie stimulation for up to eight muscle groups). However, the detachable Hasomed FES unit can be used either on its own, or in combination with other therapy equipment such as a rowing machine, or with therapy activities (eg sit to stand, therapeutic walking). Currently, there is no Internet link.

BerkelBike

Many of the BerkelBike models dispense with a motor in preference to the user assisting the turning of the pedals with their arms via a hand crank much like a handcycle. Power-assisted models are also available. The FES controller has six channels (ie stimulation for six muscle groups) and is activated soon after the user has started to turn the hand crank. There are options for static indoor use and even outdoor cycling which opens up the opportunity for true leisure cycling. The latter is dependent on arm function and on the terrain. The current BerkelBike models do not offer arm stimulation or Internet link.

How can I try one?

- Contact one or more the suppliers to arrange for a personal demonstration at your home
- Try one out at NAIDEX, Mobility



Roadshow etc (bring shorts!)

- Contact an FES Cycling Physiotherapy Specialist for an independent assessment.

RT300: Cyclone Technologies

www.cyclonemobility.com

0800 180 4850

RehaMove: Anatomical Concepts

www.anatomicalconcepts.com

0141 952 2323

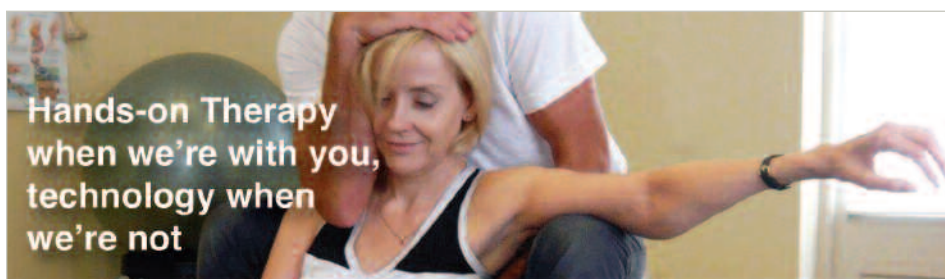
BerkelBike: Active Linx

www.activelinx.co.uk

07872 187078

Of course not everyone will wish to commit to a purchase of an FES Cycle system for home use. An increasing number of private Physiotherapy clinics offer FES cycling therapy and exercise sessions.

If you want to talk to Eva or Jon about FES cycling, why not post a question on the featured forum on SIA's message board?





Our services:-

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- Supervised gym sessions
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Travelling with your PA



The number of Active Assistance clients going on holiday continues to grow. Last year our clients visited a number of locations ranging from Spain to Sudan! We have some fantastic pictures and most importantly our clients and their PAs have some great memories.

When planning a holiday it is important to remember the obvious! Here I am of course referring to things such as insurance and vaccinations. It is important that you are open and honest about your disability as well as the support you have at hand from a specially trained PA and back-up from the Active Assistance Care Services Manager at head office. Failure to disclose anything may invalidate your insurance. Photographs of resorts are great, but it is as well to ask questions like:

- Are there any steps to the hotel entrance/ in the reception area/to my room?
- How wide is the doorway to the

bedroom/my bathroom?

- Do you provide specialist equipment such as a self-propelling shower chair/ a mobile hoist/a commode chair? If so, what type?

You must make sure that neither you nor the PA is placed in danger through lack of appropriate equipment or poor space to manoeuvre.

Inevitably there will be unforeseen circumstances which just can't be planned, but a good PA will take this in their stride and be able to adapt and overcome challenges in consultation with the client.

Whilst the PA is still 'at work' when you are on holiday, there can be few jobs

as rewarding as being able to sightsee or sunbathe and get paid for it! The PA's working day will include the usual established routines that clients have, from getting up and ready in the morning to eventually retiring to bed at night. The success of the trip relies on first class communication and negotiation of what both parties want to get out of the trip, and also in respecting time off, rest time and the opportunity for both of you to be alone sometimes. Over 80% of Active Assistance clients have permanent PAs. The good working relationships established will help the individual get the best from their holiday.



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For more information please call 0844 84 61616

(Call charged at local rate)

Please visit us online at www.activeassistance.com



16–19 May 2014

The SIA 40th Anniversary bike ride is a classic challenge suitable for any cycling or hand-cycling enthusiast, whatever your ability.

Our four-day route will lead you along beautiful country roads, through quiet picturesque villages and across some of the most spectacular countryside and historic sites that Europe has to offer. With plenty of opportunities to stop off en route, you'll soon arrive in the heart of Paris at the finishing point at the Eiffel Tower.

Whether you are an individual or a team that would like to enter the challenge, this will be a weekend to

remember. You will meet new people and make friends for life, sharing the knowledge you are raising money for SIA in our 40th year!

Registration is now open for this challenge! The Registration fee is £150 and you can either raise a minimum of £1400 or pay for your own travel costs of £640.

For an information pack please call 0845 071 4350 or email fundraising@spinal.co.uk

Hidden treasure in every home

Did you know your home is a treasure trove? There are lots of ways you can support SIA without leaving your house, asking friends for sponsorship or holding an event. Instead, you simply need to tidy up, check your bills and go shopping.

Please send us:

- Used stamps
- Foreign coins
- Old jewellery



In this issue we are enclosing a recycling envelope in which you can place used printer cartridges and old mobile phones and post them to SIA.

We can convert all these items into cash to fund SIA projects.

Please send your finds to 'Fundraising at Home', SIA House, 2 Trueman Place, Oldbrook, Milton Keynes MK6 2HH

Why not make a regular donation to SIA through your pay!

As a supporter of the Spinal Injuries Association you will know how hard we work to plan ahead in order to make the best use of your donations. Through Payroll Giving, you can provide a regular, reliable income stream that allows us to budget, while benefiting you with generous tax relief.

How does it work?

Give to SIA from your pay and you can get immediate tax relief of up to £4 for every £10 donated. The donations are taken from your gross salary, reducing the amount of income tax that is deducted from your salary.

What do you need to do?

All you need to do is ask your payroll department to deduct regular charitable donations from your salary by filling out a simple application form, stating how much you would like to give and to which charities. Your donations will show on your payslip.

If your employer does not already have a Payroll Giving scheme in place, don't worry, it's quick and easy to set up. Your employer simply signs a contract with a Payroll Giving Agency who will transmit donations on their behalf.

Contact Elizabeth Wright on 0845 678 6633 ext 229 to find out more about Payroll Giving

Last Chance for Adidas Half Marathon

Adidas Half Marathon has opened up its entries to include wheelchair entries that are not elite participants – if you would like to apply for a place, send an email with your level of injury and your contact details and you will be assessed by the London Marathon.

For further details please contact Elizabeth Wright on 0845 071 4350 or email fundraising@spinal.co.uk



BUPA Great North Swim – Why not join me in the challenge?

14–16 June 2013

My New Year's resolution is to swim in Lake Windermere by taking part in the BUPA Great North Swim. This is the UK's biggest outdoor swimming event. Now run over three days, swimmers can choose from three different distances (1 mile, ½ mile, or 2 miles). This is a fantastic event for all swimming abilities and gives both spectators and competitors the chance to enjoy the majestic beauty of the English Lake District.

SIA has guaranteed entries and applications have now opened! A registration fee of £30 will secure your place, and the minimum fundraising target is £150. Call now on 0845 071 4350 and request your registration form so you can join me, Elizabeth Wright, and conquer Lake Windermere. If enough of us enter we will have a team reception at a nearby hotel.

To find out more please call us on 0845 071 4350 email fundraising@spinal.co.uk or chat to us online by clicking the chat online above



A thank you to our SIA Corporate Partners

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Silver

Anthony Gold, Bolt Burdon Kemp, Campbell, Courtney, Cooney, Clarkson, Wright & Jakes Ltd, Field Fisher Waterhouse, Freeth Cartwright, Harrowells, Hay & Kilner, JS Parker Ltd, Leo Abse & Cohen, Mackenzie Jones, OCS Group (UK) Limited, Origin, Prestige Nursing + Care, Wellspect Healthcare.

Bronze

Almond Care Ltd, Ashton KCJ, Atherton Godfrey, Barratt, Goff & Tomlinson, Boyes Turner, Brownbill Associates Ltd, Burnetts, Carrs Solicitors, Clarke Willmott, Comer Crawley, Dawson Hart LLP, EAD Solicitors, Fletchers, Foot Anstey Solicitors, Gaby Hardwicke, Geldards, Harris Fowler, Helping Hands, JCP Solicitors, Lanyon Bowdler, Minster Law, Nelsons, Penningtons Solicitors LLP, Pictons, PJ Care, Potter Rees Serious Injury Solicitors, Rachel Lund OTC, Sampson Coward LLP, Serious Law, Spencers Solicitors, Trethowans, Wolferstans.

For more information on the Corporate Partnership Programme please contact Kate Gelder k.gelder@spinal.co.uk Tel 0845 678 6633 ext 232

In the December 2012 issue of *forward* we published our annual Christmas Appeal letter which was signed by Ian Hosking. Unfortunately, we incorrectly stated his level of injury as T4 when we should have stated it as C7. SIA apologies for any confusion caused.

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- Our short term respite services, from 48 hours or longer offer flexibility
- Origin PAs can accompany you on holidays abroad or on business trips either in the UK or overseas

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7.0.6. Cameron House White Cross, Lancaster LA1 4XQ



An invitation to celebrate **Women in Spinal Cord Injury**

In 2007 my brother Kaid sustained a spinal cord injury whilst on a night out with friends.

Rebuilding a life with spinal cord injury has been a challenge, not just for Kaid, but the whole family. It was of great benefit, to us all, to have the advice and support of the Spinal Injuries Association (SIA).

