APRIL 2013
ISSUE 114

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forward

for thinking people with spinal cord injury

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APRIL 2013
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forward message

As SIA approaches its 40th birthday, I am well aware that one of the reasons the Association has lasted through the years is because we have embraced change and evolved when necessary.

We live in a difficult economic climate and nobody seems to know when the difficulties will end. Membership subscriptions are important to SIA, but even more important to us as an organisation is the support, ideas and enthusiasm that new members give us.

I am delighted that SIA is now reaching out to people – with and without spinal cord injury – in ways like never before. SIA's Master Class programme, the work of our Community Peer Support Team and our study days for healthcare professionals all bring SIA into contact with non-members.

I want these people to support SIA and the work we do well into the future, but in order for them to do so, we must welcome them as members now.

The changes to SIA membership which are explained in this copy of *forward* will, I hope, result in everybody who comes into contact with the Association joining us free of charge and furthering the vital work being done by SIA on behalf of all of us with a spinal cord injury.

Jonathan Fogerty, SIA Chair C5/6

forward thinking

In the news

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SPECIAL SECTION | FASHION & BODY IMAGE

forward matters

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

sia
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MAILBOX
You write to us

Happy Memories

I have been reading forward for nearly 30 years and will continue to read this splendid magazine. Two things in the latest edition prompt me to write. First, the sad news of the deaths of three former members of the Governing Council all of whom I remember with affection as I also served with them on the Council. In particular, I enjoyed the debate we had at the time, often heated, but always with the best interest of SIA at heart. And we nearly always left the best of friends. My particular memory is of Carl who I first met in Gladstone Ward at Oswestry SCI Centre, in the happy days of Florence Nightingale-type wards. Conversation with Carl was always interesting and stimulating I will remember him for a long time. We both served for some time on the board of Transhouse Ltd and the idea behind the concept was very much Carl's together with his widow Val.

Secondly, in the February edition holidays were featured. I have never had any desire to go on holiday anywhere except within the UK as there is so much to see here. I expect there are many, like me, who would love to see suitable hotels advertised; but they do seem to be largely missing in both *forward* and other accessibility guides. I list below some hotels my wife and I have stayed in over many years. I accept no responsibility for what others may think or find and as it is now some time since I stayed in some, the usual telephone call to ensure that things have not changed is advised: but sufficient to say I am now 70 years old and a fairly active T4. As we rarely go for more than five or six nights, preferring several short breaks rather than longer holidays, I am prepared to miss baths or showers so have never tried those facilities; but we do get by! Lindeth Howe – Bowness on Windermere; Borrowdale – Borrowdale overlooking Derwent Water; Coach House at Crookham – north Northumberland; Green Park – Pitlochry, Scotland; Little Silver – Tenterden, Kent; Sidmouth Harbour – Sidmouth Devon; Isle of Erisca Spa Hotel – just north of Connell Ferry, West Coast of Scotland. You need to dig deep in your pocket for the last one. However, they do offer 40 different cheeses after dinner each evening!

Jim Hart T4

Hard to swallow?

I am a Speech and Language Therapist working at the London Spinal Cord Injury Centre and I am developing a research study to explore the experiences of people with SCI who have had swallowing problems or difficulties eating and drinking, especially in the early days after the injury. There have been no studies in this country on this subject, yet I have seen many patients with these problems, so we need to find out more. I would like to interview people to find out about your personal experiences and whether you were seen by a Speech and Language Therapist. Did the problems just get better or do you still have difficulties. This will help us to plan and design better services for patients in the future. At present I am shaping the research project, so having people help me design a survey from their experience means that the right questions get asked and issues don't get missed. I will be interviewing medical and therapy staff to find out about their level of understanding about these problems. The aim would be to develop an accurate assessment to identify swallowing problems early and treat them properly.

If you would like to participate either to help design the project or to be interviewed or are just curious about this subject, please email me: jackie.mcrae@nhs.net or call 020 8909 5466.

Jackie McRae, Specialist Speech & Language Therapist

Good financial advice

The benefits of independent advice (*forward*, Feb 2013) should not be understated. After receiving a small compensation award in 1980 I was advised first by Barclays Bank for four years then by Lloyds Bank for about six and was unhappy with both. I never felt in control, I wasn't really advised on risk or ethical investing and, while there was some growth, it was less than sector average as they only promoted their own bank investments. I moved to Legal & General, who advised buying their own products and little discussion on risk. I felt more in control but received little advice. In 2010 I was facing redundancy and a colleague recommended Entire Wealth Management (EWM) independent financial advisers. Duncan visited us at home, with a free consultation and listened to our circumstances and assessed our attitude to risk rating us 5 on scale 1 – 10. Duncan examined current investments and savings and

Editorial & Advertising Lynne Punchard | Tel **020 8361 6971** | Email **lynnepunchard@btconnect.com** | **Next copy date** 29 April 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**

provided a verbal assessment. We had a mixed bag of investments with a risk rated 7-8, too high for comfort. We received a written report and investment options. We felt in control, we understood how the options were chosen with growth potential (risk 7) and stability (risk 2-3) and average for sector (risk 5). Since Jan 2011 EWM have visited us at home three times and we reviewed our portfolios, at no additional charge to the agreed fees. Not only are we in control, but we feel properly advised and understand our investments. Very importantly, after fees our investments are above inflation and the sector average. I agree with *forward*, we should always seek independent advice where money is concerned and our banks are not independent. Happy to be contacted about my experience with EWM. **ab.reid@btinternet**.

Andrew Reid C5/6

Money for research

I would like to take this opportunity to thank you for the work that you do and the help that you give to people with new SCI injuries. I could not but notice when looking at the financial statement for 2011/2012 that you have no outgoings to Spinal Research. Can I ask you, have any donations ever been made from SIA? I was of the impression that you did. If so, how much do you give? I'm sure this would be a great help to them for let's not forget most of us are in wheelchairs. Just because doctors say there will be no cure doesn't mean there won't be one day.

In your booklet you say that in the next three years you are keen to work with like-minded organisations and collaborate with them to provide the best possible outcomes for SCI people. Surely they are crying out for help too? I cannot help but wonder whether any other SIA member thinks the same?

Cormac McAdam T6
Northern Ireland

Paul Smith, SIA's CEO replies:

SIA works very closely with Spinal Research, in fact a previous Chief Executive was one of the founders of the organisation. Today we work alongside Spinal Research with the other SCI charities Aspire, BackUp and Spinal Injuries Scotland through the umbrella group Spinal Injuries Together (SIT). You may be aware that Spinal Research has a fundraising team and our team often works with them on joint events and applications when there is benefit to both organisations. In answer to your question about SIA making donations to Spinal Research – we do not, nor do we make donations to other charities. SIA has been established as a direct service provider (Peer Support, Advice, Publications, training, campaigning etc) and as such can only use the funds we raise for the purpose for which they were given as to do otherwise would be against Charity Commission rules. Prior to the setting up of Spinal Research we did raise funds for medical SCI research but stopped this when the new organisation was established so as not to compete with them and cause confusion for potential donors. Both of our organisations have found it best to have clarity as to what each of us do – that way our donors know exactly what their funds are being spent on.

I hope the above answers your question and assures you that we do work together.

Waste and continence products

I am grateful for Coloplast's lengthy reply to my concerns about waste and packaging of their products, published in the February issue of *forward*.

It confirms that none of their products, except the cardboard boxes, can be recycled. And whilst they say they appreciate my comments, they do not actually address them, or promise a different approach in the future.

It is commendable to hear that they take their environmental responsibilities seriously. They cite as examples a recent change of materials from PVC to polymers, and a change of colour of the cardboard boxes from green to white, and the use of some recycled paper. This is surely the least we could expect.

But this does not address the fundamental problem that items still cannot be purchased individually, rather than as a 'system' which includes items that may not be needed, and that all items are over-packaged to the extreme. The company has omitted to address these concerns completely.

I can only surmise that it is business as usual for this company, and lucrative business at that.

Maria Parnell T5

As a Coloplast Urostomy system user it is my opinion that their products are of a high standard. It is also correct to say that various parts require different properties for manufacture and security of use. Being experts in continence is not in any way an excuse for the UK Marketing Director's reply.

It would be interesting to establish just how much research has been carried out in what, if any, biodegradable plastics/polymers could be used The company stresses that each part is for once-only use. For small items such as the disposable caps, there's no reason for these not to be recyclable.

There is a much more significant waste of packaging material.

Take their two piece ostomy system. The flanges and pouches are in boxes and non-sterile. The boxes are far bigger than is necessary. However, the night bags and leg bags that attach to the pouch/leg bag are in sterile packages, individually wrapped and hence in much bigger boxes. With the components closest to the ostomy being non-sterile why is it necessary to have the more distant parts sterile? Not only does this considerably elevate the price but vastly increases the box sizes and packaging which also appear to be unnecessarily large.

The company's reply states they "seek and encourage people to provide us with feed back". The tone of their reply suggests this is just sophistry.

John Upton T6/7

Editor's note
No further correspondence on this topic will be published in *forward*

Q&A
You ask us

Q **I have heard that a petrol station chain has brought back the forecourt attendant to help in filling up your car with petrol/diesel. Do you have any details?**

A Apparently, Shell has set out to improve the forecourt experience by reintroducing close to 400 forecourt attendants this year to deliver a more personal service, at no cost to motorists. This includes helping them fill their vehicles. For more information and for the list of petrol stations, please follow the link to Attended Service through Products and Services on the following website **www.shell.co.uk**

Q **I would love to see the England Rugby Union team live. Is Twickenham accessible?**

A Twickenham Stadium provides 336 wheelchair bays of which 64 are located in three covered wheelchair terraces and all are managed by match day stewards. 272 bays can also be used for those who require non-wheelchair disabled access and in total, 7000 stadium seats are suitable for non-wheelchair easy access, in the lower tiers of the stadium. The RFU is continually striving to maintain and improve its services and facilities. Further information on tickets for disabled visitors – covering international and non-international matches and parking facilities – is available in the Disabled Ticketing section under the the Tickets link at **www.rfu.com**

Q **I have a car through the Motability scheme and due to the deterioration of my heath, I am finding it difficult to drive. Can I terminate my agreement early?**

A Yes. If there is a valid reason for cancelling your agreement, for example, if your mobility needs have changed and the car is no longer suitable, please contact Motability's Customer Services team on **0845 456 4566**. If you do cancel, there may be an administration fee to cover any costs incurred. Any Advance Payment you have paid may be refunded to you on a pro-rata basis, less any administration fee, where applicable. Please contact Motability as soon as possible to discuss your needs.

Q **I currently receive Incapacity Benefit. Can I remain on that benefit?**

A Unfortunately no. Incapacity Benefit, Severe Disablement Allowance and Income Support paid on illness or disability grounds, are all being phased out. If you are getting one of these benefits, your claim will be reviewed to see if you can get Employment and Support Allowance (ESA) instead. The reassessment programme began in April 2011 and it is expected to be completed by Spring 2014.

Some people are not affected by the changes. For example, you will not be affected if you are due to reach state pension age by 6 April 2014. You do not have to do anything until Jobcentre Plus writes to you. Until then, you will continue to get your current benefit for as long as you continue to satisfy the rules. For more information and advice, please call Ray on the Freephone Advice Line: **0800 980 0501** or you can visit: **www.gov.uk/incapacity-benefit**

Q **I have recently had some items stolen from my Motability car. Can I claim for these items?**

A Personal belongings are not covered under the Motability insurance policy, this includes satellite navigation systems and stereos not fitted as standard. If you wish to cover personal belongings, you will need to arrange your own insurance cover. One option is to extend your household insurance.

For more information, please visit: **www.motability.rsagroup.co.uk** or, call RSA Motability on **0500 37 37 37**

Q **Before my accident, I loved to go bird watching (the feathered kind). Are there any organisations out there that can advise me, now that I am a wheelchair user?**

A Birding For All, formerly known as the Disabled Birders Association, has an excellent website that gives information on their services. This includes access to reserves, facilities and services for birding, along with the details of reserves in England, Wales and abroad. For more information please visit **www.birdingforall.com**

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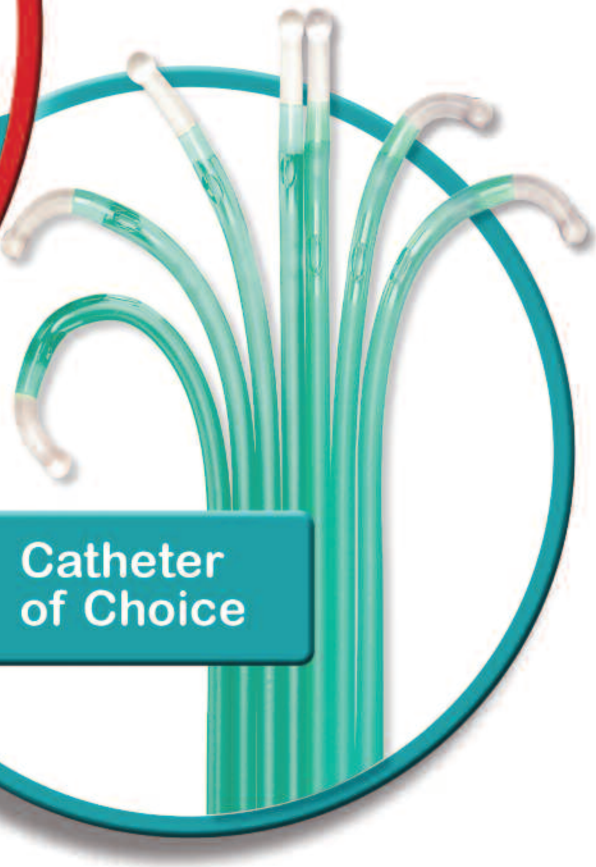

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size 14	IQ 3204.14	PIP 377.1995
size 16	IQ 3204.16	PIP 377.2001
size 18	IQ 3204.18	PIP 377.2019

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helpline@manfred-sauer.co.uk

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Membership and *forward* magazine subscriptions

Over the years, *forward* has become synonymous with membership of SIA and is seen as a major reason for joining. However, asking newly injured people for a membership subscription can, and has been, a barrier to some people joining. Therefore, it has been decided that as from 1 April 2013, membership of SIA will be free. Hopefully, this will encourage more people to join and become involved in the organisation. Benefits of the free membership will include:

- 10% discount on all SIA publications
- Access to advocacy services e.g. Continuing Healthcare and Social Care
- Supporting letters from SIA Advice Line
- Access to New Leaf software
- Access to SIA link scheme
- Solicitors Directory (on request)
- Online Campaigning toolkit
- Discounted rate on all *forward* advertising

SIA's Trustees have also agreed that *forward* should become a subscription-based service with a cost equal to the current level of membership fee, which is currently £20 per annum.

We hope that members will be happy for their annual membership fee to be converted into a subscription for *forward*. The Trustees believe that receiving six copies of forward a year for £20 is good value and members will wish to continue receiving this unique publication which is focussed on issues that matter to people with SCI.