It is because of the help my family received, that I am committed to supporting SIA and the launch of their new event, Women in Spinal Cord Injury.

This unique awards event has been launched to recognise and celebrate the outstanding contribution women make to the lives of spinal cord injured people, which includes dedicated health care professionals, enthusiastic fundraisers and inspirational carers.

The event culminates in a glamorous awards evening on 6 June at the Botanical Gardens, Birmingham, where award winners will receive their Women in Spinal Cord Injury award from a prestigious SIA Ambassador.

I invite you to get involved. Nominate your colleagues, your friends, your family and together let's celebrate their achievements and the impact they have had on the SCI community.

Join me and SIA as we say THANK YOU to the Women in Spinal Cord Injury.



Danielle Bux

Danielle Bux Lineker
SIA Ambassador

Nominate a dedicated colleague, an inspirational carer or an enthusiastic fundraiser for an award! Nomination period is open from **2 January** to **28 February 2013**.



WISCI

women in spinal cord injury

Join SIA as we celebrate exceptional women involved in the treatment and care of SCI people, across the UK.

Nominate online: www.spinal.co.uk/page/WISCI
or contact us for a nomination form.
Call **0845 071 4350** or email WISCI@spinal.co.uk

WISCI is kindly sponsored by:



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To request a sample of the Advance or Advance Plus Intermittent Catheter call **0800 521 377** or visit our website: cathetersample.co.uk

Confidence. Pure and Simple.

I know this is the holiday edition of *forward*, but I'd just like to take a minute to talk to you about

Camping



It's hard to believe, but up and down the country there are people who like nothing better than to spend their precious holidays locating a storm, nailing a kite to the ground, then attempting to sleep in it whilst boy scouts sing Kumbayah about a metre away from their heads. Yes, whilst the rest of us are happily sunning ourselves on the Costa del Sol or catching a dose of Delhi belly in... well, Delhi, this masochistic mob are readying themselves for a nice little argument with their nearest and dearest as they once again watch their £20 holiday 'home' take off into the ionosphere. If I was a refugee, huddling with my family around a tiny stove and a tin of Red Cross bully beef, I'd be somewhat surprised to hear that, thousands of miles away, millions of Britons were doing exactly the same thing for 'fun'.

Yep, I hate camping. That is not to say that I haven't had my moments under canvas. As a child I spent a memorable – if not necessarily happy – week sleeping on a nest of beetles whilst on school camp. The highlight of this arduous trip was losing the tidiest tent competition when a rogue Chewit wrapper ensnared itself on our guy rope. Donning her black cap, the teacher informed us that our prize was to clean out the communal latrines – a punishment which, in fairness,

would have put me off a week in the Seychelles with Kelly Brook. Still, looking on the bright side, at least it prepared me for life with a spinal cord injury...

It may seem unfair to base my opinions on this isolated episode, but I can assure you that my camping experiences in adulthood have not been much better. Forever etched into my memory is the time my companion and

I arrived late at our campsite, just as darkness was falling. In our foolishness we decided to erect the easiest tent first, so that at least we would have somewhere to sleep should the light fail before we could put up the second. Our strategy may appear sound, but we had failed to factor in my limited ability to help and my friend's complete ineptitude when it comes to anything practical. Needless to say, a cosy night huddled together in a ten-year-old's Action Man tent was not my idea of fun, and it shouldn't be your idea of fun either.

These days I am much more likely to watch campers trying to set light to a pile of rotting moss through the safety of a camper van window, chuckling away with a cup of tea on the hob and a bacon sandwich in my hand. On the rare occasions I have been found under canvas I'm more likely to jump into my car and go home for a nice shower than I am to even look inside an accessible portaloos. No, I am most certainly not intending to go camping this year, and I wouldn't advise you to either. That said, just in case I haven't convinced you that camping really is Satan's crowning glory then let me leave you with this final thought: What do Captain Scott, Lawrence of Arabia and Hiawatha all have in common? That's right – they all died camping.

I rest my case...

Dan Burden T5




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If you're not 100% satisfied, return the device in original condition with all accessories within 30 days for full money back for the purchase price.





Adventures on the water

In 2003 I had an accident whilst cycling that broke my spine completely at T5 at age 44. As I had always been active (always worked to live rather than lived to work) I looked around for new sports to participate in.

Scaling Dam Sailing Club in North Yorkshire have a fantastic Sailability group and I learned the rudiments of dinghy sailing with them, starting in 2004. I subsequently purchased my own Challenger trimaran *Mad Scientist* and have participated over the years in some of the well-organised UK Challenger regattas, as well as club racing. A trimaran is a boat with three hulls and provides great stability for disabled sailors.

I love being on the water and sailing offers a superb combination of freedom, beautiful scenery, competition and challenge.

Gypsy Dancer

Last year, my wife Rosi and I sailed (as crew) on the Jubilee Sailing Trust's tall ship *Tenacious*. After a few days in Nassau, capital of The Bahamas, we sailed the 920 miles to Bermuda. The trip took about eight days and we were blessed with good weather most of the time. As crew we are expected to participate in watches. After my initial overnight watch I was excused subsequent night watches as I need my sleep badly! This was our second time on *Tenacious* and we were keen to see how we'd fare on a long passage. OK as it turned out! Bermuda was beautiful and we spent a few days



there before departing for the UK.

My main water-based activity in 2012 involved a 40-foot, Bavaria 38 yacht, called *Gypsy Dancer*. Purchased in March 2010, I sailed mainly in the North Sea during the 2010 season, based at Hartlepool Marina in North East England. All the time I was making her more accessible to a paraplegic, including fixed helming seat, hoist to transfer me up/down the companionway, grab bars and commode in the cabin. I also kitted her out with a storm jib, trysail (mainsail for very strong winds) and cruising chute (like a spinnaker) plus much more which would enable us to sail longer voyages away from land. I mainly helm the boat from my seat at the stern of the boat and

can easily shuffle around the cockpit.

On one of our earlier outings in strong winds, we allowed a rope to foul the boat's propeller and had to call out the lifeboat to tow us into harbour! Lots of embarrassment all around but lots learned also. I made sure the RNLI got a hefty donation to soften the guilt!

Last year, we (myself and three crew) decided to take *Gypsy Dancer* to explore the west coast of Scotland and in July we finally headed north. After a night at Blyth we had dinner anchored in the Farne Islands. There followed an overnight sail to Peterhead. The following day, in excellent conditions, we passed the infamous Rattray Head and reached Whitehills marina in the Moray Firth. Cullen Skink and excellent fish & chips saw us piling on the calories. Strong northerly winds kept us at Whitehills for a day before making it to Inverness via Buckie. Rosi then joined us at the start of the Caledonian canal for the next leg of the journey.

Travel through the Canal, Loch Ness and other lochs saw us below Ben Nevis. What a beautiful sight. No sighting of Nessie was made, but crew Pete included the monster in a water colour of his – proof that she was there. We ended this leg of the trip in Oban.

A few weeks later, a new crew, including Rosi and I, participated in the West Highland Yachting Week, coming last in our Class of 7 boats! Next year we'll be back and will ensure the two water tanks (total 300kg) are empty and there's not so much wine aboard so we'll be lighter and might have a better chance of getting higher in the fleet.

A later trip involved sailing from Oban to Inverkip on the Clyde via the Crinan Canal, another lovely journey.

All-in-all the west coast is stunningly beautiful. We've had relatively little bad weather, some great sailing and lots and lots of good food. We intend to explore the west coast of Scotland fully next season, visit Skye and a few distilleries, perhaps make the trip to Northern Ireland. In between, I'll still compete in the Challenge regattas and be seen enjoying the scenery.

Tony Flinn T5



Adapting a motorhome

This is how I managed to turn my idea for a fully accessible, high specification motorhome into reality – and how it is now available to others...

In 1992, while working as the Manager of a country estate, I fell 36 feet from an aerial zip wire, sustaining a spinal cord injury. Paraplegic following the accident, I went on to become a regular on the corporate circuit, delivering presentations and providing consultancy services to various firms on matters relating to disability awareness. For two years I was a Regional Peer Support Officer for SIA.

As a result, I found I was frequently travelling across the country, often needing to stay in places that weren't particularly well suited to my needs. After encountering numerous situations in hotels lacking appropriate facilities, I began to formulate an idea. What if, instead of simply hoping for the best when booking somewhere to stay overnight, I could actually take my own

a commode to a hoist system, whether it is your own equipment or hired from a specialist medical hire firm. Details can be provided at the point of enquiry regarding rental of the motorhome.

Attention has also been paid to the front of the vehicle, which has a lock-down tracking system so that wheelchair users can be part of the family group while travelling. There are hand controls so that people who are paraplegic or semi-ambulant can drive. The presence of the hand controls doesn't preclude anyone who is non-disabled from getting behind the wheel.

A major consideration was to ensure the vehicle's manufacturer would honour the warranty cover of Coachbuilt GB's work in addition to the standard vehicle warranties. This

"What I hope is that other people will realise that there's now a vehicle available that they can use either to try before they buy, or rent as and when they want to have a family holiday"

accommodation with me? Caravans could only provide so much. To cater properly for the access needs of some disabled individuals – be it a specialist bed, a level access wet room or something else – I realised that a motorhome was the only way go.

Now, having arranged for the construction of a uniquely accessible motorhome for our own use, I hire the vehicle out so others can enjoy the freedom of this type of holiday.