From here on

- Membership of SIA will be free to those individuals who qualify for Full or Associate classes of membership as defined in the Association's Articles of Association – Sections 4 (a) & 4 (c).
- SIA's bi-monthly magazine *forward* will be available on an annual subscription basis to anyone who wishes to receive it. Those who have other forms of membership will continue to receive copies of *forward* magazine under the same terms as their current membership.
- Members who have taken out a fully paid up 'Life membership' of SIA, prior to 1 April 2013, will be deemed to have paid in full for a lifetime subscription to *forward* magazine and will be entitled to receive it, free of charge, for as long as they remain a member of SIA.
- Any individual resident in the UK, becoming a member of SIA as either a Full or Associate member from 1 April 2013, will be entitled to receive a year's subscription to *forward* magazine free of charge should they so wish. At the end of this period, they may elect to continue to receive *forward* magazine by paying the annual subscription fee current at that time.
- Junior members, on becoming 18 years of age (and no longer being eligible to Junior membership) will, when they become a Full member receive a further one year of free subscription to *forward* magazine. At the end of this period, they can continue to receive the magazine by paying the annual subscription fee current at that time.
- Members who are fully paid up prior to 1 April 2013 will continue to receive copies of *forward* without further charge until the due renewal date of their membership. On that date, they will remain a member of SIA, in the same class of membership, but shall only be entitled to receive further copies of *forward* on payment of the annual subscription fee current at that time. Prior to their current subscription expiring they will be notified and asked if they wish to continue to subscribe to *forward*.

Full membership shall be open to spinal cord injured people aged 18 or over and resident in the United Kingdom.

Associate membership shall be open to all persons, whether disabled or non-disabled interested in furthering the Objects of the Association.

If you have any questions regarding the changes please contact Paul Smith, via email at p.smith@spinal.co.uk or by post. If you have questions regarding membership and payment for *forward* please contact Catherine Stribling at c.stribling@spinal.co.uk

Gibbs Memorial Fund

SIA's Trustees held the draw for the 10 life memberships provided with funding from the Gibbs Memorial Fund at their meeting held on 16 February 2013. SIA has been in touch with the 10 fortunate individuals who will now receive *forward* free of charge for life. There will be another chance for those who were disappointed to apply at the end of 2013.

JOB ADVERTISEMENTS

COMMUNITY PEER SUPPORT OFFICER (PSO) – SOUTHERN REGION

Due to internal promotion, SIA is seeking to appoint a Peer Support Officer to join its Outreach Services team specifically to provide support within the Southern region.

The role of the PSO, who must be spinal cord injured, is to address the needs of newly injured people not receiving treatment in a specialist Spinal Injuries Centre. The postholder will build relationships with key staff at SCI Centres, District General Hospitals and other non-specialist centres in order to identify, and offer support to, SCI individuals and their families living within the specified region. In addition, they will deliver in-service training to relevant healthcare professionals about SIA and its services, and take an active part in the organisation and delivery of SIA Study Days held in the region. As the PSO will be required to cover a specific geographic region, a willingness to travel is essential. The post is part-time (28 hours per week) and includes visits to SIA House in Milton Keynes when required.

The post is offered on a three year fixed-term contract (with the possibility of renewal) and carries a salary of £24,027 per annum (pro rata) plus pension scheme and 28 days annual leave (pro rata).

For a job application pack please visit the Vacancies page of the SIA website www.spinal.co.uk or email c.pinches@spinal.co.uk. Closing date for completed applications is 26 April 2013 with interviews taking place on 8 May in Milton Keynes

sia
spinal injuries association

SIA Survey on Future Strategy

Many thanks to all those who participated in our recent survey, asking for comments on our proposed three-year strategy. We had an excellent response and will be publishing the results of the survey in the next issue. Meanwhile, we'd like to send our appreciation to all those who responded with their views, and congratulate the winner of our prize draw for those who completed the survey, who is now the proud owner of a Kindle Fire.

Continence product adviser(s)

MANFRED SAUER UK
Continence Products

required for Central/Southern England (part-time)

MANFRED SAUER UK began in 1995 and their product portfolio has since grown to be the most extensive and diverse in the UK. Most products are manufactured at our German headquarters in Lobbach, where quality standards are exceptional. Profits from our products help support the Manfred Sauer Foundation – a not-for-profit organisation which aims to guide both disabled and non-disabled people towards a healthier lifestyle through physical wellness and creativity.

We are looking for someone who

- is self-motivated, conscientious, has good listening skills and is comfortable talking about urology products – sharing their own experiences as well as others
- can communicate with both healthcare professionals and product users
- is happy to go into hospitals and spinal centres
- is computer literate and can produce written reports
- has their own transport and can attend study days where required
- is willing to have occasional overnight stays away from home

Experience is not necessary as training will be provided. Life experience is essential. There is flexibility within the role to allow a limited number of hours work per week so any benefits are not affected. There is also potential for the post(s) to become full-time as the company grows.

Send your CV with a letter supporting your application to: Mr Barry Kaighin, Managing Director, Manfred Sauer UK Ltd, Unit 3, i.o Centre, Lodge Farm, Barn Way, Northampton NN5 7UW. Closing date for applications is 30 April 2013

sia ACADEMY
promoting excellence • raising awareness

Welcome to the new Academy training year!

We are pleased to launch our Master Class and Your Voice training programme for 2013/14, and hope there is something there that will be of interest to you

All confirmed dates and venues are now on the SIA website **www.spinal.co.uk/page/mclasses** so check what's available and sign up – you can book online too. We also have a new Academy brochure with information on the courses we offer for SCI people, healthcare professionals and members of the legal profession. You can download a copy from our website, or contact Karen Mikalsen if you would prefer a hard copy.

We are holding Master Classes in:

- Housing
- Funding and managing your care needs
- Becoming a parent after spinal cord injury
- Options: Life and work after spinal cord injury
- Making a claim under the Equality Act
- Choosing your wheelchair

We will be rolling-out Options and Choosing your wheelchair to more centres than before thanks to the popularity of the trial sessions. We are also taking the Making a claim under the Equality Act Master Class on the road to Southport and Oswestry, in response to requests from members. We are working to refresh the Your Voice advocacy course, responding to feedback from attendees and members. We hope to re-launch it in the autumn. If you have attended Your Voice and have any comments on how we can update or improve the content then please let us know.

And it doesn't end there! There are currently two new Master Classes in development. We are working in partnership with Motability and the Forum of Mobility Centres to develop a course on motoring and mobility, and the other course under development will look at ageing with a spinal cord injury.

Coming up in April & May 2013

Becoming a parent after spinal cord injury
Southport SCIC 10 April 2013
Salisbury SCIC 18 May 2013

Choosing your wheelchair
Middlesbrough SCIC 15 May 2013

Funding and managing your care needs
Stoke Mandeville NSIC
6 & 13 April 2013
SIA House 9 & 16 May 2013
Sheffield SCIC 14 & 21 May 2013

Housing
SIA House 17 April 2013
Oswestry SCIC 11 May 2013

Do keep checking our website for details, or contact Karen if you would like to be provided with more information.
The majority of the courses, all of which are CPD-accredited for professionals, are delivered by spinal cord injured trainers and are FREE to attend. Corporate delegates are subject to a fee – contact Karen for more details.

For more information
please contact Karen Mikalsen at
k.mikalsen@spinal.co.uk
or on **0845 678 6633 x221**

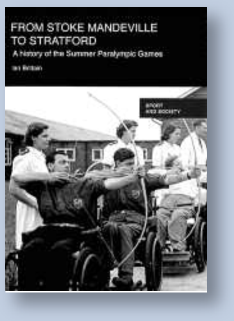
SIA Library

SIA's National Library on Spinal Cord Injury houses a unique collection of publications and periodicals on all aspects of spinal cord injury, as well as on wider disability issues, and, of course, our own publications. The library is based at SIA House in Milton Keynes, and our catalogue is available online at **www.spinal.co.uk/page/SIA-library**. If you have any queries on anything held in the collection, or see any publications that you think would be useful additions to stock, please let us know.
An increasing number of publications are being added in electronic format, and if this is the case you will be able to access them from your own PC.

The library, which is open from Monday to Friday, 10am to 4pm, is a reference only collection, but anyone is welcome to visit. It is particularly useful to spinal cord injured people and their families, health, social care and legal professionals, and anyone with an interest in finding out more about SCI. The library area is fully accessible and there are PC workstations (with internet access), study areas (including private bookable rooms) and (for a small charge) photocopying facilities.

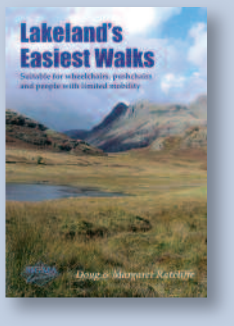
If you would like more information on any of the library services please contact us at **library@spinal.co.uk** or on **0845 678 6633 ext 221**

Recent additions to the library include:



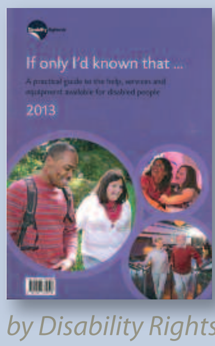
From Stoke Mandeville to Stratford: A history of the Summer Paralympic Games
by Ian Brittain; Published by Common Ground Publishing; 2012 (ISBN 9781863359870)

This book, the culmination of 12 years of research, documents the history of the summer Paralympic Games and presents it in an accessible and easy-to-read way. The author has brought together all of the facts, figures and interesting stories that have occurred in the development of the summer Games from their roots at Stoke Mandeville Hospital to the global event they have become today. This book is the first publication to include images of posters, winners' medals, and other artefacts connected with the Games, some of which have never been seen in print.



Lakeland's Easiest Walks: Suitable for wheelchairs, pushchairs and people with limited mobility
by Doug & Margaret Ratcliffe; Published by Sigma Leisure; 2009 (ISBN 9781850588481)

Written by a wheelchair user, this guide details selected walks in the Lakeland area with wheelchair accessible paths. All of the walks (there are 36 in all) have been tested in a standard powered wheelchair and there is information, points of interest and maps and photographs for each one.



If only I'd known that a year ago… 2013: a practical guide to the help, services and equipment available for disabled people
by Disability Rights UK; Published by Disability Rights Enterprises; 2013 (ISBN 9781903335598)

An introduction to the services and facilities which can help people dealing with unexpected ill-health, injury or disability to lead as independent a lifestyle as possible. This book, which is updated annually, signposts readers to support and information on areas such as housing, benefits, social care, education, employment, equipment, holidays and leisure, relationships, transport and motoring.

Benefit Rates from
April 2013 – March 2014

NON MEANS TESTED BENEFITS	Old Rate 2012/13	New Rate 2013/14
Attendance Allowance		
Lower Rate	51.85	53.00
Higher Rate	77.45	79.15
Carer's Allowance	58.45	59.75
Child Benefit		
Only/eldest child	20.30	20.30
Other children	13.40	13.40
		(See below)
Disability Living Allowance		
Care Component		
(Lower Rate)	20.55	21.00
(Middle Rate)	51.85	53.00
(Higher Rate)	77.45	79.15
Mobility Component		
(Lower rate)	20.55	21.00
(Higher rate)	54.05	55.25
Employment & Support Allowance		
Personal Allowances		
under 25	56.25	56.80
25 or over	71.00	71.70
Incapacity Benefit		
Long term	99.15	101.35
Short term (lower rate)	74.80	76.45
Short term (higher rate)	88.55	90.50
Industrial Injuries Disablement Pension (100%)	158.10	161.60
Statutory Maternity Pay		
Standard rate	135.45	136.78
Retirement Pension	107.45	110.15
Severe Disablement Allowance		
Basic rate	69.00	71.80
Statutory Sick Pay		
Standard rate	85.85	86.70
Earnings threshold	107.00	109.00

MEANS TESTED BENEFITS	Old Rate 2012/13	New Rate 2013/14
Income Support Personal Allowance		
18-24	56.25	56.80
25 or over	71.00	71.70
Couple (under 18 responsible for a child)	84.95	85.80
both aged 18 or over	111.45	112.55
Premiums		
Family	17.40	17.40
Enhanced Disability Premium		
Single rate	14.80	15.15
Disabled child rate	22.89	23.45
Couple rate	21.30	21.75
Disability Premium		
Single rate	30.35	31.00
Couple rate	43.25	44.20
Severe Disability		
Single, one qualifies	58.20	59.50
Couple, both qualify (higher rate)	116.40	119.00
Disabled child	56.63	57.89
Pensioner		
Couple rate	106.45	109.50
Carer	32.60	33.30
Permitted work earnings limit		
Higher	97.50	99.50
Lower	20.00	20.00
Carer's Allowance earnings limit	100.00	100.00

Changes to Child Benefit

A new income tax charge has been introduced, since January 2013, and will apply to those taxpayers affected by the Government's measures to reduce or remove the financial benefit of receiving Child Benefit. The charge will be applied to taxpayers whose income exceeds £50,000 in a tax year and who are in receipt of Child Benefit and to taxpayers whose income exceeds £50,000 and whose partner is in receipt of Child Benefit. In the event that both partners have an income that exceeds £50,000, the charge will apply only to the partner with the higher income.

For taxpayers with income between £50,000 and £60,000, the amount of the charge will be a proportion of the Child Benefit received. For taxpayers with income above £60,000, the amount of the charge will equal the amount of Child Benefit received. The amount of Child Benefit payable will be unaffected by the new tax charge, earned income will be taxed.

A career in rehabilitation medicine

By Kanchana Devinuwara, Dan Burden, Rory J O'Connor

Rory J O'Connor and colleagues outline the purpose and the pathway of a career in rehabilitation medicine

Rehabilitation medicine entails the treatment of disabling conditions, active management of disability, and prevention of secondary complications. Doctors in rehabilitation medicine deliver the medical management of people with complex disabilities. Although the patients are predominately adults of working age, doctors in rehabilitation medicine may also work with children and older adults.

What is rehabilitation medicine?

Rehabilitation medicine consists of four main clinical areas: neurological, musculoskeletal, amputee, and rehabilitation following spinal cord injury.

Neurological rehabilitation entails working with people who are recovering from acute brain injury, including stroke. Services are also provided to people with long term neurological conditions such as multiple sclerosis and cerebral palsy, generally as outpatients within community settings.

Musculoskeletal rehabilitation is closest to rehabilitation medicine's origins in physical medicine. This area covers the medical management and rehabilitation of disabling rheumatological conditions such as the arthritis, chronic soft tissue injuries, and back pain.

Amputee rehabilitation is focused mainly on outpatient care, although an important role is pre-amputation counselling, which includes inpatient assessment. Many doctors working in this branch of the specialty also provide medical input to orthotics clinics, wheelchair centres, and other services providing technological solutions.

In recent years much has changed in the management of spinal cord injury, with developments in spinal cord regeneration, advances in helping patients to walk again, and the key part that spinal cord injury centres play in bringing expertise and specialist management to patients coming to the major trauma centres. Doctors who work in one of the 12 spinal cord injury centres in the United Kingdom and Ireland are involved in the acute management, rehabilitation, and lifelong care of people affected by spinal cord injury.

Why choose a career in rehabilitation medicine?

Rehabilitation medicine is a bright, exciting specialty especially suited to doctors who want to work with a team to develop creative and innovative solutions to their patients' problems. Doctors working in rehabilitation medicine need a wide range of competencies to provide holistic and lifelong care to their patients.

The core clinical skills of making a diagnosis, formulating a prognosis, and providing expert medical care – common to all specialties – are important in rehabilitation medicine. However, the diagnosis of a spinal cord injury, for example, may be made in the context of multiple traumatic injuries, and in an older person after a fall, as part of a complicated presentation. Furthermore, the prognosis is given to a frightened patient at a time that their life is changing, sometimes irreversibly.

Doctors in rehabilitation medicine also provide information, support, and counselling for patients and their families and carers. This service will include functional and prognostic information as well as information about vocational rehabilitation or return to work. Combining these skills with the specialised medical interventions that you can provide, and an ability to lead the multidisciplinary team in challenging situations, make rehabilitation medicine

>

Advantages and disadvantages

Advantages

- **Knowing you can make a real and practical difference to the quality of life of your patients**
- **Working with active and knowledgeable patients and their families**
- **Wide range of clinical work, from acute rehabilitation to elective and outpatient rehabilitation**

Disadvantages

- **Patients and their families come with high, sometimes unrealistic, expectations**
- **In some areas, rehabilitation medicine has a low profile**
- **Advanced training in certain competencies is not available in all deaneries**

> a tremendously satisfying career.

Career path

Training in rehabilitation medicine takes four years and starts at specialty training year 3 (ST3) after core training in medicine, acute care, surgery, psychiatry, or general practice. Specialty trainees work in each of the four main clinical areas in rehabilitation medicine before developing advanced competencies in one, leading to a certificate of completion of training in the specialty. Academic clinical fellow and clinical lecturer posts are available in programmes with links to academic rehabilitation medicine.

Rehabilitation medicine has difficulty recruiting suitable trainees at ST3 level: in 2011 the fill rate was only 55%. As a result the Royal College of Physicians describes the competition ratio for ST3 posts as 'particularly favourable'. Roughly 20 training places will be available in the next round of national recruitment, which is coordinated centrally by the Royal College of Physicians. Applicants must have the same experience and qualifications as any other applicant for an ST3 post; however, the advantage for applicants to training posts in rehabilitation medicine is that membership of the Royal College of Physicians, Royal College of Surgeons, Royal College of Psychiatrists, and Royal College of General Practitioners are all acceptable entry qualifications.

Trainees are expected to develop advanced competencies in one of the four main clinical areas of rehabilitation medicine and will spend most of their training in one of these areas. There are ample opportunities to develop these competencies but not all deaneries offer advanced training in every clinical area, so talk to the director of the training programme in the deanery in which you would prefer to work.

There is an excellent balance between training posts and consultant posts in rehabilitation medicine, so career opportunities for dynamic, proactive doctors are good. As of April 2011, there were 159 (134 whole time equivalent) consultants in rehabilitation medicine employed in England. The consultant workforce in rehabilitation medicine has expanded by 4.2% in the past five years and is expected to increase by 4.6% a year to about 170 full time equivalent posts in 2020 (around 180 head count).

Consultants in rehabilitation medicine provide rehabilitation to critically ill and injured people by working in general hospitals alongside the acute medical and surgical teams. They also work in post-acute rehabilitation units to facilitate patients' recovery and safe discharge. These posts have on-call commitments, particularly those attached to major trauma centres, where there is an expectation that rehabilitation prescriptions are completed rapidly once a patient is stabilised. Often these roles include outpatient and community rehabilitation – managing people with long-term conditions in their own environments.

Consultants in rehabilitation medicine have the knowledge and skills to confirm medical and functional diagnoses and

Day in the life of a specialty trainee in spinal cord injury rehabilitation

9 am—ward round

The day starts with a ward round and I see two new admissions from the day before. The first patient has T12 incomplete paraplegia after a fall and her family are understandably anxious about her prognosis and the length of the rehabilitation process. The second new patient is a middle-aged man with central cord syndrome caused by a car crash. I continue with the ward round and arrange an x-ray examination of a patient with suspected heterotopic ossification causing pain and reduced range of movement at her elbow.

12 noon – protected meal time for patients

I do some administrative work before going to the lunchtime radiology meeting.

1 30 pm – clinic

The first patient I see in clinic has cauda equina syndrome and was discharged two months ago from the regional neurosurgery unit. She was seen by me as a new patient when she was struggling with faecal incontinence. We initiated an anal irrigation system and clean intermittent self-catheterisation. At follow-up today she tells me she has returned to work.

My last patient of the day has been paraplegic for nearly 30 years. It reminds me that before spinal cord injury centres existed, people with spinal injuries had a life expectancy of less than a year.

I do my dictation and finish the clinic at 5 pm.

prognoses, prevent and treat secondary and tertiary complications, manage symptoms, facilitate treatment, and contribute to life decisions. In addition, consultants lead and coordinate the activities of the multidisciplinary rehabilitation team.

Patient's view – why specialist doctors in spinal cord injury units are so important (Dan Burden)

For those people with spinal cord injury who never make it to a spinal cord injury centre, the outlook can be bleak. While many people with spinal cord injury will find themselves under the care of specialist doctors in the UK's spinal cord injury centre service, a substantial minority will find themselves rehabilitating in a non-specialist district general hospital. The prospects for these patients are considerably worse than for those who have been under the care of a specialist in a spinal cord injury centre.

The contrast between the experiences of these patients and my own is considerable. I was one of the lucky ones. From the moment I was admitted to the spinal cord injury centre my consultant was the "conductor" of my care. As the head of a multidisciplinary team, he ensured that my fractured spine was stabilised, the most suitable regimen was found for my bowel and bladder management, my spasticity was controlled, and that I was sufficiently educated to understand the implications of my injury and how I could live independently despite my impairment.

Little over a year after being discharged I got myself a job. Ten years on, I have been employed continuously with no serious health complications. I am fully independent and mobile, and I have the positive outlook on life that is shared by many of the people I know with spinal cord injuries who were also rehabilitated under a specialist doctor. I still see my consultant every 18 months for what people with spinal cord injury refer to as an 'MOT'. He knows my name, my lifestyle, what problems I have faced since I fractured my spine, and what problems I may face in the future, and it is through this ongoing care that I can live an active, daily life with little thought to my spinal cord injury.

Conclusions

Rehabilitation medicine has a promising future. As a result of the national stroke strategy and the more recent trauma network initiative, clinical services in rehabilitation medicine are expanding across the United Kingdom. Advances in restorative rehabilitation technology are promoting research opportunities and shaping how rehabilitation is delivered.

If you want a career that is challenging and rewarding, arrange a taster day at one of the rehabilitation centres around the United Kingdom to experience the passion that doctors in this field have for the specialty.

For further information contact
Spinal Injuries Association
www.spinal.co.uk
British Association of Spinal Cord Injury Specialists www.bascis.co.uk
Training in rehabilitation medicine
www.jrcptb.org.uk

This article was first published in the British Medical Journal *on 4 January 2013 to encourage more medical students into a career in Spinal Cord Injury medicine*

Public Affairs Blog

The Public Affairs team have launched their very own blog. The blog will hear from all members of the team on a regular basis and provide an insight into their work. The blog will feature news and comments on disability current affairs.

So far there have been two instalments of the blog by Mick Hutchins and Catherine Stribling. You can read the blog on the campaigning pages of the SIA website.

Sign up to campaigning news!

Want to know what the Public Affairs team are up to? Want to know more about the latest campaigning work?

Our bi-monthly campaigning email provides up to date information on the work of the Public Affairs team and all of our campaigning activity.

If you would like to receive this information email your contact details to cfc@spinal.co.uk

Do you live in Manchester or Cornwall?

Following on from the survey produced as part of our work with Back Up and ASPIRE we are now looking for people living in Manchester and Cornwall to take part in focus groups in the spring. The groups will ask people to discuss their experiences of using health services in these areas.

If you would like to take part in these discussion groups please contact Catherine Stribling on cfc@spinal.co.uk or 0845 678 66 33

Public Affairs Diary (Feb & March 2013)

The Public Affairs Team share their meeting diary for the past two months

- Clinical Reference Group on SCI
- Clinical Reference Quality Group
- Neurological Commissioning Support
- PIP Independent Stakeholders Forum
- APPG on SCI
- ILF Transition Consultation Event – London
- APPDG Seminar – Transport & Disabled People – Westminster
- Fulfilling Potential Disability Strategy Stakeholders Group – DWP

The Stoke Mandeville Experience

This exciting new event is for all corporate supporters of SIA and requires you to get together a team of keen staff to participate in five Paralympic wheelchair sports. Don't worry – we'll provide the chairs!

To be held at Stoke Mandeville Stadium on 30 May, in partnership with WheelPower, the Stoke Mandeville Experience enables company teams to try five sporting activities: Wheelchair Basketball, Wheelchair Rugby, Wheelchair Tennis, Hand-cycling, Archery or Powerlifting, and to compete against other teams undertaking the same challenge.

Ray Cross, SIA's Advice Line Officer, is a past GB Paralympian athlete. He competed in the 1980 and 1984 Games in Wheelchair Basketball. Ray says the equipment has evolved significantly over the years. Today, the chairs are lightweight and designed to protect and move fast.

All monies raised in this challenge will help to continue to provide services to SCI people and their families.

For more details please call Elizabeth Wright **0845 678 6633 ext 229**, visit the SIA website or email **fundraising@spinal.co.uk**

Spinal Cord Injury Awareness Day – 17 May

What's going on?

Each year Spinal Injuries Together (SIT) charities come together for one day in May to help raise awareness of SCI. As always there is a host of awareness raising activities that you can join us in.

The Great British Fish and Chip Supper

Why not get together with friends and family to hold a Great British Fish and Chip supper whilst raising money for SIA? It is a great opportunity to have a night off from cooking.

If you would like to host your own dinner you can find a helpful starter kit and a fundraising pack on our website.

Charity Raceday at Newbury

Scope and SIA are both delighted to be the beneficiaries of a Raceday at Newbury Racecourse. The day will begin with a reception followed by lunch and an auction, and this will be followed by an afternoon of exhilarating horse racing.

All monies raised will help SIA to continue to provide support and information to SCI people and their families.

For more information on how to get involved in The Great British Fish and Chip Supper please visit **www.siafishandchips.co.uk** or email **fundraising@spinal.co.uk**. **For more information** on the Newbury Raceday please visit **www.spinal.co.uk**

Forthcoming events

21 April	Virgin London Marathon
30 April	Case Managers Training Day, Manchester
1 May	Ascot Charity Race Day
12 May	An Ace Day Out – Motorcycle ride-out
17 May	Great Fish and Chip Supper /Newbury Raceday
27 May	BUPA London 10k
30 May	Stoke Mandeville Experience
6 June	Statutory Provision of Care Course, Birmingham
6 June	Women in Spinal Cord Injury Awards
8-9 June	Nightrider, London
27 June	Case Managers Training Day, Bristol
30 June	Salisbury Race Day

To find out more about any of these events visit **www.spinal.co.uk** or call **0845 678 6633 ext 2**

An Ace Day Out Motorcyle Challenge

SIA is delighted to announce that Talan will be attending this year's An Ace Day Out Motorcycle Challenge to help us celebrate the lead up to Spinal Cord Injuries Awareness Day. An Ace Day Out takes place on Sunday 12 May 2013.

Setting off from SIA House to the famous Ace Café in NW London, a place where 'petrol heads' share their passion for motorcycles, cars and rock 'n' roll, a challenge will be set for non-disabled people to experience paraplegic riding. Each rider will have four volunteers to help launch and stop them – balance is key, no touch down! All monies raised will help SIA to continue to provide support and information to SCI people and their families.

For more details please visit the website or email **fundraising@spinal.co.uk**

You can view a video on YouTube of Talan showing everyone how it is done called: **Mike Spike Edwards finds out more about The Bike Experience Charity**

SIA member Talan Skeels-Piggins is a former Royal Navy fighter controller and Winter Paralympian (Vancouver 2010). After he was paralysed from the chest down following a motorcycle accident in March 2003, he became a founding member of The Bike Experience, a charity established in 2011 to help motorcycle riders who are paraplegic to ride again. This service is free for participants.

The Bike Experience instructors, operating on airfields and racing circuits, have created a progressive, step-by-step schedule which allows a disabled rider to enjoy the freedom and pleasure of getting back on a motorcycle. Whether it is only one visit, or the desire to become a regular track-day participant at UK circuits, the riders have a life-changing experience. Andy Trollope, a paraplegic who has attended three events, says:

"I never thought after my accident I would ever feel the adrenaline rush of being able to ride again, but The Bike Experience definitely proved me wrong!"

Thank you MASS

Craig Budsworth, Chairman of Motor Accident Solicitors Society (MASS) presents Kate Gelder SIA's Corporate Partnership Manager with a cheque for £12,415. The funds were raised by a voluntary contribution from members and from a charity golf day which was held at the Welcome Hotel in Stratford in June.

There are two easy ways to support SIA

Raise money when you search the web

When you search the internet and use easysearch, half a penny is donated to SIA for every search you make! **Go to www.easysearch.org.uk**

Do you shop online?

Every time you buy something you could be raising money for SIA! It doesn't cost you anything – just shop online using easyfundraising to reach popular favourite retailers. There are over 2000 including:

- **Amazon**
- **M&S**
- **Boden**
- **Waitrose**
- **House of Fraser**
- **Vodafone**
- **Virgin Atlantic**

and many more…

It works like Nectar but instead of earning points, each purchase generates a donation.

So whatever you need to buy, from your weekly grocery shop or fashion must-have, to your business travel, office supplies or mobile phone, buy it via easyfundraising and raise money for SIA at no extra cost to you! **You can register at www.easyfundraising. org.uk/causes/sia**

Mark Harding climbing Skiddaw

Help for a HERO

Spinal injuries happen in many ways. For Mark Harding, a retired Lance Corporal with the Duke of Lancaster's Regiment, it was a sniper's bullet.

Mark was shot whilst defending colleagues during a patrol in Afghanistan in 2010, he suffered serious injuries to his spinal cord which left him paralysed for many months. With hard work and excellent treatment at the Golden Jubilee Spinal Centre and Defence Medical Rehabilitation Unit at Headley Court, Mark has learned to walk again, but does still require a wheelchair and crutches. Mark has also been left with constant severe nerve pain and numbness, particularly in his right leg.

Mark, who served in Bosnia, Kosovo, Northern Ireland and Iraq, was introduced to the sport of kayaking. Long term Mark hopes to represent Team GB in 200m sprint kayaking at the 2016 Paralympic Games in Rio. He has climbed 3,054 ft up Skiddaw Mountain to raise funds. His next projects are a parachute jump and an abseil.

Mark was been helped along the way by his *Bioness* L300 Plus. Like many people with an incomplete spinal cord injury, Mark has foot drop and hip and knee weakness. His foot drags and his knee snaps backwards whilst walking. The device stimulates his nerves to help the muscles contract at the right time – firstly when the foot is off the ground to clear his toes; then when he is standing on the weak leg to stabilise the knee. A walking sensor, wireless remote control and easy-to-apply cuff make the *Bioness* so simple to use. There is also the H200, which helps people with upper limb weakness to open and close their hands around objects, for functional use.