Built from a stock vehicle (a Swift Sundance 630L) and extensively modified by the motorhome and caravan conversion specialist, Coachbuilt GB, the end result is a decidedly high-spec vehicle. It has a cartridge loading ramp, a large wet room and a fixed double bed at the rear of the motorhome with a pressure relieving mattress. Furthermore, the layout allows users to bring along other specialist equipment of their own. From

is obviously very important. If you're spending £50k on a base vehicle, you don't want someone else to do lots of work on it only to find that the initial warranty is null and void.



External view of John's motorhome showing entrance lift



John's motorhome showing wheelchair restraints and kitchen layout

This collaboration between the manufacturer, Coachbuilt GB and me has worked, because of the trust and professionalism of all those involved. We now operate as partners in the hire of the vehicle.

Hiring

In terms of what those looking to hire the vehicle can expect, drivers will be totally covered. They can drive it anywhere in the UK or Europe, with insurance and breakdown packages provided as part of their contract. The only thing people will need to bring is their own bedding and towels – the cutlery, crockery and other essentials will all be provided.

The project has already generated interest among potential users living a considerable distance away, which would seem to bode well. My wife and I have only had one trip in it so far, although several other people enjoyed the experience in 2012. This year's enquiries have already started, so book early is the message. People are driving long distances to collect the vehicle, which shows that it is difficult to find an adapted motorhome more locally. We are also providing a deliver-to-the-door service so people only have to pack and unpack once during their holiday.

If the project is successful I hope to build further accessible motorhomes and make them available for hire.

John Gillett

For more information on the tariffs and booking arrangements relating to John Gillett's accessible motorhome go to www.wheelyindependent.co.uk

California dreamin'

Aged 11¾, I became paralysed at T6/T7. This turn of events dashed my hopes of ever funding my travels through becoming an air hostess, but it didn't mean that I would no longer be able to travel.

Travelling with an SCI is far from impossible, but it does require extra research, plenty of patience, verbal independence, and a little surplus cash. I quickly discovered that 2* hotels were less likely to have suitable access compared to the 5* ones, which was perfect when parents were funding the holidays, but less so when I became an adult and realised the true cost of these hotels, and moreover, how much I had unwittingly relied on my parents and younger brothers to ensure all my care needs were gratuitously met and that I was able to access all the places we visited.

When friends were deciding whether to take a gap year, I never entertained the thought, mostly because I didn't know which of my 18-year-old friends would be able to cope with travelling with a wheelchair for nine months on end, in far flung places. To rectify this, I began to acquire a collection of 6-foot-tall men, who were at a minimum able to carry me up at least one flight of stairs. This project served me well, but along the way I acquired a 5'8", size 8 female friend, named Steph, who was equally insistent that she could carry me up a flight of stairs. We collapsed in a heap and never completed the experiment,

but I liked the fact that her determination equalled mine.

Fast forward to October 2012: I've qualified as a clinical negligence solicitor (alas, not an air stewardess), and Steph and I are embarking on our two-week trip to California.

Whilst we had a great time, there were definitely moments when both of our patiences were tested. We flew with Virgin Atlantic, and this being my second transatlantic flight, I had learned a few lessons. Accessing the 'adapted' bathroom is not possible independently. I would struggle to transfer and would need someone to steady the aisle chair. I'm glad I trusted my instincts, wore an indwelling catheter and did not rely on what I had been told by customer services.

"Despite our initial teething problems, the Californians did a good job in the end!"

Upon landing, we discovered that our car hire arrangements were not as promised. This was perhaps the most frustrating part of our trip. We had planned to share the driving, but despite confirmation of requests for right-hand controls with a spinner, we were provided with left-hand controls, no spinner and a car with a foot brake rather than a hand brake. Despite attempts to find a car that suited, Alamo were unable to fulfil the contract, so Steph and I were left with no option but for her to do all the driving in a car we later christened, Randy.

Undeterred, we headed to Yosemite and clambered up 8,000 feet (courtesy of Randy) to see some simply breathtaking views. The best element was off-roading through Mariposa Grove. It was great to be outdoors, and despite all the tree roots we had a great day out. With our



lungs stocked full of fresh pine air, we commenced our trip down 'Rout' 1 (as Americans would say), and on to Santa Barbara and Santa Monica.

The thing that struck me about California was that their equivalent of the DDA has teeth. There was no lip-service, no anxiety over whether there would be a disabled toilet and there were no excuses for why access was impossible. The 'Can Do' attitude was omnipresent, consequently Steph and I had very few issues with access. All the hotels we stayed in had suitable bathrooms. If the mattresses on the bed were piled too high, the bed was dismantled and a lower bed provided.

So whilst I scour possible holiday homes in Santa Barbara, I'll leave you with my Facebook status update summing up our holiday:

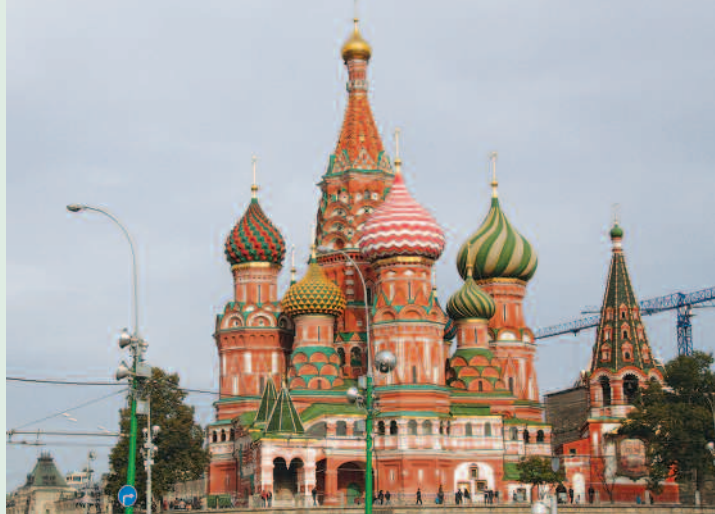
"Leaving California with some great memories of the hardcore hills in SF, Japanese films whilst eating dinner, political satire at beach blanket Babylon, hiking in Yosemite, route 1 coastal views, rooftop pool in Santa Barbara, shopping in Santa Monica, beach walking, American men, interesting taxi drive to Ivy, hundreds of Starbucks and watching the real housewives of Miami in bed. All of this would not have been possible had it not been for Steph who, for those in the know, is now top dog in the Top 5 List."

Raquel Siganporia T6/7



Mariposa Grove

From RUSSIA with LOVE



I've recently returned from a holiday visit to St Petersburg and Moscow.

Those who know me will be surprised to hear that I enjoyed the trip. In general I don't like holidays, I find them boring and I find the hassle at airports, particularly with regard to my wheelchair, more trouble than it's worth. I find travelling round looking at things that have nothing to do with me, shopping, sunbathing or otherwise resting very stressful. I do enjoy eating and drinking but perhaps because of the boredom I eat and drink too much and put on weight which annoys me. I guess I'm just a grumpy old man that needs to get a life other than work.

Whilst I look forward to holidays with trepidation, the alternative of being left on my tod appeals even less. And she who must be obeyed, must be obeyed, and so a-holidaying I go.

Despite myself I had an extremely interesting and enjoyable holiday in Russia. The airports and flights were hassle free, the palaces, churches and museums were the most amazing I have ever seen. And I've never seen so many beautiful, long legged, high-heeled, elegantly dressed women in one place before. Unfortunately unlike women at home who are often happy to make eye contact and give a smile (one of the small compensations of being a male in a wheelchair) the Russian ladies were aloof and ignored me completely.

We flew BA to St Petersburg and from the check-in desk through to exiting the aircraft we were treated with respect and courtesy. At the check-in desk I was asked if I required any help, what my capabilities were and how I would like to manage my

wheelchair. I explained that I would like to stay in my wheelchair up to the aircraft door, needed no help in the plane as I can use the backs of the seats like parallel bars and would like to have my wheelchair present at the aircraft door on arrival. All these requests were met with information passing smoothly down the line. My chair was even given a large label stating that it was to be bought to the aircraft door on landing. The BA flight from Moscow went just as smoothly.

Have things improved since I last flew? Are BA, Heathrow, St Petersburg and Moscow airports particularly good? Or was I just lucky?

While the palaces, churches and museums are magnificent most of them, like most of St Petersburg and Moscow have poor accessibility. There

were some dropped curbs but more often than not one had to negotiate a nine-inch granite kerbstone. The poor accessibility is well illustrated by an almost total lack of wheelchair users seen in public. In 10 days of being out-and-about in St Petersburg (population three million) and Moscow (population 15 million) I saw just two other wheelchair users both of whom were tourists. Nor did I see any walkers with severe mobility impairments. What do disabled Russians do? Where are they?

One of the most moving parts of the holiday was visiting various Russian churches. The Russian Orthodox Church conducts its services differently. There are no pews, worshippers stand and services last for a number of hours. Most of the service is composed of >

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> singing by the priest and an out-of-sight choir. Worshippers come and go as they please, stand quietly, respond by crossing themselves, touching the floor or just nodding and occasionally touching the various icons or lighting a candle. I was entranced by the music and by the dignity and devout appearance of the people who were of all ages and all types. There were many young parents with their children.

Some of the palaces had lifts and many of the churches were more or less accessible. The Hermitage Museum (of art) in Moscow is the second largest in the world and is accessible. We were told that if you spent one minute looking at every exhibit it would take 11 years to see them all. It was full of thousands of paintings from most of the world's famous artists. The magnificent Peterhoff Gardens with its hundreds of fountains was accessible as was the cemetery of Russia's great and good. This was much more interesting than it sounds having thousands of sculptures, religious, secular and bizarre.