> *"The Bioness gives me freedom. It means I can be normal"*

Mark was introduced to the *Bioness* device at Headley Court. Back then his goal was to be able to walk his dog. His first walk with the *Bioness* surpassed his expectations. "I felt trapped without the *Bioness*, like not having a car", explained Mark. "The *Bioness* gives me freedom. It means I can be normal."

A soldier's motto is 'to be the best'. Mark lives by this and 'because life needn't stop when you're paralysed', Mark continues to go onwards and upwards.

Matthew Dale
Bioness Clinical Specialist
UK & Ireland
www.bioness.com

Film review

Sexuality and relationships are topics *forward* will be discussing in an edition later this year. A recent film *The Sessions* and Madam Becky Adams' announcement of a proposed 'sexual health centre' to be located in Milton Keynes ignites discussion.

The movie *The Sessions*, which reached our British screens in January this year, re-opened the discussion of sex, sexuality and relationships amongst the disabled community. The story line is based on the true life story of the Berkeley-based California journalist and poet, Mark O'Brian. He contracted polio as a child and, apart from a few hours each day when he could be wheeled around on a trolley bed, was confined to living in an iron lung. At the age of 38 he was acutely aware he had had no intimate sexual experience with any woman and embarked on a venture to lose his virginity.

Seeking support from his priest, changing his carers to ones more sympathetic of his emotions and with support from a wheelchair using female friend, he employed a sexual therapist to help him with his quest. The therapist was Cheryl Cohen-Green. She prescribed six sessions, giving rise to the title of the film, in which Mark explores his sexuality.

The movie covers many of the challenges that someone with a severe mobility impairment may encounter when wanting to explore their sexuality.

It also highlights the challenges Mark had in finding considerate carer support, the search for an appropriate location where he and the therapist could be together uninterrupted, the initial embarrassment he felt as he encountered a naked woman for the first time, and, the misunderstanding that arose as O'Brian developed a deeper level of feeling towards his therapist.

He later went on to meet Susan Fernback, a hospital volunteer, who became his companion and literary collaborator until he died at the age of 49. All the while he remained friends with Cheryl after his 'sessions' concluded.

Several reviews written about this movie described it as a sensitive portrayal of the problems Mark faced. It is not out of touch with those some disabled people face today in their quest to explore their sexuality. A few comments describe the movie as bawdy.

This movie reached our big screens just as Madam Becky Adams announced she would like to open a sexual health centre in Milton Keynes in 2014. Already operating under a temporary website, Para-Doxies, named after an old English name for prostitute, she announced she would like to grow the services already offered under this name and build an accessible centre available to disabled and terminally ill people. It will operate on a 'not for profit' basis. It is subject to planning permission and funding.

The newspapers had a field day following this news. Breakfast TV and radio interviews followed. 'Vulnerable people are being put at risk,' were the sentiments of some. 'Disabled people have the same rights to sexual services as non-disabled individuals,' were the feelings of others.

We will be discussing the issue of sexuality and relationships in the August edition of *forward* and would welcome your contributions. How have you found love, through an internet dating agency perhaps? If so, did you reveal that you were disabled at the outset or wait to get the measure of the other person first? Do you have experience of mainstream or specialist dating agencies you would be willing to share? What are your thoughts on the possible opening of such a 'sexual health' centre for the disabled community? Anonymity will be given to any contributors on request.
Christa Dyson C4 incomplete


Helen Hunt and John Hawkes in *The Sessions*

Pressure sores two cautionary tales

Simon's story

The article about pressure ulcers in June 2012 of *forward* was of particular interest on account of my son, Simon aged 49. He sustained a C6/7 complete injury in 2007.

Simon is also autistic but keen for me to contribute so long as nobody wants to ask him questions! He is a member of SIA.

Last week he was allowed out of bed for 30 minutes in his wheelchair after being bedbound totally for two years, three months and two days. He is keen to know if that is a record?

There is still a long way to go with two enormous pressure ulcers.... one on his back and an even more serious one in the sacrum/scrotum area very near the bone.

Hospital negligence

Problems started four years ago with a fractured left femur. Surgery to pin this at Scarborough Hospital resulted in an MRSA infection. There were other cases and a ward was closed. We now know that further surgery, when we were assured all infected bone had been removed, also failed. Within six months an abscess developed on the site. When it burst he was returned for urgent treatment. Unfortunately, the orthopaedic consultant failed to heed the A & E consultant's recommendation for urgency. Indeed, he is the only doctor we have met at Scarborough with any knowledge of SCI. As a result of the orthopaedic team's failure to act for five weeks, osteomyelitis, gangrene & septicaemia set in. Repeated requests that they contact Pinderfields SCI Centre were ignored until it was almost too late. When a transfer was finally agreed Simon was close to death. Finally a blood clot developed near the femoral artery and the only option was an unusually high amputation of his left leg.

As someone with autism Simon has always had an unusually high pain threshold. His SCI Consultant thinks this probably saved him. He repeatedly says that 98% of his patients would have died and has told us it was the most challenging surgery in the course of a 38-year surgical career. Staff at Pinderfields have been wonderful.

After surgery Simon was very emaciated and only able to accept small amounts of food. Peg feeding became essential. He returned home for a few months until he was thought strong enough to cope with skin grafts, including plastic surgery. This only resulted in a 20% improvement. Further surgery was ruled out. In August of last year he transferred to a nursing home in York which was able to provide the skilled nursing required and where the food is appetising and nutritious. Simon worked in York for many years prior to his accident so former colleagues visit and he feels nearer home too.

> *"As a family we have been helped so much by the SIA workshops"*

His back ulcer is now 65% healed. His sacral ulcer is less deep and healing round the edges. Hence the decision to allow him out of bed, initially for 30 minutes a day from the end of this month when his powered wheelchair and Roho cushion will be ready. Psychologically it would have been harmful to keep him in bed until his ulcers are healed completely but the situation will be monitored carefully and staff from Pinderfields visit to advise and check on progress with community personnel.

As a family we have been helped so much by the SIA workshops, initially with Jackie Bailey and then Brian O'Shea's Master Class where I also met Jonathan Fogerty. The initial education sessions at Pinderfields were also invaluable. We still have a long way to go until healing is complete. However, Simon has hope now that things are going in the right direction and that he will be able to return home eventually.

Unfortunately, autism precludes him ever being able to explain and press his own vital medical needs. His three siblings live far away. They maintain close contact by phone, and visit at weekends whenever they can, but are unable to do so mid-week. In view of our own advancing years we envisage Simon needing someone in the North Yorks area who might eventually be willing and able to take on the role of advocate for him.

Finally, on the District General Hospital issue, even the complaints procedure failed!
At least our MP sorted that out for me and Scarborough eventually apologised for their failure to contact Pinderfields.

Appropriate prevention with pressure sores could save the NHS a considerable sum of money. At least that should concentrate minds!

Sheila Wright

A sore story May 2011 to February 2013

Edward's story

Edward has been in a wheelchair now for 45 years after a car accident when he was 23. His injury is at T4/5 and, apart from being paraplegic, the occasional bladder infections and catheter problems, Edward has been healthy for most of that time.


Jill and Edward

As he reached his sixties Edward started to get heavier and as a consequence decided that it would be a good idea to start trying to lose some excess pounds. He slowly and sensibly lost two stone over a couple of years and felt the benefit of not having to lift the extra weight. But then came that awful day in May 2011 when I noticed, on helping him dress, that there was 'something' on his bottom. It looked like a bit of a sore. It looked as though the fat on his bottom had gone with the decrease in weight, and the pressure relieving gel-topped cushion had failed to do its job.

We called the District Nurse to have a look and she suggested keeping off it as much as possible for a week or so, which might help it heal. Unfortunately, the sore rapidly got bigger as it had been forming under the skin before it broke through. On 21 June 2011 it was decided to take a swab to see if there was an infection present but it came back negative.

A last resort

The pressure ulcer just seemed to get worse. After a few weeks of being very careful and not sitting in one position for too long, Edward and the nurse agreed it would be best if he reduced his time out of bed to about two hours a day. By 13 July 2011 he was on complete bed rest.

The nurses and I got into a routine with dressings being changed every day. In September 2011 the Tissue Viability Nurse suggested they try the Venturi Topical Negative Pressure Therapy, (TNP). This sucks away at the wound to keep the exudate away from the wound and surrounding skin. The TNP seemed to make a slight difference in just a couple of days. However,it was taken off until the sore could be checked by a Urologist, in case it was tracking into 'unknown territory'.

It wasn't until the end of October 2011 that the TNP was put on again but, by early January 2012, it was decided the skin needed a break from all the adhesive dressings required. During this time Edward was not even allowed out of bed for the sheets to be changed so I had to change them with him rolling back and forth. They needed changing almost daily which was hard.

It was January 2012, 8 months after first noticing the sore, when the Tissue Viability Nurse first came to see the wound. Her suggestions for different treatments were carried out, but she didn't return to review the situation when she intended to, due to pressure of work. She didn't come back until July 2012. Negative Pressure Therapy was started after the Tissue Viability Nurse's visit but Edward's skin reacted badly to the tubing used with red weals from the tubes criss-crossing his skin.

We had regular contact with Odstock Spinal Centre through the Spinal Liaison Sister, who was a great support to us. She told us of a Pressure Ulcer Outreach (PUO) team who would visit patients at home to assess the situation and see if plastic surgery was needed. They could come here and look at Edward's sore, general health, home conditions, wheelchair, bed etc. to find the best way of getting a sore healed in the most appropriate way. Unfortunately, we were told, they were only to be called out as a last resort. It later turned out they prefer to be called earlier rather than as a last resort!

The visit of the PUO Team on 11 September 2012 was a memorable day for us. At their request the wound was treated for the MRSA which was discovered to be present. The dressings being used were changed for more absorbent ones, a dietician was recommended, and they offered helpful expert advice to the nurses.

Three more months

The best thing of all for us was that it also gave Edward and me expert help at the end of the phone, or by e-mail, making a huge difference to our morale. As a back-up, in case the sore didn't heal well, an appointment was also made to see the Plastic Surgeon. The PUO Team were present at this appointment and so could tell the full story from a professional, informed point of view.

We at last felt that someone would get this sore healed, and they did. From the eradication of the MRSA to the sore healing over took about three months in all.

Understandably, Edward and I got rather cross about what we saw as the waste of over a year of our lives, just waiting around for the sore to heal with little sign of it doing so. We started asking questions:

- Why wasn't the Tissue Viability Nurse called to see the wound until eight months after finding the sore?
- Why were the Pressure Ulcer Team not called in for 15 months?
- Why didn't anyone seem to want to get Edward **healed** instead of just treating the wound?

There were many more questions, which we asked of anyone who would listen.

Throughout the nearly two years of trying to heal the sore Edward became depressed, had spells in hospital for other aliments caused by the prolonged bed rest, such as low sodium levels from drinking too much liquid, non-epileptic seizures caused by the anxiety of the whole affair, and of course he became weak from lack of exercise and at one time could hardly lift his food to his mouth. Due to having to eat in bed it became necessary for me to cut up his food, and he had to use a spoon to eat. Sitting up to eat caused more anxiety as he was then sitting on the very sore he was meant to be keeping off.

It all got a bit much for us both and we found life very difficult.

From a man who had a 'normal' life before the sore, full of socialising, doing the main household shopping, reading, chatting and going on holiday, Edward became an invalid, stuck in bed day after day, relying on a few friends to visit, and watching daytime TV. He had to give up all his usual activities.

For me, as the chief carer, coping with life from day to day became quite difficult too. I had to do everything for Edward that he had always done for himself. To go out of the house and leave Edward for more than an hour was almost impossible. I therefore became very tired and run down. Had I become ill it would almost certainly have been necessary for Edward to stay in hospital, which would have depressed him further, and we all know the potential risks of a hospital stay. We tried to arrange a respite stay at a local Care Home, but even the effort of trying to arrange this became too much for either of us to cope with and we abandoned the idea. We decided to get someone in to bed bath Edward twice a week and someone to help with the cleaning. This gave me a bit of a break.

Counselling help

Looking back it seems odd that we didn't try to change things earlier but just coping from day to day was all we seemed to be able to manage. Our previously perfectly intelligent selves had become blinkered and we could only cope with one day at a time. We wonder now why we didn't insist on seeing the specialist team earlier. Why didn't we question the treatment with the senior District Nurse when it was obviously not working? Why didn't the GP get involved and ask questions about why we were costing so much with all the dressings and daily nurses visits?

> *"... he became weak from lack of exercise and at one time could hardly lift his food to his mouth"*

Why wasn't a dietician involved, as when she came in October 2012 she said special high protein drinks can make a big difference to healing, and they should have been started much earlier?

Why did we accept 'Wait a bit a longer and see how it goes' so many times? But also, why should we have to think of all these things when just coping with daily life was already so difficult?

When we were at our lowest our GP suggested counselling. Edward especially was quite depressed and neither of us could cope with much more. We contacted SIA for help and in just a few days they put us in touch with their wonderful counsellor, Helen, who spoke to us both on the phone weekly. She gave us ideas on how to cope, such as structuring our days, trying to achieve something each day, inviting more people to visit, chatting to others on the phone, and she suggested that I write this article to help anyone else with similar problems. We carried out all her suggestions and within a week or two we began to cope again.

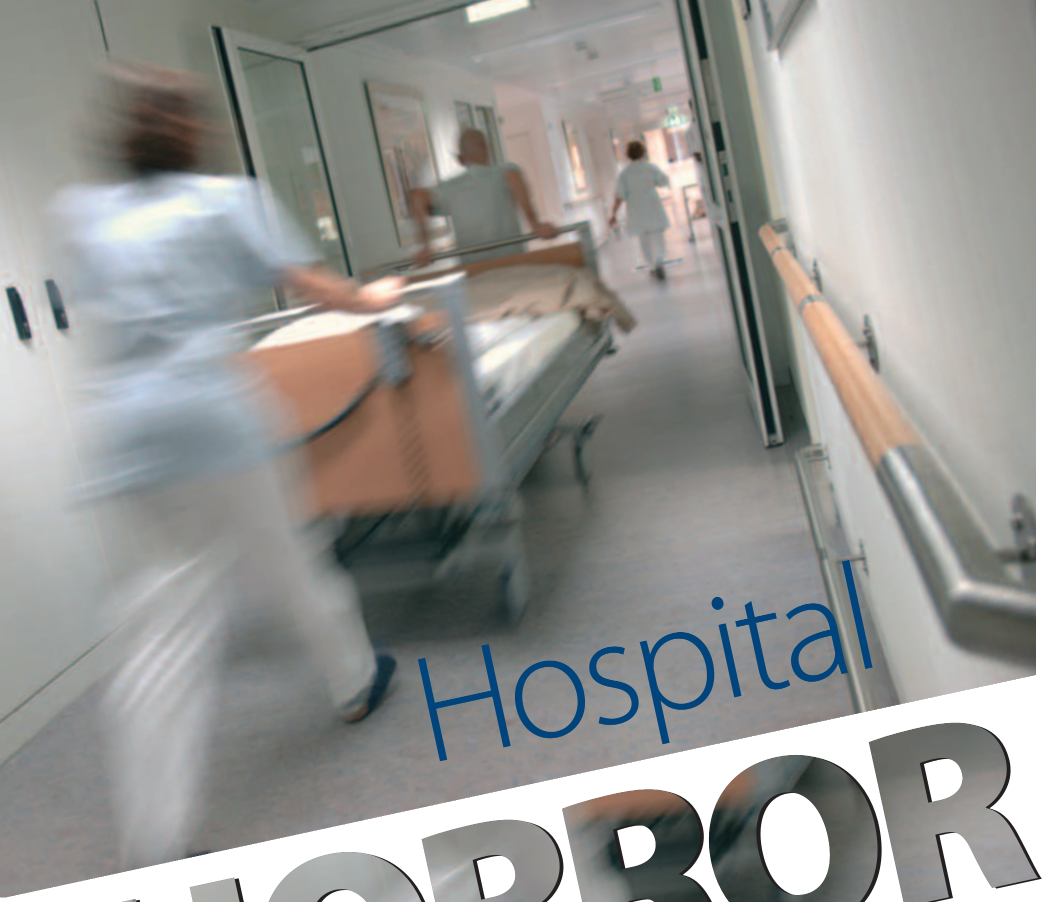
After 19 months (that's nearly two years) in bed, with no more than an hour out of bed on any one day, the sore has at last healed over. We are on the home stretch with Edward allowed out of bed for longer, five hours yesterday, and gradually we hope to build up the time out of bed to have a normal life again. Already we can go out for lunch at the local pub, drive to the seafront and watch the world go by as we used to. We can drive into the countryside and see the beauty of the outside world again. When Edward goes to the local shops he meets people he knows and can just chat as he used to. Such simple things are gradually becoming normal again after being virtual prisoners in our own home.