For full-time wheelchair users it would be a difficult, but not impossible, experience. It would be necessary to find accessible transport, possibly from a specialist tour operator or to hire a car. Having seen Moscow traffic I would not recommend the latter for those of a nervous disposition. It would also be necessary to find out in advance how much and which of the many places of interest were fully accessible. As a part-time 'walker' I was able to manage some steps. The alternative would be to take some strong companions and be prepared to be carried up stairs.

And finally, not only do Russian women not look like lorry drivers but the Red Square is not red and the Kremlin is not a building that houses the Russian Government but a 60-acre collection of buildings, including churches, a conference and concert hall, and a barracks for ceremonial soldiers, enclosed by the city walls of ancient Moscow. (Although Putin does have his offices in one of the less impressive buildings.)

Roger Fitzwater T11

The Other Side

This isn't the first time I've written about travels to 'The Other Side' Australia. Or as it is known by other epithets...

The Land Downunder, Oz, The Sunburnt Country, The Land of Thunder, Land of the Long Weekend.....There's more but I've bigged it up enough already!

And big it certainly is. And a long way from Blighty. Too far some would say. But listen up. Eyes down. And let me tell why Australia has never been more accessible.

Well firstly, what many would regard as the most significant barrier to visiting our Southern Hemisphere cousins – the journey down there, has been made a whole lot easier by a shift in what I'm calling the 'air axis'. The past 12 months or so have seen a definite tilt from the traditional 'hubs' of Hong

Kong, Kuala Lumpur and Singapore, towards the new powerhouses in global aviation – the airlines of the Gulf countries – specifically Emirates, and Etihad. Not only do these airlines (especially Emirates) have regional UK connections – Newcastle, Birmingham, Manchester, Glasgow but it means that the trip can be made into 'bite-sized' chunks. For example, Newcastle, Dubai. Singapore, Sydney. Or how about Newcastle to Brisbane, Melbourne or Sydney with just one change of aircraft or stopover in Dubai? Brilliant. And of course, because these oil-wealth funded carriers operate the best aircraft (including the double deck A380), it's going to be flying pleasure all the way.



Sydney Bridge



For those wishing to get there in a hurry and not wanting a stopover, via the Gulf is the quickest route there is.

Dubai and Abu Dhabi are fabulous stopover destinations, with accessible transport and all-category accommodation options in both Emirates. Fly into one and the other is just a short drive away, so it is possible to experience two amazing destinations in one stopover!

These are glittering showcases that demonstrate what happens when resources meet vision. Pretty much all attractions are accessible. Visit the top of the World's tallest building, biggest shopping malls, exciting water parks. Even the desert safari camp has an accessible loo! For petrol heads and thrill seekers alike, Ferrari World in Abu Dhabi is a must.

Of course, for anyone wishing to sample the delights of the Orient on their journey south, the Far East city stopovers will forever be captivating. Today, you takes your choice.

So we're there. Downunder. Where to go? What to see? Well, top of the list on anyone's odyssey is Sydney with its iconic landmarks and legendary sights, sounds and beaches. This is a city with adapted transport, accessible accommodation, barrier-free visitor attractions and views. Ah, the views. On a two- or three-week trip to Australia, I'd say five days is a good time in which to 'do' the 'Harbour City'. Some linger but this is such an expansive continent, I'd suggest

hopping on a train, plane or self-drive jalopy and go explore.

Now a quick look in the Atlas will show that there's an awful lot of Outback out there and unless you are some kind of Crocodile Dundee, you'll want to skip the dusty trails for a quicker and more comfortable way of journeying. Air is the obvious method and thanks to Virgin Australia there is a comprehensive network of domestic flights. One word of caution though. The majority of these routes offer only narrow bodies and sometime 'prop' aircraft with limitations on cargo hold dimensions. It is essential you have your travel arranger check the specific aircraft type to ensure that larger powered wheelchairs can be carried. On the ground, all the major destinations/airports, including Uluru (Ayers Rock), have adapted transport but this must be pre-arranged. I'd spend a couple of nights experiencing Uluru where there are three different categories of accommodation with accessible units to suit all budgets. From there take a direct flight to Melbourne to what is widely regarded as one of THE great cities on earth. I've never heard anyone utter a bad word about the place. Be there for the Grand Prix or the Melbourne Cup to experience one of the year's top global sporting and cultural events. Wonderful.

No trip to Oz would be complete without visiting the wonders and beautiful environment of Queensland. The Great Barrier Reef and Daintree Rainforest are must-sees. Stay out in Port Douglas, north of Cairns, for a truly exotic experience. And no visit would be complete without a trip by boat to see for yourself the stunning and fragile eco-system that is the Barrier Reef. Accessible vessels leave Cairns on a daily basis. Scuba Divers are well catered for too with qualified specialists available to train and buddy disabled divers.

So we've hopped around the country to get to distant parts. What about exploring at ground level? Well, cars with hand controls and self-drive adapted vans are available in the major conurbations. The mega tour

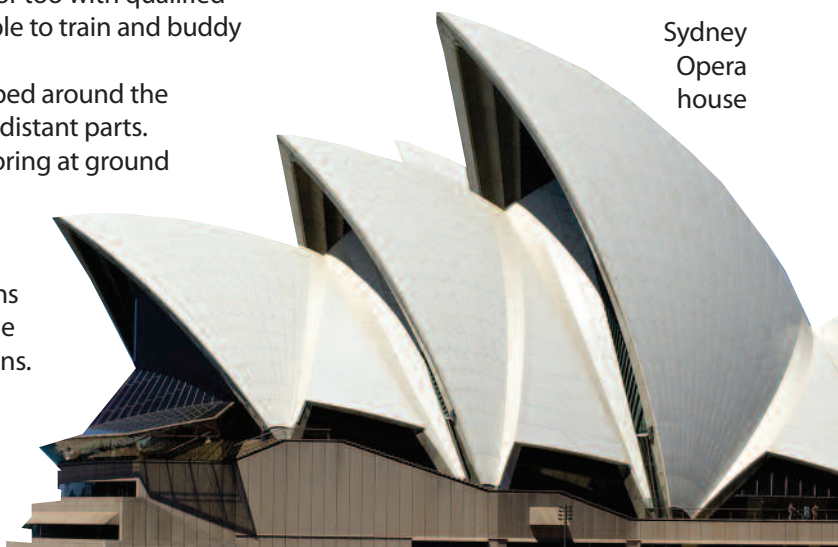


companies also operate accessible tour buses but these are limited and pre-arranging is essential. And for those who are tempted by a trans-continental epic, no worries mate, the 4,352km Indian Pacific rail journey from Perth to Sydney (or vice-versa) has one accessible sleeping berth (on certain departures). As ever, early booking of this is essential. But, what a way to really understand just how massive Australia really is.

We've mentioned Sydney, Ayers Rock, Melbourne and the Barrier Reef. Let's also throw a couple more delights on the barbie.... Brisbane, Adelaide, Perth and heading North – Darwin. So much to choose from – it's really a case of how much time do you have! However long that might be, you can be reassured that Australia is a do-able destination. Crucial elements such as adapted accommodation, transport, mobility equipment and even personal care can be put in place to ensure you leave home full of confidence that this will be a trip of a lifetime. So what are you waiting for all you Bruces and Sheilas, it's time to journey to the 'other side'.

Richard Thompson
Travel Counsellor and SIA member

Sydney
Opera
house





Is Corcovado Accessible?

The guide book says, "It is impossible to conceive a trip to Rio de Janeiro without paying a visit to the statue of Christ the Redeemer. Located at the top of Corcovado Hill; it is Brazil's most known image throughout the world."

We arrived in Rio with one day to sightsee before we joined a cruise going south to the bottom of South America, around Cape Horn and finishing at Santiago. The flight from Heathrow had been very long and my husband John (T12) and I were tired. But we were determined to see the enormous statue of Jesus and asked in the hotel if it was accessible. The tour guide looked unsure, made a phone call and said it was possible but we could not use the funicular railway we would have to go by taxi.

Health and Safety?

Corcovado is the name of the hill, 2,300 feet above sea level and the ascent is very steep. Our taxi began to climb and the narrow road was cobbled. We could see why tourists generally went by funicular from the town centre as we bounced uncomfortably along. Eventually we arrived at a ticket booth and the taxi

driver spoke at length explaining that John could not walk and could not go into the minibus that was waiting. The minibus set off up the hill and we followed. Finally at the top we were told it was only a turning circle and the taxi would have to wait further down so we agreed to meet our driver in one hour. We then discovered that the journey skywards was not over. We entered a lift and when we got out we were faced with an open air escalator. The man operating the lift then came and offered to help John onto the escalator. We were both reluctant to take the risk but having come so far it was tempting. Finally John nodded and the man supported his chair and they rode up the



escalator together. I followed and arrived in time to see John and his strong escort ascending escalator number two. When I met John he had agreed to be collected in forty five minutes and then we were free to wander and enjoy the views. The statue was huge and it was necessary to go along the walkway in front of it to see the face. He stood, 100 feet high, with arms outstretched and a loving expression on his face that cannot fail to move anyone contemplating it. The phrase, "suffer little children to come unto me," went through my head and at that moment I felt very small, dwarfed by his bulk. Eventually we tore ourselves away from gazing up at him and turned to see what he looked at every day. Far below us was the sea and Sugar Loaf Mountain looking insignificant from this viewpoint. To the right was the famous Copacabana beach flanked with hotels and to the left the Airport, Zoo and the Maracana Soccer Stadium. It was glorious and we had that feeling of disbelief that we were actually there, experiencing this wonderful place. The time soon passed and as it was noon the heat was becoming unbearable so I went to look for our strong helper to get John down the escalators. They did this with John facing into the escalator and it was managed without mishap, much to my relief.