Edward's wheelchair has been reassessed and seating checked for pressure. The PUO Team from Odstock has pressure-mapped various cushions with Edward and found the best one for his chair. The wheelchair clinic is looking at other issues with the chair and hopefully it will soon be safe and comfortable again as Edward's posture has changed after lying in bed for so long.

If this situation happens to you then question everything, don't accept that everyone is doing their best, push and push for better care at every step. I also found taking regular photographs of the sore every week showed us the progress, or lack of it, and this helped enormously.

If this should happen to you, keep positive, there is help out there you just need to find it, and of course – check your skin daily.

Jill Floyd



Hospital HORROR story

Having just read the article by Tim Rushby-Smith in the December issue of *forward*, I feel I must add to the debate about the treatment of SCI patients in District General Hospitals.

In November 1969 I sustained a spinal cord injury at level C5/C6 the result of an industrial accident followed by nine months rehab at the National Spinal Injuries Centre Stoke Mandeville. In July 2012 I was admitted to the Duke of Cornwall Spinal Injuries Treatment Centre at Salisbury District General Hospital where previously my consultant had advised a sphincterotomy and a transurethral resection of the prostate gland procedure to relieve the symptoms of dysfunctional voiding and retention of urine resulting in occasional UTIs.

I was discharged two days later after a successful operation with urine drainage via an indwelling catheter. Two weeks later a community nurse came to remove the catheter and I reverted to my usual sheath drainage.

However, the next day I became unwell and suspected a UTI. My symptoms became progressively worse and my wife called an ambulance. I was admitted to a local District General Hospital where, after a period of time in the medical assessment unit, diagnosis of a UTI was confirmed and I was given intravenous antibiotics and fluids. Later I was moved to a bed in a high dependency dementia ward.

> *"The physician asked my wife 'What is his quality of life like? Is there any point in intubating him?' she was shocked and horrified"*

The next day when my wife visited I was barely conscious and she found I was having difficulty breathing and asked the doctor looking after me 'did I now have a chest infection and could I have oxygen to help with my respiration'.

He was very abrupt and said 'no it wasn't a chest infection', turned his back on her and continued to speak with his junior doctors. No further discussions took place that day. On visiting the following day she found my breathing to be very shallow and I was drifting into unconsciousness. She rushed to get assistance. On returning to my bed side an anaesthetist and his team were around me. The physician asked my wife 'What is his quality of life like? Is there any point in intubating him?' she was shocked and horrified and explained 'he is very precious to me and is important to his family and friends'. She was asked to wait outside.

At this point the consultant from the SCI Centre in Salisbury rang her on her mobile phone (she had desperately been trying to contact him for advice) she immediately passed the phone to the anaesthetist dealing with me.

I was then taken down to the Intensive Care Unit where she had to wait to see if I had survived.

Fortunately I did survive and after two days in the ICU I was moved to a general ward. The treatment prescribed by the doctor whose care I was under seemed very haphazard and unprofessional dealing only with the presenting symptoms not taking a holistic approach into my underlying condition. We later learned from the discharge notes that the reason for my breathing difficulty, as shown by a chest X-ray, had been due to fluid overload after treatment with intravenous fluids.

Both my wife and I had been asking for me to be transferred to the SCI Centre in Salisbury. Once the doctor said 'are you suggesting we are not capable of dealing with him here' in a most aggressive tone. On asking again for a transfer, the doctor asked did we have a contact number mentioning the wrong hospital in the wrong county! Even though my wife had left written details at the nurse's station giving the contact details of the correct hospital and the name of the consultant.

Following this incident I had several attacks of autonomic dysreflexia which, because of our experience, my wife and I were able to control.

I wanted to ask some questions about my care. The doctor was unable to answer for example, who was the urologist dealing with the initial UTI problem and was unaware that a bedside cardiogram had been taken or the reason for this procedure. He did venture to say at one stage 'that was a very close call you had'.

My wife had kept from me how desperately ill and near to death I had been as a result of the pulmonary oedema following the intravenous fluid treatment.

Although desperately anxious and worried at this time she kept a record of the events of my stay at the hospital, since I was unaware of what was going on because of feeling so unwell and tired. These notes proved invaluable later when we made a complaint via the Patient Advice and Liaison Service.

On the 20 December 2012 we received a letter from the Customer Relations Manager which we feel does not address the problems we experienced or produce any solutions.

For all of the fifteen or so days that I was in hospital my bladder and bowel management had to be carried out by my usual home carers, who travelled to the hospital every day, as there appeared to be nobody available or willing to undertake these procedures for a tetraplegic patient. Why is this so in such a large District General Hospital? Surely they must have the resources to provide these essential services. My experiences in our local District General Hospital do not inspire confidence in their ability to handle spinal cord injured patients.

Editor's note

We are currently up-dating the SIA Medical Emergency Card. This can be given to staff in a general hospital or other non-specialist SCI environment to highlight the risks associated with autonomic dysreflexia and provide basic information regarding your spinal cord injury. The card is the size of a credit card so can easily be kept in a wallet or purse so that it is readily available whenever required. Watch the SIA website and *forward* magazine for details of when the card becomes available.

Coloplast
Continence Matters

Charter Healthcare updates website

Fran Maher

www.charterhealthcare.co.uk for easier, more convenient online ordering

More of us than ever are choosing to use the web for services like online shopping, catch-up TV and to connect with friends and family on social media. Much like these popular online services, Charter's updated website is offering SCI internet users, their families and carers, the convenience to go online to order their daily continence care prescription products. The bonus with ordering online is that it can be done at any time of day, at home or on the move – and comes with total discretion that only the web provides.

Charter Healthcare, which is part of Coloplast UK, first launched its online ordering service in 2010. Back then it was one of the first home delivery companies to offer online ordering as part of its service. Fast forward to 2013 and thousands of customers are now placing their regular prescription orders with Charter's service.

Fran Maher, who runs the site, said: "We all have increasingly busy lives and going online is giving our customers the flexibility and convenience to order their continence products when it suits them. Customers are telling us that it's another useful tool to help manage their everyday needs and get on with life."

The refreshed site provides a number of improvements that, overall, are providing a much better user experience. One of the biggest changes is the product catalogue, which extends not only across Coloplast's portfolio, but includes all other leading manufacturers.

The improvements include:

- Improved product searching and browsing – making it even easier to find and explore today's continence and ostomy care products
- Product information – with supporting user guidance, videos and imagery
- For existing Charter phone customers, there's speedy registration – taking just 2 minutes to get started
- Quick reordering from a "my favourites" listing of regularly ordered products
- Social media contact – with updates and support via Charter Healthcare's Twitter feed.

"We're committed to making the Charter Healthcare website and our online services even more attractive to use – and I'm always grateful to receive feedback from our users on ideas to improve it further," says Fran.

The Charter Healthcare site is designed to work on a range of devices, from smartphones, tablets, laptops to traditional desktops.

Visit today
www.charterhealthcare.co.uk
Alternatively, e-mail Fran at
WebUK@Coloplast.com
or call Freephone 0800 132 787

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A new career in fitness

Fran felt embarrassed about going to the gym after her injury but, thanks to fully funded training through InstructAbility, she's now a qualified fitness instructor!

Fran Brown sustained a spinal cord injury when she fell off a ladder whilst working as a lighting technician. Many will know her as a Peer Adviser for SIA at Stanmore.

"Before my injury I was representing the UK in rock climbing and swimming at club level. After the injury I was initially very depressed and was thinking, 'What am I going to do, where am I going to live?' Getting back into sport kept me positive but my first experience of going back to the gym was not very successful. I was told by staff that there wasn't much equipment I could use. I sensed that I wasn't very welcome and left feeling embarrassed."

Fran then found out about InstructAbility, an award-winning programme that gives disabled people the opportunity to train as fitness instructors. The programme was created by Aspire, the spinal injury charity and YMCAfit, the leading fitness industry training provider, and offers free training for a professional qualification in Gym Instructing followed by a voluntary work placement at a local gym. Fran reflects,

"InstructAbility is a great initiative. It has given me the skills and experience to secure an entry level job in the fitness industry. If I'd had a disabled instructor it would have definitely made me feel more comfortable. I now represent Great Britain in the disabled ski team and para climbing."

Thanks to a recent grant of over £850,000 from Sport England, disabled people across the UK will have the opportunity to benefit from InstructAbility. The project has already been delivered in a few areas of London with 37 disabled people qualifying as instructors. InstructAbility graduates who have completed the programme have since gained employment with private and public organisations such as Virgin Active, YMCA and Fitness First.

Training Opportunities in 2013

Venue	Selection day	Course dates	Placement period
Maidstone YMCA	Tues 30 April	May – July 2013	July – Oct 2013
Romford YMCA	June 2013	July 2013	Aug – Nov 2013
Berkshire (TBC)	Aug 2013	Sept 2013	Oct – Dec 2013
Lewisham (TBC)	Sept 2013	Oct 2013	Nov – Jan 2013
Brighton (TBC)	Oct 2013	Nov 2013	Jan – Mar 2014

If you're interested in getting involved, are over 16, disabled and unemployed with some gym user experience, go to www.aspire.org.uk for more details or to apply.

Active Assistance
Your life, your choice™

This article is brought to you by
Ejaz M Nabi, Managing Director
Active Assistance

Choosing to be Beautiful

Ejaz Nabi from Active Assistance kick starts our section on fashion and body image

Body image is a misused term to describe broadly three separate things

- *Body image* per se is the physical dimension of our self perception. It represents the view of the whole body, or its constituent parts, their function and indeed the sensations we get from their normal (or otherwise) function. Our perceptions of what others perceive of us is often incorporated into body image.
- *Body image* is linked to, but should not be confused with self concept. This is essentially how we perceive ourselves and how we think others may see us.
- *Self concept* is formed from a very early age by our culture and our experiences. It guides the way we behave.
- *Self esteem* is really about how much we love our selves and our bodies! It is a measure of self acceptance and approval. Like self concept it develops from a young age and is guided by others' feedback.

Other more eminent writers have written whole theses on all of the above and how they interact with one another over the course of a life time. Virtually all investigators are agreed that the impact of a catastrophic injury like SCI can have a devastating impact on an individual's feeling of self worth and esteem as well as self concept. It is part of the tremendous journey that people make when they start their second life following SCI.

For many young men it is particularly challenging. There is understandable resistance to male PAs managing the most intimate parts of one's body functions. At the same time many men would prefer to be seen with an attractive, female PA when out with friends, rather than a surrogate mum or 'another bloke'.

This is all understandable. However, PAs need to be judged primarily on their technical abilities and interpersonal skills. There are many male PAs who aside from being (physically) stronger have a lot in common with male clients and can form good relationships if given a chance.

We are all different, and therefore some find the journey to build greater self esteem easier than others; there is no right way or path. At Active Assistance our training programme covers these issues, and hopefully our PAs (male or female) are empathetic with our clients in this regard.

Wheelchair Jeans

Didn’t know they **existed**? Maybe it’s time to take a closer **look**

There are a few wheelchair jeans manufacturers around: Rollitex, Rollimoden, USA Jeans & Rolling Elephant. Only Rollitex are currently represented in the UK.

How are they different?

I love this question at exhibitions, as it shows how similar they are to their mainstream branded cousins! However they have a number of design tweaks making them suitable for wheelchair users. This list is for Rollitex:

- Higher at the back, so they cover your derrière properly when you’re sitting. If jeans fit properly, they don’t slip and twist while transferring.
- No pockets, studs or poppers at the back minimises risk of skin and pressure issues.
- Seams sown side to side at the back – not one on another – minimises the risk of skin and pressure issues.
- Strong nylon threads fasten belt loops to the jeans so they do not come off or tear when you use them as transfer aids.
- Front belt loops closer to the fastener enable tetraplegics to fasten their own jeans and maximise limited hand movement.
- Tougher and better designed fastener that does not easily break or tear the fabric when being assisted on transfers or given a pressure lift from the waistband.
- A longer zip makes access to catheterise easier while seated. And it provides easier access when dressing and undressing. And it’s a slightly bigger grade so it slides more easily for those with poor dexterity.
- The legs are all cut long avoiding that irritating sock gap! As customers range from amputee to 6’6” they need to be cut long to be inclusive, as shortening the leg is the easiest alteration.
- Winter Jeans have a soft and warm lining which is laminated to the denim, so no pressure-risky crinkles.

What do they cost?

If you didn’t buy branded jeans before your accident then likely as not these aren’t for you. Rollitex are made in the same factories as major brands such as Pepe and True Religion. They start from £49, though normally they are about £69. Though if you’re a small size, there are a limited number of ends of lines jeans in smaller sizes from £10!

For more information go to
http://disabledgear.com/categories/wheelchair-jeans
Guy Harris (L1) www.DisabledGear.com

Body image following spinal cord injury

Dr Carol Smyth T12 Chartered Counselling Psychologist SCIS, RNOH gives the academic and professional view

As anyone who has sustained a spinal cord injury knows, whether the injury results in paraplegia or tetraplegia, the loss suffered is immense and far reaching in terms of loss of physical function, control, pleasure sensation, identity, independence, spontaneity, relationships, occupation and life itself. Studies have shown that prior to the injury, the able body and quality of life are taken for granted, but that the spinal cord injury is experienced not just as a physical transformation with its frustrations and challenges but as a major life disruption leaving a sense of devastating loss. Further studies show how a spinal cord injury disrupts not just the person's body but their interests, sports and occupations, severely impacting how they value themselves. In other words, if a person's self-value was aligned with their prowess at a certain sport that they can no longer do, they feel their value had been lost with the injury, leaving them feeling worthless.

This sudden shattering of daily activities, work, plans and everyday life creates a sense of incoherence where the future becomes uncertain and unpredictable. If the injured person can no longer perform everyday tasks they lose their perception of their own competence and self-worth.