Whilst we waited for our taxi I bought us some drinks and we found a shady spot. We felt delighted with the experience and agreed that we were glad Rio had not introduced stringent health and safety measures because we would never have been able to see Christ the Redeemer if they had.

The answer to the title question is no, it is not accessible, but where there is a will there's a way.

Hazel Goss

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"With me it's personal"



Prague: Baroque and Roll

(the city that un-disables you – well, nearly)

The good news is that you don't have to be going on a batchelor or hen's night out party to enjoy Prague. I knew it was a fun city with not probably, but actually, the best lager in the world. But I had no idea how wonderfully accessible Prague is.

Normally if a place is historic its geography makes it a 'no-go' place for wheels. Not so with Prague, both its glorious past and its layout makes it a 'come-see' choice for all of us who push not stride.

Prague, like every other European city worth its name, lies on a river. The Vltava is wide, majestic and be-bridged, if there is such a word, by a host of sturdy, whimsical and imposing bridges. The real legacy though of this unique setting is its compact size and flatness. No hills and little distance to cover makes for minimum effort with maximum effect. This benefit is compounded by the unusual advantage that there's no wasted space.

Prague is a continuous wonder. In other great cities like London, Paris or Rome the sites are spread about. You see one of them and find that the next has been plonked down elsewhere: a short and demanding (if you're in a chair) trip away.

That's not so with Prague. It's all in one extended area and it's non-stop. There are no pauses between one delight and the next. Not all of it is grand but all are gems of a kind. Push across one square and around the corner another is waiting for you. Scoot down a dark alley cut through with shafts of sunlight and you are at once into the next. You'll find rows of looming houses, each jostling for your special attention. And each of them worthy of it too.

The most majestic buildings are the Castle and the Cathedral. Two huge

tributes to brute power posing as embodiments of elegance and confidence. It never fails to amaze me how the Super Rich managed to persuade the Super Poor to labour so diligently on their behalf. I suppose back then it had a lot to do with the actual threat of the sword and the even worse fear of foregoing heaven after a life of hell on earth. Everyone was a loser, unless you happen to be the one with a crown or sceptre.

The airport is nearby. It's modern, speedy and efficient with accessible links to the heart of Prague. It's the city centre that I recommend you use as your base. The Old and the New Towns are cheek by jowl and interchangeable. Both are more baroque than a wedding cake. Each makes you feel that the Middle Ages, despite the painful absence of good dentists, might, if only for the architecture and the human scale of it all, have been a good time to have been around.

There seems to be lots of the 'best thing about Prague is ...': so you can't go wrong no matter what you choose. The centre is well on the way to being car free and the trams are not a menace, they are accessible. You press the reachable wheelchair button, the tram driver alights, a steel platform appears and hey presto you're riding the iron way.

The Metro too is a boon. Again not all of it is useable, but there's more than enough to get you around to all the places worth seeing. As the Metro

system is fairly new it's impressively benign and easy to use. It serves passengers first, makes money second. Take note Transport for London.

The Charles Bridge is pedestrians only. It's like a long open-air shopping mart, full of small, one-man stalls. They mainly sell touristy stuff but there's the odd gem. The Czechs are a clever lot. Their history is littered with leading names in the Sciences. In particular they had a love of Maths together with Mumbo Jumbo (or Alchemy as they, and our Isaac Newton, preferred to call it).

In Staromestske Namesti square, as testimony to this, stands Prague Orloj. This is the famous multi-chiming, all-action, upmarket 'cuckoo' clock. Which whenever it strikes the hour it eats up five minutes of your time with its farce-like opening and shutting of secret doors and waving of swords. It's a wondrous example of engineering ingenuity. A time piece that tells you the time while telling you about the Astronomical obsession that characterised the time in which it was built.

Despite his skills and brilliance Mikulas of Kadan, the clock's architect-cum-builder, paid the price of meddling in numbers. He was eventually shunned by an ungrateful orthodoxy but not before he'd used his wizardry to determine the most auspicious time to start work on the Charles Bridge. The number code he devised recommended that the work began in thirteen fifty seven at precisely one second after three minutes past five on the morning of July the ninth, or to put it another way 135797531. Phew!

Prague is full of such stories and sites and I haven't as yet mentioned that the great King Wenceslas was another of the city's favourite sons. You will find traces of him thankfully without Rudolf scattered everywhere. Another 'best thing about Prague' is that it is affordable. Suitable hotels include the Yasmin and the Elephant.

If you need to know more then contact the helpful and lovely Lea at www.accessibleprague.com And, yes, there are cobbles but there are also well-made mosaic pavements with drop kerbs. If an old, bump-averse tetra like me can enjoy it, then Prague is definitely worth looking in to. Raise high your Pilsner and Czech it out.

Barry Brooks C6

Dorset

I had never previously visited Dorset and my parents have often said how lovely an area it is having already sampled its delights on a few occasions. So fortified with a week off from work, a lot of warm clothes (we visited in October) and the aforementioned parents, my husband and I drove the long trek from Newcastle upon Tyne to Dorset. Now, as a paraplegic wheelchair user I'm slightly obsessed by accessible toilets so no apologies for mentioning them here!

We stayed at Ellwood Cottages, Woolland near Blandford Forum. The cottages are well away from the madding crowd so a car is essential. We stayed in Blyton cottage which was all on one level, with easy access from the courtyard. There was a warm welcome from the owners, John and Ann, and a lovely welcome basket of local goodies. The lounge and kitchen had laminate floor which is easy to manoeuvre around in a wheelchair and easy to clean (especially when visiting in damp conditions). There were two bedrooms in this cottage, one being a twin with en-suite wet room and a family room with twin beds and bunk beds again with an en-suite wet room. The bathrooms were well equipped with grab rails by the loo and an assisted shower chair. There was room under the beds if a portable hoist was required. The cottage had plenty of room to move around freely.

In one of the other buildings in the courtyard was a splash pool with hoist



The Courtyard at
Ellwood Cottages

(you had to supply your own sling) with two separate changing rooms again with wet room showers and assisted shower chair. There was a family room with a piano if anyone in the family has a musical bent and plenty of games and toys to keep children amused if you fancied a day in.

In our first couple of days we managed to visit a few places including Portland Bill (accessible loo in the car park), Weymouth (Radar key loos available), and West Bay (Radar key loos available in car park) where we had a lovely smoked haddock chowder outside, whilst pretending it was a warm hazy day! Next was my favourite place, Sherborne with its beautiful abbey, surprising number of level access shops which were not all chains stores and a lovely garden centre where we had lunch (yes it too had an accessible toilet).

We also managed Poole with a visit to the museum and pottery, Walford Craft Centre, which looking at it from the

outside didn't look accessible, however there was a lift up the middle of the building allowing wheelchair users to (carefully) navigate the lovely arts and crafts and then to discuss which was your favourite at the café next door which had a very good menu choice (and toilet).

On our final day we visited the tank museum which was also very interesting.

We had a lovely time and would recommend both the accommodation and the area. It would have been great to visit in better weather in order to enjoy more daylight hours to take advantage of the peaceful gardens, lovely views and spectacular sunsets. The dark nights did allow us to dress up on Halloween though!

To find out more about Ellwood Cottages visit www.EllwoodCottages.co.uk or telephone John and Anne on 01258 818 196

Di Bewick L2

Below: internal views of the cottage where Di Berwick stayed



Cornwall



Penrose Burden

In June 2012 we stayed in Troutstream Cottage, Penrose Burden for a week. It was our first visit to these cottages in the lovely hamlet of St. Breward near to Bodmin. The cottages are all spaced a considerable distance from each other giving a feeling of 'away from it all.' It's certainly off the beaten track, yet perfect for fishing in the river Camel as well as doing the Camel Trail which is very suitable for wheelchair uses. The whole location of all the cottages is peaceful and tranquil with their own gardens too.

Our cottage was very spacious and easy for my husband, Jason, to move around from the sitting room, to the kitchen, and into the wet room and into the ground floor bedroom. Nancy, who runs Penrose Burden has one electric bed which they move from cottage to

cottage as needed. We did have a look round the cottage next door to Troutstream, which was far enough away to not impact on our privacy as it faced a different direction. On our last day we also had a look at the largest cottage, Toad Hall, which we have booked for a week this year with the rest of our family.

The cottages had everything we needed, including a large shower commode chair. We were especially pleased to have a log fire for the evenings as the weather was chilly

last summer, and the log store was generously re-filled during our stay.

Going away with a tetraplegic (C7/T1) is rather like a military operation, however, we found this to be the best equipped cottage for my husband's needs, as well as being charmingly rustic and comfortable, hence us booking here again. Our dog loved it too!

To find out more about Penrose Burden visit www.penroseburden.co.uk or telephone Nancy Hall on 01726 883240
Celia Caulkin



View from
Otterbridge



Troutstream

Derbyshire



Lane End Farm Trust has opened a Room for All Seasons on a working farm in Derbyshire. The interior has been specifically designed for wheelchair users with adjustable-height kitchen facilities and generous space to move around the open plan living area. It is all on one level and the bedroom has an adjustable bed and ceiling hoist, a wet

room with shower chair and facilities for a PA or other family member.

There is wheelchair access around the immediate farm buildings and guests are invited to join in with feeding the animals and collecting the eggs, although it's not compulsory. The owners hope it will be of particular interest to young people coming to

terms with a new spinal cord injury, although the property is available for any SCI person to book.