Research has also shown that traumatic events such as a spinal cord injury disrupts our understanding of self. In one study, a person who had an accident resulting in the amputation of both legs and visible scarring on his body was unable to recognise the person in the mirror, his sense of self being so drastically disrupted. Thoughts are disrupted by painful memories and sensations of the traumatic event, which in turn challenge the person's ability to make sense of life. This could be manifested following a spinal cord injury by rejecting the affected parts of the body such as the legs; 'they don't look like they belong to me so I won't bother how they look'. In order to restore the self and reintegrate the body, the individual must identify which aspects of their identity have been lost through their injury, what aspects remain and what parts have formed their new identity. This process can take time. Some people adjust by themselves, others require psychological input to help restore their self belief, to feel understood and have these feelings acknowledged, or they may simply need help to make sense of what has happened.

Read on to see how staff at the NSIC, Stoke Mandeville have been addressing the issues of body image and how individuals have taken matters into their own hands...

Fashion at Stoke Mandeville

Nicola Carrig, Occupational Therapist, writes about her work with a group of in-patients


Sarah Thomas on the catwalk

We can all think of a moment when perhaps we felt a bit down on ourselves, were in desperate need of a haircut or colour, felt frumpy in something that we were wearing or just generally lacked that bit of confidence in ourselves. Now recall how good you felt about yourself after you'd had that haircut or colour or treated yourself to that amazing, but maybe slightly expensive, outfit and received compliments about how good you looked...makes you feel better, right?

Whilst the media and catwalks are full of beautiful models modelling the latest fashion trends hot off the streets of Milan and London... you will very rarely see anyone with a disability modelling the same clothes on the same catwalk.

Whilst most of us regard fashion as a choice, for many disabled people it is a crucial aspect of their lives. Newly injured individuals can struggle in finding the confidence to regain their personality through fashion and image. As their body changes shape some individuals can struggle with self esteem and confidence as they no longer look the same, nor feel the same. Looking good is well documented in helping with self expression, improving self esteem and confidence and fashion and style are just elements of this.

After a spinal cord injury, a person must not only adjust and adapt to the medical complications but also face a new image, not one of their choosing, and try to express their personality through the image that reflects back at them in the mirror.

As an Occupational Therapist working at the NSIC, Stoke Mandeville, >

Beauty therapy students use their skills to pamper the patients

> I felt that it was important to show how valuable fashion and self expression is for everyone, especially disabled people, in improving self esteem and body image. With this in mind I organised a couple of events.

The first was an inclusive fashion show in conjunction with the local shopping centre. Three spinal cord injured wheelchair users took part in modelling high street clothing on a catwalk to showcase that high street fashion was accessible to all, regardless of disability.

The second event was a 'look-good, feel-good' pamper session, in conjunction with Aylesbury College and students studying hair and beauty. It was held at the NSIC and was aimed at patients initially, but relatives and staff joined in after seeing the positive benefits of being pampered. Treatments offered were haircuts, make-up, eyebrow shaping, beard trimming, nail shaping and hand massage. Everyone involved thoroughly enjoyed the session and would like to see more regular events like this.

Nails, eyebrows and beards all got attention!

The feedback was excellent

"I could finally look at myself in the mirror and not see a scraggly old fart. I felt much better about myself"

"Felt human again after seven months of bed rest"

"A boost to my morale. A real tonic"

From my experience in arranging these events, I believe that promoting fashion, health and well – being as part of a person's rehabilitation journey can help with improving self esteem, body image and confidence. It is important that people are still able to express their personality through fashion and image, regardless of their disability.

Above all it gives people choice and empowerment. As a result of the success of these events it is hoped that they will happen on a more regular basis... so watch this space.

If you would like to know any further information then please contact nicola.carrig@buckshealthcare.nhs.uk for more details

Sarah Thomas T12 incomplete writes...

I have learnt so much about my body since my SCI. I guess there are just so many things that we do automatically and take for granted until something like this happens and halts us in our tracks. I had no idea (biology not being my strong point) that every single action you take starts from your brain transmitting that idea, the message transmitted travels down your spinal cord and the end result is whatever you have asked your body to do, be that an itch on your nose or taking your very next stride.

If you spend any amount of time in Stoke Mandeville SCI Centre you are certainly guaranteed to see other injured people a lot worse off than you are – it is humbling and makes you realise that you are fortunate to have the function that you do have. You have to get your head around all the things that have now changed. It's not just about the physical adjustment there is also the mental adjustment that comes with it. You have to get your mind around what's happened to you, you have to realise and accept what's happened and then deal with it.

Life totally carries on, you just have to go with it – from a seated perspective. True, things are harder to do but you've got to focus on what you can do, not what you cannot and things just take longer than they did before and that takes readjustment on your part.

> *"I love shopping – what girl doesn't and it's nice to be able to try different items on seeing what suits your shape – disabled or otherwise"*

Fashion is something that is really important to me. It was about six months post accident that I began to take a more serious interest in my appearance. I guess that was when I was back home and rather than have the nurses dress me and rather than me telling them what I wanted out of my limited hospital wardrobe, I could choose for myself and do more things for myself.

I distinctly remember putting on my favourite dress and feeling like a blob of colour sitting in my wheelchair – perhaps it was my self consciousness at that time, but I have had a re-think about how I dress and now I tend to accessorise a few items to make my already favourite clothes work for me still. I make more of an effort than I used to.

I love shopping – what girl doesn't and it's nice to be able to try different items on seeing what suits your shape – disabled or otherwise. I think most of us want to look nice and feel good about ourselves. So, be brave and just try on lots of different things, mix and match items that you wouldn't normally put together, you will be surprised what actually works. I think it's nice to be unique and have your own taste. I am loving this season's accessories and have already added a couple of items to my own collection.

Tosin Adeloye's story...

I am a Fitness Instructor from South London and have been for about three years. I have quite a few interests and hobbies. I like going out with mates, playing on the computer, watching videos on YouTube, going swimming, going to the gym and I am a big fan of Moto GP and Formula1.

My accident happened on the 18 October 2011 when a pedestrian ran out in front of my motorbike. I lost control of my bike and collided with a lamp post. I suffered damage to my spine and my spinal cord at T1. This has left me with lack of movement and strength to my lower limbs and I have to use a wheelchair to mobilise.

Fashion is really important to me, because it helps me get into my comfort zone. When I first started using a wheelchair I wanted to lock myself away from the outside world. While I was at Stoke Mandeville hospital, my OT, Nicola Carrig, gave me positive mentoring. After a few months I started to deal with the situation better. I now dress and groom myself as I did before my accident, it has given me a big confidence boost to go out and feel comfortable around other people.

Earl Broad C4 incomplete writes...

Fashion has always been very important to me. As a nation, I think that generally people's fashion standards (particularly males) are very low. It seems to me that British men are either extremely lazy, devoid of style and taste, or scared of ridicule for breaking the status quo. When I look around me, I find I am surrounded by shabby blue jeans, baggy tracksuit bottoms and T-shirts bearing logos that the wearer clearly hasn't thought to consider before pulling it on. Either that or they are clad in hiking gear from Blacks >

> or fleeces and cagoules from North Face and these items worn to everyday events and social functions, which I feel is highly inappropriate. When I compare the everyday fashions of today, to the razor sharp suits of the 60s, or the high couture of Paris & Milan, I am ashamed and appalled. As a result of this I have always gone out of my way to seek out clothes that fit well, look sharp and more importantly make a statement. If I wear something, it says something about who I am, and I have to consider that every time I get dressed. I think that people on the whole don't question what they wear, as long as it looks OK. I don't think that's good enough and as a result we have become a nation of scruff bags.


Earl Broad sporting one of his hats

Having an SCI severely affects your fashion style and what you can wear. To begin with I was in such shock after my accident, and spent most of my time in bed, that thoughts about clothes went out of the window completely. As I began rehab, I was told to wear loose clothes that would be extremely comfortable. I had a selection of clothes sent up from home, but was promptly told that most of it would be unsuitable. Many items were too 'dangerous', for fear that they would mark my skin. Certain items no longer fitted as I had put on some weight around my waist. My treasured skinny jeans were a definite no-no, as there was zero room for my leg bag. In short, I had to acquire a whole new wardrobe. I purchased a selection of big plain T-shirts, vests and loose shorts. I got myself a pair of hideous slip-on shoes that had been recommended. I even succumbed to buying a pair of baggy sweatpants, something that I never would have dreamed of prior to my accident, but I figured needs must.

> *"There is a saying that you leave your dignity at the door in Stoke Mandeville, but that is no reason to dress shabbily"*

But, after settling into my rehab programme I started to reassess my image. I looked at myself in the mirror and was aghast at what I had become. My hair was all over the place, I had grown a shoddy beard, and I was dressed in exactly the same sort of clothes I had been censorious of in the past. I duly went about trying to make amends, I shaved off my hair and beard and went shopping. I found that some smart loose chinos would work just as well as joggers in the gym. Certain tops with patterns and images that I liked suited a looser fit. I bought some hats that I felt gave my image the edge that it had been missing. Some patients mocked me for what I wore, to others I became a figure of fun. But I told them to take a look at themselves first. The trend of 'dressing down' takes on a new meaning in the SCI Centre. There is a saying that you leave your dignity at the door in Stoke Mandeville, but that is no reason to dress shabbily. As in the outside world, people in rehab favour comfort and mediocrity over style. Either that or they are happy to wear moth-eaten, stained relics from the bottom of their wardrobes. It doesn't have to be that way. But, we could do with a hand from the retailers. If more clothes shops had things that were tailored to our unique needs and requirements, if there were more styles on offer to us, then perhaps SCI people could feel more confident and proud of their image and the clothes they wear.

A different kind of fashion

Only somebody in a wheelchair might reflect on how fashion for the upright could be adapted for those permanently seated in a wheelchair.

That's how it started for Manfred Sauer in 1988. A tetraplegic wheelchair user since an accident, he began with the design of trousers and bathrobes. He gave his company the name Rolli-Moden. Over the years many more practical items have been added to the range of products, for both men and women, which now fill an attractive catalogue.

This specialised wheelchair clothing in no way looks inferior to 'normal' clothing, however, the functionality of the product has always had priority when designing and developing new items.

Trousers and jackets

In particular the design of the trousers shows how many different and important functions have been taken into account.

As with the trousers, the functionality of tops has been of utmost importance and all jackets, suit jackets and blazers are cut short so that the fabric does not rub on the wheels. The lapel is shorter than normal to ensure an ideal fit. Sleeves and shoulders are formed to fit the typical arm movement of a wheelchair user. Ponchos and bathrobes have a free seat with no excess material.

Shoes and accessories

Unfortunately many wheelchair users are susceptible to pressure or have swollen feet and legs which makes wearing 'normal' shoes impossible. Rolli shoes are broad fitting, can be opened widely so are easy to put on, and the width can be regulated. Soft seams are a must and there are no hard heels or toes, thereby minimizing the risk of pressure.

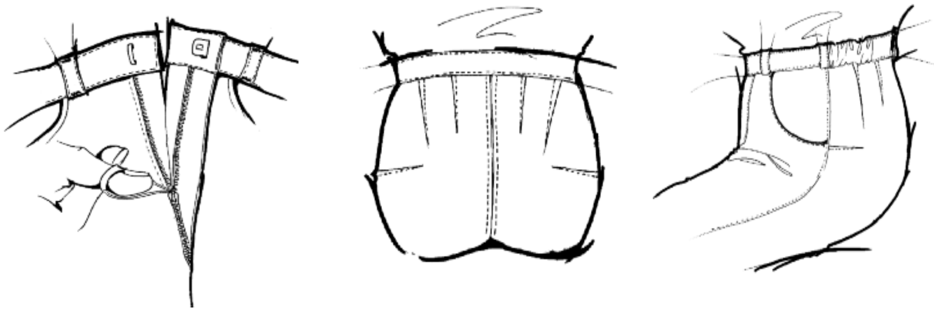
Bags and rucksacks to fit the wheelchair, gloves and further practical accessories top off the range of products.

Shop in person or online

In Lobbach, near Heidelberg, customers can visit a Rolli boutique to shop at leisure with the help of experienced staff. Height-adjustable beds in the changing rooms make trying on less of a chore. Not only can clothing be bought 'off the peg' in the boutique: experienced seamstresses can measure customers who need special alterations or who want custom-made trousers, suits, skirts or blazers for that special occasion, in the fabric of their choice.

The boutique is situated in the Manfred Sauer Foundation, where visitors can stay overnight and enjoy the facilities of a totally accessible spa, treatments, gym or relax with a drink from our inhouse brewery and a meal in the restaurant all set on the edge of a nature reserve **www.manfredsauerstiftung.de**

The Rolli-Moden website offers information about the special features of the styles and current offers in the Online Shop can be ordered with just a click of the mouse. Rolli-Moden customers receive a catalogue twice a year, with wheelchair specialised clothing such as jeans, trousers, suits, jackets, shoes and accessories to suit each season. Rolli-Moden delivers all over the world and their customer advisers speak English!



Further information can be found at Rolli-Moden, Neurott 20, 74931 Lobbach, Germany.
Telephone **0049 6226 960203**
email **export@rollimoden.de**
visit **www.rollimoden.de**

Bra strap bondage

What goes up must come down', or so the saying goes. However, there is nothing more irritating for us women when it is our bra straps that we are talking about; bra straps that have a habit of slinking down off shoulders, uninvited, where they proceed to put our arms into 'lock down' mode.

For all bra wearing women this can be an occasional problem. Generally a deft movement of the hand to catch the offending strap and put it back in its place resolves the situation. The problem comes when you don't have a functioning pair of hands to 'deftly do' anything with. With my limited hand and arm function the best I can muster is 'clumsy' occasionally and that does not include resurrecting fallen bra straps, unless I have my trusty dressing aid to hand.

After my spinal cord injury my upper body shape changed. My high cord injury has resulted in two shoulder blades that protrude more than they used to, my shoulders slope more and my arms are much thinner.

In my early rehabilitation days nurses did their utmost to persuade me that bra-less was the way to go. As the minutes ticked by to dress me each morning they figured that one less item of clothing to wrestle me into would be time spared. I did not share their passion for convenience. My spirits were sagging enough. This girl was in need of a more uplifting experience and that required wearing a bra with straps that behaved and stayed put on my shoulders.

When in rehabilitation, and even when first home, I did not find it easy to get out and about shopping. It took me a while to find the best clothing solutions for my new found body shape, but especially to find a good-fitting bra.

All I can say is perseverance pays and here are a few tips that might help others that get trapped by falling bra straps.

1 'Bra strap holders' as advertised by Amazon.co.uk. These are advertised as, 'stopping your bra straps slipping down your shoulders'. What can be best described as a plastic tag is used to draw the straps together across your back to prevent the straps falling. I consider these a temporary, quick fix solution. Depending on your level of feeling, ask someone to check for pressure marks periodically when first using them. Anyone with limited hand or finger function will more than likely require assistance to place these tags correctly and ensure straps are not twisted.