Close to attractions such as Chatsworth House, the plague village of Eyam with its museum and Little John's grave in Hathersage, it is also close to Bakewell, famous for its puddings, and the 18th Century spa town of Buxton. Details of other local attractions, such as Peak Rail, helicopter rides, glider flights, and other accessible destinations in easy reach are provided in the house. There is a range of sport and leisure opportunities available at Carsington Water.

Local author Gillian Scotford has published a book of accessible walks and there is a copy available for visitors.

For those who look for a different kind of holiday Sheffield, with its theatres, music and other cultural venues, plus Meadowhall, one of the country's leading shopping sites and truly wheelchair friendly, are all within easy reach.

To find out more about Lane End Farm Trust and what it has to offer visit www.laneendfarmtrust.co.uk or telephone 01433 650043

The 'Room for All Seasons'



Holiday Access Warning

A cautionary tale from one SIA member who booked a property advertised as M3 Access Exceptional and subsequently found it wasn't!

The National Accessible Scheme (NAS) is the only scheme that rates the accessibility of visitor accommodation throughout England. It is administered and policed by Visit England and aims to help holiday accommodation operators improve and promote their true level of accessibility, so disabled people, like our member, can be sure the accommodation they are booking will meet their needs.

NAS standards for serviced, self-catering accommodation and holiday parks cover three types of impairment: mobility, hearing and visual. Businesses can apply for classification in one, two or all three of these areas, based on relevant features such as the size of the rooms, widths of doors and the facilities that are available to benefit target users. For example, M3 covers places suitable

for independent wheelchair users. NAS ratings are in addition to the star-ratings offered to all accommodation, which are determined by the services and facilities provided for all guests. The official star-rating and NAS classification systems help potential guests know what to expect before they arrive.

Access Exceptional is awarded only to establishments that meet the requirements of independent or assisted wheelchair users.

On arrival at the property our member found the accommodation so small there was insufficient room to manoeuvre her wheelchair, and a ceiling hoist that went from over the bed deposited you somewhere between the basin and the loo.

Although she challenged the owner at the time and made some helpful suggestions about how the accommodation could be improved, on returning home she voiced her concern to Visit England. It transpires they move

very slowly and it took several months to investigate the complaint.

In fact, the property owner had not been inspected for access by Visit England and had awarded himself the M3 Access Exceptional accreditation. Even when it was apparent to Visit England that this was the case, the only action they were able to take was to write to the property owners asking them not to make a false claim about the award. There are no civil sanctions as the scheme is voluntary and Visit England have few teeth.

Ultimately, had the property owner continued to claim his M3 Access Exceptional rating, the matter could have been passed to Trading Standards, but those wheels move slowly too and generally a successful claim under the Trade Descriptions Act doesn't include compensation for, as in this case, the person whose holiday is ruined.

The moral of the story is always to ask for evidence of the M3 Access Exceptional rating and double check with Visit England that they have inspected the property. You can do that on their website www.visitengland.org

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Rabina and Kajol leading an activity session

A trip with a difference

Problem solving in Bangladesh...

Recently I spent two weeks in Dhaka volunteering for the recently-founded charity Vitality – helping to coach four new trainers in healthcare and promoting independence for the first week and then supporting them to deliver the training to a new cohort of trainees for the second week. The UK team included Lucy Robinson (founder of Vitality), Louise Wright (head of Vitality trustees and CEO of Back Up), Angela Maset (Occupational Therapist and PA for Lucy) and me.

Usually I would think of myself as being pretty well travelled but I'm not sure that I had prepared myself for the bustle, noise and intensity of this crowded city. Maybe having our accommodation opposite the mosque with the five daily calls for prayer didn't help with the volume control but it certainly added to the atmosphere and made sure we were submerged into our experience immediately!

We were based at the CRP hospital (Centre for the Rehabilitation of the Paralysed) which was set up over thirty years ago by Valerie Taylor – who had previously worked at Stoke Mandeville Spinal Centre. At this unique hospital complex, SCI services are provided for over 350 new admissions each year. It is staffed by a number of dedicated professionals but also manages to attract a large number of overseas volunteers. In fact, Motivation worked in partnership there over twenty years ago helping to transform the wheelchair provision available and Pete Donnelly used it as a base last year and his starting point for his journey "rolling back home". Despite all of this expertise, life expectancy for a

tetraplegic is between six months and two years and for a paraplegic is less than three years. Vitality's aim is to change this through education and support and the first solo course for spinal cord injured people and their families was delivered in May 2012. This was when our two couples (Hasi & Kajol and Rubina & Nasril) were identified as having great potential to lead courses in the future.

Roll on six months and I find myself in a classroom, working with translators and devising a course to build confidence, knowledge and skills. Having had limited experience working outside the UK, one thing that I do know is that not everything always goes completely to plan – in fact, it would be almost disappointing if it did! Very early in the first week it became apparent that the manual that had been translated was not usable. This was a pretty big blow as it's a crucial resource for our new trainers who were still learning some of the fundamentals for themselves. This is where the lessons of problems solving get practised...

It was a totally exhausting, exhilarating and ultimately rewarding few days with lots of re-thinking, modelling delivery, demonstrations and practice alongside some incredible support from some local translators (who more or less re-worded the manual). We all managed to get through the first week.

In the second week we had twelve new families join us for the full training course – a spinal cord injured person and

their main carer. About half of the group were still going through their initial rehabilitation and the rest had taken the journey from their communities.

I was really impressed with the design of the trolley beds used by those still in CRP, where people still doing their bed-rest could be mobile with two large self-propelling wheels. I wouldn't have minded that twenty-plus years ago when I did my rehab, rather than looking at the same hospital ceiling for three months.

A highlight of the course was the outing into the community to drink tea. We were quite a convoy wheeling and pushing, wheelchairs and trolleys in a group of thirty people. For some participants it was their first time in a wheelchair post-injury and for others the first time out of the hospital.

In essence, that's what makes it work – having other spinal cord injured people and their carers supporting and delivering training means that the problems and challenges that might be faced in the future are really understood. It doesn't matter if you live in the UK or Bangladesh, being able to talk about your situation and share ideas enables people to find their own solutions and find a way to cope. There really are so many ways to problem solve in Bangladesh...

Plans are currently being made to run the second train-the-trainers course and subsequent participants' course in March 2013.

Trish Thompson
T6 incomplete/T8 complete, RTA 1990



The new Bangladeshi trainers with Lucy, Trish & Angela

Useful links:

www.vitalchange.org.uk (or Vitality on FaceBook), www.crp-bangladesh.org

Geodome accommodation at Portuguese campsite

Camping Gaio is a new ecologically sound campsite opening this Spring in the foothills of the Estrella Mountains, near Coja in Central Portugal.

It offers full facilities for disabled people, as well as their non-disabled friends and family, by accommodating them in Geodomes or Yurts (wooden floor, bed and clean sheets included!) on a small site also offering high-class cuisine every day in a central Geodome. You can have an all-inclusive holiday with the emphasis on socialising and integrating with other campers and a high-degree of comfort. The owner, Lynn Alexander, has experience with the needs of high-level spinal cord injured people having worked as a PA in the UK. She says she wants to create a friendly festival-feel environment where people can make new friends.

Contact Lynn in Portugal on 00 351 961 074 719 or by email at lynnipin@yahoo.co.uk Be sure to check that the campsite facilities will meet your needs. www.gaiocamping.com

Jeff's wheelchair walks

Wheelchair user Jeff Mason has designed a website for those people who like a scenic walk, with café or pub stop, in the South Yorkshire, Derbyshire and Nottinghamshire areas. Walks are from one to six miles long and have been tried and tested by Jeff and his sister Audrey over many years. The website is easy to use and benefits from lots of pictures of the various routes.



Why not take a look at www.Jeffswheelchairwalks.net

A car service with a difference

Mobility Funeral Services was set up by Trevor Macey to enable a wheelchair user to travel to a funeral with dignity, riding in their own chair and sitting with other mourners. Trevor was inspired to convert a vehicle and offer this service when his own sister, a full-time wheelchair user, was unable to source a suitable car to take her to the funeral of a close relative. Trevor decided there must be lots a people in this situation and he now offers his car, and himself as driver, to individuals and funeral homes around the country.

Although the car has privacy



windows, it would be just as suitable to take a group of people which includes a wheelchair user to a wedding or a stag or hen night!

There is more information at www.mobilityfuneralservices.co.uk or you can call Trevor to discuss your requirements on 07774 919899

Disabilinet.com

This is a unique and fairly new social media site which aims to help disabled people make new friends safely. Unlike Facebook, it is not for managing existing relationships. Although new, it's already an interesting site, with people contributing from overseas as well as the UK www.disabilinet.com



The complete guide to everything accessible

This website covers a broad range of topics pertinent to disabled people. There are sections on Holidays & Leisure; Mobility & Fitness; Home & Lifestyle; stuff 4 kids; News and Charities. There's even an online shop selling some useful aids and gadgets.

Why not take a look at www.theaccessibleplanet.com



Joy Sinclair, SIA's Advice Line Officer
and Ageing-well adviser, writes about

Memory & ageing

Losing your memory is not necessarily a consequence of ageing. At any age, we are all capable of going into a room and forgetting why we went there in the first place!

With age, physiological changes occurs in the brain which can affect our memory. Most of us experience these changes as memory lapses, taking longer to learn new things such as languages, and taking longer to recall information.

Fortunately, the brain is capable of producing new cells even as we age.

It's certainly frustrating when we can't remember names or the title of a book, but these lapses do not mean dementia has set in.

What contributes to memory loss?