> *"In my early rehabilitation days nurses did their utmost to persuade me that bra-less was the way to go. "*

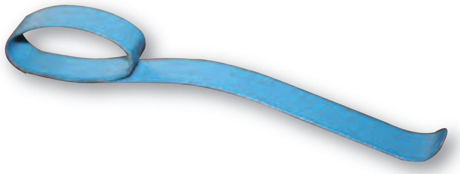
2 Measure yourself for a bra. Depending on which website you read over 70% of women wear the incorrect sized bra and straps that regularly fall are a classic sign of an ill-fitting bra. Visit a lingerie department in a reputable store and ask for a professional fitting. After all that we go through in spinal rehabilitation a discreet bra fitting should not even raise a blush. But if it is getting out and about that is the challenge then visit one of the many sites, see three below, which give advice on how to measure for a well-fitting bra. Ask a friend, partner or carer if they would to help take and record the measurements.

www.marksandspencer.com
www.amplebosom.com/measuring-guide.php
www.houseoffraser.co.uk

3 If you have limited hand function and require assistance to get dressed do ask your carer to spend some time making sure your bra is sitting correctly and adjust the clasps at the back and straps accordingly. If before injury you were someone who used to lift their breasts into their bra to adjust the fit you may not feel confident, or wish, to ask a carer for such intimate help. Instead, ask your carer to stand in front of you and help you lean forward safely so that your breasts sit correctly in the cups before the straps are lifted onto your shoulders. A bra can be the correct size but is neither use nor ornament unless 'the girls' are seated comfortably.

It can take time to adjust having someone to help with what previously were such basic tasks of getting dressed; something that was rarely thought about before injury. Now it can feel awkward to have to ask someone to check that our breasts are not spilling out one side or other of our bra because it is not correctly placed or check they are not trapped in the underwire. But, as with any other layer of clothing, it is so important a bra sits correctly and is comfortable to wear.

4 There are many sports bras that offer crossed straps that prevent straps slipping. The problem is, these are designed with function in mind. If you are a woman that likes a little glamour to their underwear this sportswear rarely makes the grade. Then it is a case of trawling the websites, or lingerie departments, for the best fit and finding a bra with all elastic straps; not padded or part satin which tend to glide off any shoulder with the least provocation.



5 If falling straps are just an occasional problem then consider asking your OT to make a dressing aid to help you 'fish' and replace the strap to your shoulder. See picture above for an example. If you have limited or no hand function but some range of arm movement then a loop can be designed into which you can slip a hand; the length and angle of hook at the end to catch the strap can be modified to the range of your movement. Ideally the dressing aid should then be made up in a more durable material than thermoplastic material which can go brittle and snap over time. The one in the picture is made of plastic-coated metal.

A few years ago I lived in Houston, Texas and went to a presentation given by an Image Consultant. Jane talked about the effect that clothes can have on how we feel about ourselves. She said that one of the most important items of clothing to making a woman feel positive about herself was her bra. Further, in every woman's closet there should be three types of bra. A sports bra, an everyday bra and a Texan bra; the latter is one that rounds 'the girls' up and heads 'em out'!

Regardless of our level of injury we SCI women need to feel good about ourselves. I'll leave you to dwell on your search for a 'Texan bra' if you are not already in possession.

Meanwhile if you have any tips to share on the challenges clothing present and how you have overcome them, do contact the editor.

Christa Dyson C4 incomplete

Dressage

Getting dressed, or 'dressage' as my girlfriend christened it, is a tricky task for any C5/6 tetraplegic and I should know, I am one. In fact 'tricky' doesn't begin to convey the endless hours of blood, sweat and tears I've put into perfecting the art of 'dressage' over the fifteen years I've been living with a spinal cord injury.

The commitment and dedication needed to master the technique of putting on one's own sock could easily be equated to that of an Olympic athlete, and if you were to ask me, tetra 'dressage' is a far worthier event in the Paralympic programme than the current equine derivative. Dancing horses? Give me a break. Findus lasagne anyone?

Dressing practice formed part of my rehabilitation right from the start. Encouraged to do whatever I could for myself, putting on a baggy T-shirt might have sapped every ounce of energy, but by golly, it was a seedling of independence that I was keen to nurture.

I clearly wasn't prepared for what would become the Everest of dressing tasks… trousers. As anyone who's been a patient in an SCI Centre will know, healthcare professionals will persuade your relatives to go out and buy you incredibly unfashionable tracksuit bottoms and ice-white trainers, what's known in the sector as 'newly-injured gear'. Of course, this is all a conspiracy to not only make you look foolish (what the hell do I need running shoes for?), but also make life as difficult as possible. Why? Well, unwittingly, your relatives will choose tracksuit bottoms that come with a cunningly concealed inner lining. This lining behaves completely independently to the outer shell, and whose sole purpose is to entangle feet, thus making it nigh on impossible to get paralysed limbs through. I imagine it's a struggle similar to that most reservists encounter when attempting the camouflage netting on a military assault course for the first time. Couple this with a tiny single bed and a mattress that behaves like the bouncy castle at a Hugh Hefner pool party, and hospital dressing was always going to be a struggle.

So upon discharge I was a fair distance from independent 'dressage'. Bowed but not beaten, I was determined to conquer the dressing behemoth… trousers. Armed with single-layered jogging bottoms and a double bed with firm mattress, I set about my task with renewed vigour. Possessing the necessary tools and a can-do attitude, after much toil, tears and tantrums, I finally pulled on a pair of elasticated-waist jogging bottoms for the first time. Welling up with the sense of achievement cursing through my veins, and at the very height of sartorial elegance, 'going solo' was becoming a tantalising possibility.

When it comes to dressing independently as a C5/6 tetraplegic I have two pieces of advice, number one – don't choose clothes that make your life more difficult than it needs to be with regards to getting them on and off. That doesn't mean resigning yourself to a uniform of newly-injured gear, just use common sense when buying clothes; avoid skinny jeans and knee-high Doc Martins. And number two – persevere and devise a technique that works for you. The more you try and the more you practise, the easier and quicker you'll become. Granted, the days of rolling out of bed and throwing on whatever's at arm's reach may be behind you, but the days of donning your own glad rags, however long it takes, are not.

Jamie Rhind C5/6

Image is everything – if we believe the messages we receive through marketing and the media – but, ironically, focusing on how you look can be very positive if you have a visible disability.

Fix up, look sharp!

by Lara Masters

After years of using a wheelchair due to a degenerative condition, I've learnt our appearance affects not only how others see us but more importantly how we see ourselves and if you're struggling with physical self-confidence, manipulating your image can be very empowering.

The problem is that if you have a spinal cord injury, your looks can become a low priority, as just surviving – washing, dressing, eating, exercising – all those things that have to be done daily, take up so much time and energy.

The trick is it to find quick-fixes that guarantee spectacular results – minimum effort for maximum impact. Here are some of my top tips:

1 Start as you mean to go on! Bin tired undies and only wear knickers and bras that are cute and comfortable. It's a psychological boost when you feel a bit womanly from the get-go and if everything else that day goes bottoms up, it won't be a catastrophe if you do too.

2 Turn your chair into a chariot! A tatty pair of wheels will ruin your look. I always vavavoom my chair; currently my spokes are covered in silver and black mesh and I've made several crystal-encrusted designs in various colours, with the help of carers, which Velcro to the back of my chair so I look like I'm driving full-spec rather than headed for the scrap. (See pic of the back of my chair on my wedding day in September.)

3 Be repetitive! Finding clothes and shoes that are practical and look good has got to be the bugbear of every wheelchair user. I am an ultra-slim size 4 so rarely find clothes in my size and anything baggy makes me look scarily skinny. If I miraculously find something that fits, whether it is a top with stretch in that's easy to get on but flatters my womanly curves (!), a satin corset for nights out that supports my back, or shoes with heels that are not too high or too flat, with enough grip to sit on my foot plates, I buy them in every colour, every season, every year they make them!

4 Nip and tuck! It's not always possible to get your favourite styles in wheelchair-friendly format. I bought a sewing machine to take in clothes that I love but are too large off-the-peg. Also, I like jeans as denim has structure that, unlike track pants or leggings, makes my legs look slightly fuller, but coarse seams are not great for pressure sores so my carer unpicks the pockets on the back of my jeans to make them comfortable for my delicate derriere.


Jan Gamble

Lara on her wedding day

5 Chill out! Banish chilly pins in style – rather than tights which bag around the crotch, are difficult to get on and highly unflattering, I wear thigh-high wool socks layered with thigh-length leg-warmers (American Apparel/Tabio); they look sexy, provide some pressure and are easy to put on.

6 Use your head! There is nothing like a hat or fascinator to make you stand out from the crowd – even when you're sitting. Hats don't discriminate; whatever your size or shape, you've got a head! That was the inspiration for setting up my burlesque fascinator business Kiss My Cherry www.kissmycherry.com and whenever I go out I'll top off my outfit with a fabulous fascinator.


Rachel Lewis

Chair back

It's true that life with a spinal cord injury can be very difficult, but life without style…? No one should have to live like that!

THE *Feminine* TOUCH

Shopping

In December I wrote about my efforts to apply make-up and take pride in my appearance. In this issue I want to talk about shopping for clothes, so here goes...

I am sure many female readers will remember their time in the SCI Centre and how demoralising it was to wear just track suit bottoms. I was never given any hope that I would be able to wear jeans again, well luckily this has not been the case for me. At the time one senior nurse said to me, "You will only be able to wear maternity trousers." I was absolutely horrified and extremely dismayed as I have always liked to wear fashionable clothes. Another option given to me was to buy specialist clothing from catalogues for disabled people, which was not good for my image at all!

Since my accident five years ago, I have done plenty of shopping and as many tetraplegics will know, one's abdominals are not quite the same as before. I decided to swallow my pride and actually look into maternity departments within shops such as New Look, H & M, Dorothy Perkins, Next, and Red Herring in (Debenhams) and to my amazement I actually found many trendy jeans and trousers. If you are like me and are unable to try on clothes in the shop, then trying on at home is the only option. Luckily maternity trousers have proved to be more flattering and comfortable than I realised and at least they look fashionable when they are covered by a lovely top, cardigan or jumper. Another store that I personally love is TK Maxx, because you never know what you will find. Regarding trousers, it is well worth having a look in the sporty exercise section. I have found some stretch trousers that look like normal trousers, but are more comfortable to wear. Beware of any stripes – not fashionable at all!

On a serious note I must emphasise that we do need to check seams etc due to the boring old problem of pressure sores. I myself have suffered from pressure sores always in the sacral area. When this occurs, I switch from jeans and put on a softer option such as the stretchy ones.

To round off any outfit I like to pick out colourful tops, sometimes with a scarf to finish off the look. I usually succeed in any of the listed stores, plus many more, including online.

If any *forward* readers have other bright suggestions, then please share them.

Peggy Sutton C5/6/7 complete

Equal representation

Sophie Morgan has been responsible for revolutionising shop window displays by designing and producing Mannequal™ – a wheelchair –shaped piece of kit on which a model can be posed. Sophie says, "In its very name the Mannequal™ denotes equality, in its design it reflects acceptance and in its inclusion it expresses unity."

The topic of inclusivity within the fashion world has been increasing in momentum and the benefits of a product such as the Mannequal™ cannot be ignored. Not only does it offer equality to all customers, but it is a valuable asset to the retailer as it reflects his commitment to ensure that responsibilities under the Equality Act are being met and goods and services are accessible. The presence of a Mannequal™ in a shop window clearly suggests an attitude of acceptance and indicates the retailer is making an offer of assistance and guidance to any customer, disabled or not. Its presence reflects the retailer's moral and ethical conduct and helps to empower disabled shoppers.

The Mannequal™ has been designed to seat both male and female mannequins of standard height and width and it can be decorated and styled to co-ordinate aesthetically and subtly with either an in-store display or a shop window.

It is available in white or a range of colours, including Pantones. It can also be personalised to show a company logo or design.

Look out for the Mannequal™ in your local shopping centre and if you don't spot one, ask why not.

The Mannequal™ in Debenham's shop window

More information can be found at www.mannequal.org

My own particular style

Shannon Murray, disabled model from the 2012 Debenhams campaign writes...

I was 14 when I had my injury, a time when teenagers are growing increasingly obsessed with their body image and appearance. While in an SCI Centre most of us aren't that concerned with our physical appearance, the baggy tracksuit is *de rigueur* and let's be honest, in the early stages of rehab we've got other things on our mind. However, that didn't stop me reading every magazine and fuelling my obsession with fashion at that time. With the help of my mother and grandmother (both tailors) I learnt exactly which styles would work for my body in my new seated position.

Apologies if this causes any offence but I have no interest in clothes designed specifically for disabled people. I've never seen anything I like and I prefer to create my own style, incorporating classic pieces with current trends, and to be honest my main problem when buying clothes is my height, at six foot I find it quite difficult to find clothes long enough for my frame. To be honest I feel more comfortable in more fitted clothing. I think my lack of muscle tone bothers me more in loose fitting clothes, which are also more likely to catch during transfers.

Fortunately, modern clothing technology is on our side; now denim is much softer and most jeans have a lycra content that makes them stretchy and easy to pull on as well as complement our slim legs. Spanx and their like hide a multitude of sins and accoutrements, binders and waist cinchers not only help my breathing and tetra belly, they also give me a tiny waist and ankle boots hide any swollen ankles yet let you reveal some leg if you fancy.

I would love to become a personal stylist and body image counsellor for men and women post spinal cord injury. There are so many little tips I've learnt over the years, whether it's sourcing the softest cotton, the most seam-free underwear, the importance of hidden pop fasteners or hook-and-eye clasps (thanks Mum).

I've always felt that the importance of body image and personal appearance was highly neglected in the rehabilitation process, so many people end up hiding beneath baggy sportswear years later (probably still living in fear of a pressure sore. Do they still show those photos pre-discharge?!). I've always maintained that my personal style and tastes haven't changed just because I'm sitting down and using a wheelchair. I'll confess I don't really enjoy wearing suits to work, the jackets restrict my arm movement and shirts rarely fit comfortably so I tend to opt for smart dresses as an alternative.

I still relish any opportunity to dress up. I've learnt what my favourite body

Shannon and friends on a Christmas night out.

parts are and how to dress to highlight them and detract attention from the parts I'm not quite so keen on. Again my Mum was pretty key in helping me learn what worked best. Don't underestimate the importance of great fitting underwear in both nude and black, it's the basis for any fabulous looking outfit! I also buy quite a lot of gloves, not the weightlifting ones, but elegant and brightly coloured ones, (ebay is great for getting bargains) our hands can take a beating pushing the chair every day so I'm trying to protect mine at every opportunity.

I have enjoyed the past 19 years of modelling and I hope the Debenhams campaign changed a few perceptions about disability and fashion. The feedback I received indicated that it did. I still hope that one day other high street fashion stores will follow suit and acknowledge their disabled customers in their advertising. It's disappointing that stores still fail to address this issue, clothes are a universal necessity, we all need to wear and purchase clothes, disabled or not.

And on that note, why not wear the things that make you feel good and look good? It's sad but true that human beings tend to judge each other on appearance, and I know from personal experience that I may be treated differently depending on how I am dressed and how I convey myself; I'm not saying it makes the wheelchair invisible, but it does make me less invisible.

I assure you attitude and appearance make a difference.