- Certain medications eg sleeping pills, painkillers.
- Excessive alcohol intake.
- **Dehydration** – sometimes difficult to notice, but if it becomes severe, it can cause confusion. If you take diuretics (water tablets) you may be more at risk. Excessive use of laxatives may also cause dehydration. Revising your bowel regime at intervals, as you age, can help keep your fluid balance at correct levels.
- **Acute infections** such as urinary tract infections may cause temporary memory loss and confusion.
- **Chronic fatigue** – people affected by transverse myelitis sometimes complain of loss of concentration

and episodes of memory loss.

- **Depression** – affects concentration
- **Vitamin B deficiency** – you may be at risk if you smoke or drink heavily.

How to help prevent memory loss

- **Exercise** – performing regular exercise – exercise increases oxygen to the brain.
- **Eat five** portions of fruit and vegetables per day thus ensuring a good intake of vitamins and include foods containing omega-3, such as oily fish and walnuts.
- **Reduce or give up** smoking and drinking – smoking also increases the risk of strokes.
- **Get adequate sleep** – lack of sleep can cause lack of concentration and affect decision making.
- **Get socialising** – seeing friends and family helps keep you alert and helps prevent depression.
- **Reduce stress** – stress can cause loss of concentration, affect your ability to





brain exercise you enjoy is essential, because like physical exercise, we soon stop doing what we don't find pleasurable.

Ideas for brain exercises

- Easy options; scrabble, crosswords, word puzzles, number puzzles and Sudoku.
- Harder options; chess, bridge.
- You may prefer just to read, learn a language or, if dexterity allows, learn a musical instrument.

How to remember – easy tips

- Make daily or weekly lists of appointments or use a calendar. Increasingly people are using various forms of electronic organiser.
- Keep essential phone numbers near the phone eg your spinal centre, GP Surgery, your friends and neighbours.
- Having a routine for daily activities.
- Put items you need regularly, such as keys, glasses, watch, in the same place each day.
- When being introduced to someone new, repeat their name out loud or try to remember their name by association. Do they look like someone you know well?
- Write down instructions on how to use things if you think you'll forget eg a new phone or the microwave.
- You can set your phone to remind you to take medications or use a pill box.
- Focus on one thing at a time.
- Birthdays and anniversaries can be written in a diary, a separate birthday

book (but you have to remember to look in the book!) or stored electronically.

- Investigate telecommunications aids to suit your level of injury.
- Try to park in the same place when going on regular shopping trips – we have all 'lost' the car on occasions.
- Put a date on lists and throw used ones away – too many lists can be overwhelming and confusing.
- Put stickers on objects.
- Keep a notepad and pen by your bed. Attach a notepad and pen to your wheelchair.
- Don't feel embarrassed about asking your family or carer to assist you in anyway if you forget a trivial piece of information.

When to Consult your GP

It's important to distinguish between normal forgetfulness and what may be the onset of something more serious.

A family member or friend may be the first person to notice problems developing these could include:

- Difficulty remembering how to get to a familiar place.
- Difficulty remembering how to do things you've done on many occasions.
- A gradual worsening of memory.
- Losing track of what happens day to day.
- Problems learning new things.

BUT do remember – memory loss is not inevitable as we age.

learn and trigger memory lapses.

- **Try meditation** – you can get books to teach you the technique.

Use it or lose it!

Recently great emphasis has been placed on brain exercises. Finding a



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Another girl!

We had our twenty week scan at Stoke Mandeville a fortnight ago and have been told we're having another little girl. It was a strange feeling being told that, as I had convinced myself it was a boy. Not disappointing by any means, but it took me a good week or so to get my head around it.

Freya had been adamant from the start that she was going to have a sister and someone told me that children are usually right. How funny! Tim will have his work cut out, living in a house full of girls!

I'm in full nesting mode already as I'm well into my 'blooming phase' and am currently feeling energetic and motivated. I know this feeling won't last long and am keen to make the most of it before I get too big and tired. I have been having major sort outs throughout the house and am hoping to move Freya into the bigger bedroom in the next few weeks. But, as a self-proclaimed control freak, I am struggling with not being able to plan everything in fine detail for the birth. Many things seem beyond my control and will have to be worked out as and when they happen.

At my obstetrician appointment at Stoke we discussed my birth plan and talked about going into the spinal centre a few weeks before the baby is due (as I did last time with Freya), just to make sure that, if I don't recognise the early signs of labour or if I have a fast labour, then I am already at Stoke and don't need to drive an hour and a half to get there. This was fine first time round, but now I have a toddler to look after whom I don't want to be away from for such a great length of time. It is even more complicated by the fact that



I started having contractions with Freya at 34 weeks and delivered her at 36 weeks (4 weeks early). I'm not sure if I'm prone to early labour or if that was a one-off.

On top of the practicalities of the labour and delivery itself, there is the uncertainty surrounding employing help to assist me in looking after the

"I'm hoping that this time round I will have the confidence to be even more independent in caring for the baby and that the helper's role won't be so hands-on"

baby. It will be key to find someone who is flexible from the outset. I'm hoping that this time round I will have the confidence to be even more independent in caring for the baby and that the helper's role won't be so hands-on. I will also have a mini helper in the form of Freya, who is keen to get involved! The role will very much be 'wait and see' this time round.

I have had fun and games in the last few weeks with Social Services. I contacted the Community Occupational Therapy department to enquire about borrowing a few pieces of equipment through the pregnancy,

to assist me as my mobility changes with the weight gain. Being an incomplete lesion I don't use a great deal of equipment and have only just got Tim to put handrails up in our bathrooms! I wanted to borrow a bed raiser (an electric pillow lift to help me sit up in bed), and a bed stick (a handle that attaches to the side of the bed for me to pull/push on to get up). When I was pregnant with Freya I was living in Berkshire and I contacted the Community OTs when I was around 20 weeks pregnant. It took them seven weeks to get an OT out to me and I had no equipment until I was 28 weeks pregnant!

This time round I thought I'd contact them a few weeks earlier. But now I'm living in Gloucestershire and the difference in service has been remarkable! An OT came out when I was just 19 weeks pregnant and had some equipment sent out by the end of that week! Unfortunately, the bed raiser has been problematic; it just won't lay flat under our mattress and we are fighting with an uphill slope at the pillow end which means you wake up

half way down the bed and have a lump in the middle of the bed that rolls each of us out to our respective sides! Neither of us has had a good night's sleep since it was fitted and they came out to remove it this morning. I'm sure a solution will be found soon though and I'm still

amazed by the efficiency of the service I have received.

So on with the planning and preparation! My next task is to sort through the million vac-bags of baby clothes to see what to keep and what not to, and to sort it all into sizes. It is nice knowing I am having another girl and being able to keep all the pink flowery stuff we have collected over the last three years.

My only scary thought is of one day having two teenage girls to contend with and a house full of hormones... wish us luck!

Emily Clacy C6

Best foot forward

The in-betweeners

I love going to the theatre, but it can be a challenge if the seats are in the middle of a row as I often end up treading on people's feet trying to get through.

Sometimes I get the impression that as 'walkers' we don't really fit in. Non-disabled people wonder why I wobble and struggle to stay upright – even without alcohol – while sometimes I feel we don't really fit with wheelchair users either, whether it's my own feeling of guilt that I can walk (after a fashion) I'm not sure. Sometimes if I 'listened to my body' and the pain signals I wouldn't walk very far, but I guess I feel duty bound to make the most of what I've got.

One area we do have in common is in health. Recently I attended a repeat assessment for the UK research programme, Biobank. This extensive programme invites a random selection of people over 40 and measures various things such as memory, sight, hearing, lung function and culminates in collecting blood, urine and saliva samples. I attended one session a couple of years ago, and recently went for a follow-up appointment. My bone density measurement is borderline, maybe due to the lack of walking compared to other people. Researchers can apply to use the data collected. If the project lives up to its

strapline, *Improving the health of future generations* then it will be well worth the hour spent at the centre.

A few random jottings:

Continence

My local NHS PCT stopped providing the pads I used to get, so I buy Tena Men in bulk, wearing them to suit the faecal incontinence. I tried Peristeen anal plugs, but found the gauze strip meant I left wet patches on chairs – which rather defeated the object of a continence product. Using plastic cups has helped me stop flooding the floor when I sit on the toilet, a hazard when men sit down on the toilet and strain to empty their bowels as the action can force urine out too. I once used an expensive product called the 'P-Gard' which connected to the toilet bowl, but it wasn't ideal. Someone on the SIA message board suggested using cups instead. The pee goes into the cup and is diverted back into the toilet. This idea can be portable as you can buy folding cups from outdoor shops, so saving the bathroom carpet too.

Pain relief

In his interesting letter in a recent issue of *forward*, John Wells mentioned Dihydrocodeine Continus tablets. I was on them a few years ago, but found the normal sort worked more effectively during the day. Having some pain medication lasting through the night could reduce the 'first-hour syndrome' in the morning, when the pain can be unpleasant until the first set of tablets kick in.

Food issues

Some foods will trigger pain episodes (please see below). My GP couldn't explain this – it's not an allergy as such – but thought it was similar to how cheese can trigger a migraine in sufferers. This is connected to how I get a day's warning before a cold or virus, when immune markers in the blood set off an acute pain experience.

Don't accept the status quo

My GP referred me to the NHS specialist physio service. As part of this assessment I was referred back to the orthopaedic surgeon, who sent me for x-rays. They revealed that I have arthritis between two of my toes. This explains the food trigger. Arthritis sufferers find certain foods, eg additives such as monosodium glutamate, corn, wheat, pork, oranges, milk, oats, rye, eggs, beef and tomatoes – can aggravate joint pain. For many years I'd been told the pain was due to damaged spinal nerves but I know now that it wasn't entirely the case. If you're not sure about a diagnosis, ask for a second opinion.

David Wheeler L3 incomplete

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Benefits of independent advice



On 1 January 2013, the Retail Distribution Review (RDR) was implemented. This is the biggest change to ever hit the financial advice industry and will lead to huge differences in how many people receive financial advice.

While there are many sides to the RDR, it essentially aims to ensure that consumers are offered a transparent and fair charging structure for the advice they receive, they are clear about the services they are paying for and that the advice is delivered by highly qualified professionals. It's difficult to argue with any of that!

However, it is likely that many firms and individual advisers will leave the industry as they struggle to cope with the demands of the RDR. Of those that remain far fewer will be able to offer independent financial advice.

Currently many firms purport to be independent when clearly they are not. This could be because they predominantly sell products from a limited range of providers or in

some cases they do very little other than sell their own investment funds and products. The rules about what actually constitutes independent financial advice have been tightened so that many of these firms will no longer be able to claim independence. This is welcomed as it will give clients improved clarity over the type of adviser they are working with and the type of advice and services they receive.

We have already seen a large number of firms choosing not to

be independent. These firms have opted to provide 'restricted' advice, largely because they are unwilling or unable to meet the more stringent independence criteria as, with additional support from product providers or by focusing on selling their own products, they are able to operate on higher margins.

AWD Chase de Vere, the financial adviser behind SIA Financial Services, has chosen to remain independent following the implementation of the Retail Distribution Review. We believe that taking independent financial advice is the only way clients can benefit from a comprehensive and full analysis of their needs and unrestricted access to potential advice solutions.

This is particularly important for clients with more complex financial needs who require a wider range of financial planning solutions and aren't suited to a 'one-size-fits-all' approach.

We believe that true independent financial advice, delivered by highly qualified professionals, will be considered the gold standard for our industry in the future.

For independent financial advice call SIA Financial Services on 0844 800 9562. Our specialist personal injury advice team collectively has more than 25 years' experience dealing with the finances of spinal cord injured people.

SIA Financial Services is a trading name of AWD Chase de Vere Limited. SIA Enterprises Limited is an introducer appointed representative of AWD Chase de Vere Limited. SIA Financial Services is licensed by the Spinal Injuries Association to provide independent financial advice to SIA members.

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FRANCE

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PORTUGAL

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Your home from home in the sun including accessible transport Owned by C4 tetraplegic, 20 minutes from Faro airport with stunning views and privacy. 3 twin bedrooms, 2 with wheel-in showers. Pool with hoist heated to 25°C (May-Oct incl). Inclusive accessible vans & airport transfers, electric up and down bed, electric indoor hoist, shower/commode chairs etc. Not to be missed - to avoid disappointment book now! See full details on our comprehensive website.

Tel: +351 964 560 381

Email: sia@ouricodomar.com

Web: www.ouricodomar.com

ALGARVE, PORTUGAL

Spacious private villa with pool and hoist. 3 bed, 2 bath with wheel-in shower. Shower chair provided. Well-equipped kitchen. 2 barbecues. All doors 1-metre wide. Level access throughout villa and pool area. Paraplegic owner. Debbie Wells.

Tel: 01277 354 313

ALGARVE, PORTUGAL

3-bedroom, 2 bathroom villa with wheel-in showers (shower chair provided). Private pool with hoist. Stunning views. 20-mins from airport. 1-bedroom annexe (deal for carer) is available on request. C5 owner. Contact Jason
Tel: 07799 628 6999
Web: www.algarveview.co.uk
Email: info@algarveview.co.uk

ALMANCIL, ALGARVE

Outstanding, fully accessible luxury private villa set in beautiful countryside near Almancil. 3 bedrooms, all en-suite with wheel-in showers. Private pool with hoist. Comfortable lounge/dining rooms and well-equipped kitchen. All you

could wish for in a holiday home and so much more!

To contact us Tel: 01530 833 690 or Web: www.villas-algarve.co.uk

FLORIDA

ORLANDO, FLORIDA

Recently adapted, accessible, 4-bedroom villa, sleeps 8.

Pool hoist, roll-in shower and shower chair. Private pool and games room. Very quiet area, beautiful rear views of conservation areas. Short drive to theme parks and amenities. Tetraplegic owner. For details call Simon on 07970 491 141

www.orangetreeaccessibility.com

ORANGE TREE, ORLANDO, FLORIDA

Executive 5-bed/4 bath Villa, overlooking lake and conservation area. Large non-chlorine pool and Jacuzzi. Paraplegic owner. Wheel-in shower, pool hoist and shower chair. Sleeps 12. Easy access for Disney, golf and airport.

Web: www.ayersfloridavillas.com

Email: lucy@ayersfloridavillas.com

ORLANDO, FLORIDA

Luxury, 4 bedroom, 4 bathroom villa with its own private pool, set in a small and exclusive private gated community, close to all amenities. Very spacious, level access throughout and fully wheelchair accessible. The rear of the villa backs onto fields and is not overlooked. Wheel-in shower, pool, hoist etc. All facilities and 24-hour management company. Disney only 10 minutes, Brochure from Roger Whittle.

Tel: 01242 573233

www.accessiblefloridavillas.com

CARIBBEAN

ANTIGUA

Accessible detached villa, sleeps 6, in the resort of Jolly Harbour. T6 paraplegic owner. Open plan living room, dining area and kitchen. Fully air conditioned. Three bedrooms: master bedroom + en-suite, twin room with wheel-in shower, double bedroom, family bathroom. Tropical established garden, elevated decking around plunge pool. Gated driveway. No TV! Open all year. Contact Carl 07900 247 542

ENGLAND

Self-catering accommodation

TODSWORTHY FARM HOLIDAYS

Cornwall. 18th Century Cornish stone and slate cottages on a working farm full adapted for wheelchair users and their families. Superb rural location. Set in an area of outstanding natural beauty. Two cottages, both 3 bedrooms, sleeping up to 6. Perfect for touring Devon and Cornwall. Open all year. Tel: 01822 834 744
www.todsworthyfarmholidays.co.uk

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Newly converted, barns (sleep 4 & 6) that are wheelchair accessible. All bedrooms have en-suite facilities – each property has one level-access wet room. Adapted kitchens. Accessible decked patio areas. Detached. Ample parking areas. 4-section electric profiling bed and 160kg electric hoists available. Rise/recline chairs. Care available from local agency. Exposed beams, wood burner. Ideal location for exploring the whole county. Tel: 01726 883 240 or 07762 173 860
Web: www.treworgansfarm.co.uk

PENROSE BURDEN, CORNWALL

Fully adapted cottages for wheelchair users and their families – superb rural area with outstanding views. Open all year round. Wood burning stoves. Colour brochure. Please write or ring Nancy Hall, Penrose Burden, St Breward, Bodmin, Cornwall PL30 4LZ. Tel: 01208 850 277 or 01208 850 617 Web: www.penroseburden.co.uk

CORNWALL, LOOE

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Brochure 01579 320 344

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Self-catering bungalow, sleeps up to six. Ceiling hoists in bedroom and bathroom, wheel-in shower, clos-o-mat loo, low-level kitchen. Contact 01202 481 597
Email: info@31aha.co.uk
Web: www.31aha.co.uk

DORSET

Exceptional, fully-accessible, 4-star, self-catering holiday accommodation in beautiful rural North Dorset. Superbly equipped, comfortable and tastefully furnished cottages, heated indoor splash pool, stunning views from garden M3(I). Tel: 01258 818 196 for brochure or visit www.EllwoodCottages.co.uk

NORFOLK, HUNSTANTON

Two adjoining luxury properties. Sunny sleeps two people. Additional family and friends,

up to 6 people, can be accommodated in Hunny with its accessible ground floor. Full details www.disabledholidaynorfolk.co.uk
Tel: 01733 841 170 / 07740 055 063

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4-star rated apartment with Level 2 accessibility. One bedroom, either as a double or 2 singles. Ramped access, wet floor shower room, profiling beds. Peaceful countryside location. Perfect for exploring Norfolk. Local carers can be arranged. Bathroom shower chair and commode available. See website for details and Access Statement at www.magdalenhouse.co.uk
Telephone Keith and Lorna Cootes on 01366 727 255

LAVENDAR BARN, HOLME-NEXT-THE-SEA, NORFOLK

5* Gold Award converted barn, suitable for limited mobility. Wheelchair access throughout the ground floor. One large downstairs bedroom with wet room en-suite. Private garden area. For further details please contact us on 01733 200 908 or visit www.oceanbreaks.com

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and followbooking link. Or Email: info@gossonline.co.uk
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RATCLIFFE DISABLED HOLIDAYS

C5 quadriplegic owner. Overhead electric hoists. Electric hi-lo beds. Wheel-in showers. House flats sleep 6-10. Open all year. Heysham on Morecambe Bay. Superb sea and mountain view Access to 5-mile promenade Caravans on Haven Parks in Southern Lake District and at Filey near Scarborough. www.theukweb.com/disabledholidays or phone for more information Allan or Jan 01274 588 142

ABNEY, DERBYSHIRE

Room for All Seasons, fully adapted, luxury, self-catering property in the heart of the Peak District National Park. Wheelchair accessible, hoist available. Sleeps 3. www.laneendfarmtrust.co.uk
Telephone Viv for leaflet or more information 01433 650 043

WALES

SNOWDONIA

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www.spinal.co.uk

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You can email your advertisement to: lynnepunchard@btconnect.com. Please send your payment cheque made out to Spinal Injuries Association, to the Milton Keynes office address, with the wording you require or telephone 0845 678 6633 ext 2 and pay by card.

The closing date for contributions for the April 2013 issue is 1 March 2013.



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