Casual wear for the Olympic Park

Trousers at half mast

The youth of today, what do they look like, eh? Well the short answer is that they look like idiots. If they haven't got metal spikes sticking out of their nose like some kind of futuristic Man Friday, they've got their jeans slung so low around their legs that they're more mobility impaired than I am.

When I was their age I was much more sensibly dressed: ice white, prison issue trainers, XXL Mickey Mouse T-shirt and regulation, loose-fitting jogging bottoms. That's right: I was an inpatient in Stoke Mandeville and I was wearing the sort of clothes that said 'I'm disabled and I might need the toilet at ANY time.'

Of course, it hadn't always been like that. Several months before my accident I could be found strutting down the King's Road wearing the finest cloth Jermyn Street had to offer. However, the second I became a wheelchair user I seemed to revert to type – style was sacrificed in favour of good, old fashioned practicality. In hindsight I dread to think how close I was to buying one of those all over, waterproof wheelchair ponchos.

It soon became clear that the jogging bottoms had to go. Many years earlier a German friend of mine had remarked that in Germany it would be 'unacceptable' to wear jogging bottoms out in public. As I followed his gaze to an ample bottom heaving a trolley full of Findus crispy pancakes around Asda I concluded that it wasn't really acceptable in the UK either.

Within hours of my discharge I was pulling on a pair of the jeans which had been so vilified during my rehabilitation. Despite the horror photos we were shown of those poor unfortunates who had worn their jeans too tight (the memory still brings a tear to the eye) this was a risk I was willing to take – after all I was a young man and rather keen on getting a girlfriend at some point in the next decade.

Still, jeans bring with them their own sartorial shortfalls. I'm not sure there exists a single photo of me as a wheelchair user where I'm not exposing at least seventeen acres of my midriff to the Great British public. Recently a friend took me aside and advised me that I should keep an eye on this problem as people I didn't know might feel socially awkward around me. Well you can put me at the top of that list, chum.

Strangely, this ailment seems peculiar to wheelchair users and doesn't appear to affect regular, walking people when they sit down. What have these jeans companies got against us, exactly? I'm of a mind to sue Levi Strauss for disability discrimination.

I hear legend, there is a special type of high-waisted trouser specifically designed for our type which is regularly advertised in the inserts in most disability magazines. It sounds like this could well be the answer, but I can't be bothered to root through my recycling bin to see if it's true.

Whatever the solution, I'm going to have to do something about this soon. Recent weight loss has exacerbated the situation to the extent that, when transferring out of my car last week, two of my elderly relatives were treated to the kind of view normally reserved for my girlfriend and the district nurse.

Still, at least I can take some comfort in the fact that as I sat there in my wheelchair, talking to two octogenarians with my trousers round my ankles, any passing youngsters would probably have thought that I looked rather 'cool'…

Dan Burden T5

Tattoos tell your story...

Tim Rushby-Smith T12 bares all

While body adornment with ink or metalwork has become much more mainstream in recent years, it is still a topic that can divide opinion.

So, cards on the table time (or body on the easel, if you will). Beyond my left ear, I do not have any piercings, and as space is limited, I will stick to what I know. I do have tattoos. They do not represent the culmination of a lifelong held ambition; indeed, when my brother had tattoos as a teenager, I thought him mad. When the 'to ink or not to ink' discussion comes up, the anti-tattoo line tends to be, "Think what they'll look like when you're old and sagging..."

I may even have said this myself, though I never understood the point that is being made, because by then you'll be... well, old and sagging.

Our image-obsessed culture puts everyone under pressure to conform/perform, and leaves the majority of people feeling out of step with unrealistic expectations. With the veneration of youth, everyone gradually falls behind anyway. I struggle to understand how we reached a point where people desperately throw money at their no longer compliant bodies and go under the knife, or stain themselves with orange dye to give the appearance of imminent skin-cancer.

How have we arrived at a point where looking like you have had plastic surgery is considered preferable to ageing? People Botox their faces into paralysis until they resemble death masks rather than look like they have been alive for a while.

When it comes to body image, spinal cord injury blows such trivial concerns out of the water. With legs like a pair of over-sized pipe-cleaners and a constant 'sitting down' profile around my middle, I am hardly Narcissus these days. Clothes don't hang right, my cuffs are always covered in 'something' from my wheels, and my hands have calluses big enough to file my nails on. Sure, I have bigger arms and shoulders than before, but I also have thighs like balloons full of treacle.

Post-injury, coming to terms with never walking or running again made my appearance seem trivial at first. Then, during rehabilitation and beyond, I realised that I still cared about how I look. I just had to learn to be comfortable living in my own skin. I've even embellished it a little.

The choice of any permanent body marking should be made with care. Having a lover's name, or a portrait of your favourite pet is a risky strategy. They may dump you for another (cats can be fickle), or you might split up with said lover.

Equally risky is the 'under the hairline' option. Yes, you can grow your hair long to cover up the artwork, but the prospect of going bald is stressful enough without worrying that low tide will reveal the name of some obscure thrash metal band named after a venereal disease.

Most people who opt for ink do so with no intention of ever hiding the results. For many of us, tattoos come to represent important elements of life experienced.

SCI legend Barry 'Bazza' West has seventeen tattoos. While some of them were already in place before his accident seventeen years ago, most have come since his C4/5 tetraplegia.

"When I was still learning how to live with spinal injury, I used to get pissed off with people staring at me all the time. I remember being stared at by a man on Brighton Pier, and thinking, *I'm going to get big eyes tattooed on my knees to give him something to look at.*"

Since then, he has had tattoos recording major events in his life, be it skiing or scuba diving. But there are also tattoos that capture Bazza's feelings and help him to feel more secure.

"I don't like having a big belly, but I have no control over that. Then I realised that I could feel a bit better about it when it's tattooed, so I have a big tattoo on either side.

"Written on the back of my neck is,

The picture tells my story. My tattoos reference the traditional rhyme recited on seeing magpies. One for sorrow (the bird closest to my broken spine). Two for joy (an Australian magpie, Gymnorhina tibicen, for my Australian wife Penny. Three for a girl, for my daughter Rosalie. Four for a boy, for my son Felix. As the next two would be five for silver and six for gold, my sporting underachievement and lack of financial nous protects me from the temptation to have any more.

'One Life-Live It.' It's a strong message that conveys what I'm about."

There are additional challenges to having tattoos after spinal cord injury, as Bazza describes.

"The ones on my shoulders were really painful, because it's an area where I'm super-sensitive. The other problem is that I can't move to the perfect position for the tattoo artist."

Beyond the pain, there are more serious complications to take into consideration, such as autonomic dysreflexia. But such problems are not insurmountable.

Chantelle Michael (C5/6 incomplete) has just had a second tattoo. While her first was on the back of her neck, the latest one along her collarbone is below the level of her injury, raising concerns about triggering autonomic dysreflexia.

"I read around [the subject], and I discovered a cream called 'Speed-numb.' It's amazing. I applied it two hours before I was due to be tattooed and then covered it in clingfilm. I went along equipped with Nifedipine, in case I did become dsyreflexic, but it was all fine."

For Chantelle, tattoos represent a connection to her life before SCI.

"I always wanted to have tattoos, and without having this high level of paralysis I would have had quite a few more by now."

Taking Barry West's example, the canvas can be broad, regardless of the level of injury.

Adjusting to the challenges of later

We are all familiar with how ageing with a spinal cord injury impacts on health but what about the physical, social and emotional impact of ageing?

This can happen slowly over time and present with unexpected challenges. There are many areas to consider, some you may have made plans or provision for already. Some issues are harder to tackle than others, hopefully you will find some helpful information below.

Physical Adjustments

Pain

Pain is very individual. Pain from arthritis can become an important factor as this may affect many daily activities such as transferring. Pain may necessitate early retirement and may cause people to give up certain sports or other leisure activities. If pain prevents you from leading as full a life as you would like, seek support from professionals who can help you with managing your pain so that you can continue with daily tasks for as long as possible. Your GP can refer you to a pain clinic.

Difficulty transferring

If transferring has become more difficult, you may need to adjust your current method of transferring to make it easier for you and perhaps your partner or carer. When you cannot lift or transfer effectively, you risk knocking or rubbing against surfaces which can lead to shearing wounds, resulting in pressure ulcers. You can seek guidance from your Occupational Therapist and/or Physiotherapist as to what might work best for you. Aids to help with transferring such as sliding boards, hoists, swivel seats to get in and out of the car, may be options to consider. Consider adaptations to your car or getting a difference type of vehicle – perhaps one that has a tail lift.

Wheelchair propulsion

If you use a manual wheelchair, try to source good quality gloves for propelling to protect skin and help prevent carpal tunnel syndrome (CTS). CTS is a condition where there is pressure on the median nerve which supplies sensation to parts of the hand. This can cause tingling, numbness and weakness, muscle damage and pain, which is often felt as a dull ache. In severe cases surgical intervention is required, so best to tackle it before symptoms get too bad.

An add-on power pack to your wheelchair means you only require minimal effort to propel the chair and this relieves strain and wear and tear on muscles and joints in the arms and shoulders. They are quite expensive and are not available on the NHS. They may also require servicing.

There are lightweight manual wheelchairs on the market which you could try and many SCI people change to an electric wheelchair after many years in a chair or as they get older.

SIA's Freephone Advice Line can supply names and contact details of companies which supply manual and power wheelchairs and car conversion companies. We have details of companies which supply sliding boards, hoists and swivel seats for cars. Also available are names and contact details of companies which hire equipment, so you can try before you buy in some cases.

Social Impact

Maintaining independence

Both you and your partner may be experiencing the effects of ageing and find that your daily routine is taking longer and is more physically demanding. This is normal for everyone, even non-disabled people!

Making changes to your daily routine often means extra expense if you need to purchase additional aids and equipment or if you need more physical help. Don't be afraid to ask – funding for specialist equipment is often available.

life

Taking holidays may require more planning due to transferring difficulties and changes to your continence regime. If you are booking a package holiday, try to find out exactly what the level of accessibility is and explain to the tour operator about your requirements. Use one of the specialist travel counsellors/ agencies who understand about the needs of SCI people. There is a holiday section on the SIA website giving useful tips about how to prepare for a holiday **www.spinal.co.uk/page /holidays**.

Feelings of isolation

Often sons and daughters don't live close enough to offer regular support. Talk to other SCI people and find out how they manage, use the SIA message board and link schemes.

Services

In the SIA Ageing Well Survey (2007) some respondents reported feeling abandoned by their SCI Centre. If you have lost touch with your Centre, you can either ring them directly to re-establish contact and get regular medical checks or ask your GP to refer you for an Outpatient Appointment. If you were not treated at an SCI Centre, ask your GP to make a referral to your nearest SCIC – a fact sheet is available giving the names, contact details and locations of the 10 SCI Centres in the UK **www.spinal.co.uk/page/downloads**

Emotional Impact

The fear of losing a degree of independence can rock one's confidence. It can be difficult accepting the changes that are needed as we age.

Failing health of partner

The failing health of your partner can affect your independence and as a couple lead to feelings of isolation for both of you. If your partner's health fails, your general health may be at risk, resulting in poor nutrition, inadequate care and even pressure ulcers. Contact Social Services if you feel you need more help in the house or with caring for your partner. Your GP may be able to assist by arranging visits from the District Nursing team. You can also call the SIA Advice Line for information.

Loss of partner

Many people would consider it impossible that their non-disabled partner may predecease them and therefore this is not discussed, even less the necessary provisions made for such an event. Don't be ill prepared and find yourself unable to cope. Have a plan ready and tell your family of your wishes and intentions should the worst happen. Sourcing suitable alternative care may be very difficult, especially in an emergency situation, so plan ahead. There is some specialist residential care available now, so find out about it, discuss it with your family or social worker and make a plan.

As time goes by

In later years, you can slow down without feeling guilty, there is the opportunity to try new interests, see more of your friends and enjoy your grandchildren.

Life is not all gloomy, but anticipating problems and planning for them can help remove a lot of the anguish and distress. Be prepared! And consider this... The length of time since injury has a significant impact on the increasing care needs for daily tasks, not just the age of the person. In a US study, ageing women appeared to need less assistance with some daily tasks such as transferring out of a car or bed and doing the shopping.

Does this mean that men deteriorate quicker – or are they just more needy?

Joy Sinclair, Ageing-well and Advice Line Officer
0800 980 0501

Almost there!

If it weren't so cold, I'd consider being a naturist during this pregnancy, writes Emily Clacy C5/6

This winter has been harsh and it has been a struggle wearing the many layers I need to keep warm. Getting socks on and off is a huge challenge that sees me huffing and puffing for about ten minutes with each foot, and with one rather large swollen left foot this time, I need help getting my boots on and off. This hasn't been a problem until last week when Tim was stuck in traffic coming home from work and phoned me to go and collect Freya from nursery. I ended up driving there in one boot and one slipper as I had no chance of getting that boot on by myself! It was just as well that they brought her out to me and I didn't actually have to get out of the car when I got there!

When I was pregnant with Freya it was summertime and therefore so much easier to dress and undress. I lived in leggings and stretchy tunics or dresses, and when my feet swelled up a size bigger than normal I could get away with wearing no shoes or easy slip-on shoes. We actually had a heat-wave that year and I remember a few occasions when I sat on my sofa, in front of a fan, in my underwear, eating ice lollies; a scary sight I assure you at six-months-plus pregnant, but it was the only way to keep cool!

It's taking considerably longer to get dressed in the morning and by 7pm I am dying to get into my comfy, stretchy, jim-jam's! I suppose my (somewhat), fashion conscious attitude and my stubbornness to persevere fighting with my maternity skinny jeans each day, rather than admitting defeat and opting for a slightly looser pair of boot-cut jeans, doesn't really help!

> *"I suppose my (somewhat), fashion conscious attitude and my stubbornness to persevere fighting with my maternity skinny jeans each day, rather than admitting defeat and opting for a slightly looser pair of boot-cut jeans, doesn't really help!"*

I'm 33 weeks now (just 7 weeks to go), and this is when the pounds start piling on. I'm just hoping that it really does warm up soon so that I don't need to struggle with too much clothing for much longer!

I do have one added bonus with this pregnancy mind you; a small helper in the form of Freya! She is currently obsessed with dressing and undressing her dolls and in particular, putting on their shoes. Whilst I have been sorting out the nursery and sifting through the mountain of clothing she had as a baby, she has discovered a box full of her old shoes. She has been trying to squeeze her two-size-bigger feet into an old pair! I sound like a broken record repeating "they don't fit, they're too small". I may have an Imelda Marcos in the making... however, this does work to my advantage in that she loves helping me get my boots off and putting my slippers on.

Being pregnant in winter has another drawback; with all the layers and huge coats one needs to wear, people can't always actually tell I'm pregnant. It's fairly hard for them to see my bump when I'm sitting in a wheelchair all the time anyway and this, coupled with the layer factor, just makes me look like a ball on wheels. It doesn't bode well for my body image!

I'm being admitted into Stoke Mandeville at 36 weeks and am there until the baby arrives. Although I am struggling to get to grips with potentially being in hospital for between four and six weeks and not seeing Freya everyday, I relish the fact that I may get away with wearing a pair of tracksuit bottoms and a baggy jumper for the rest of the pregnancy...

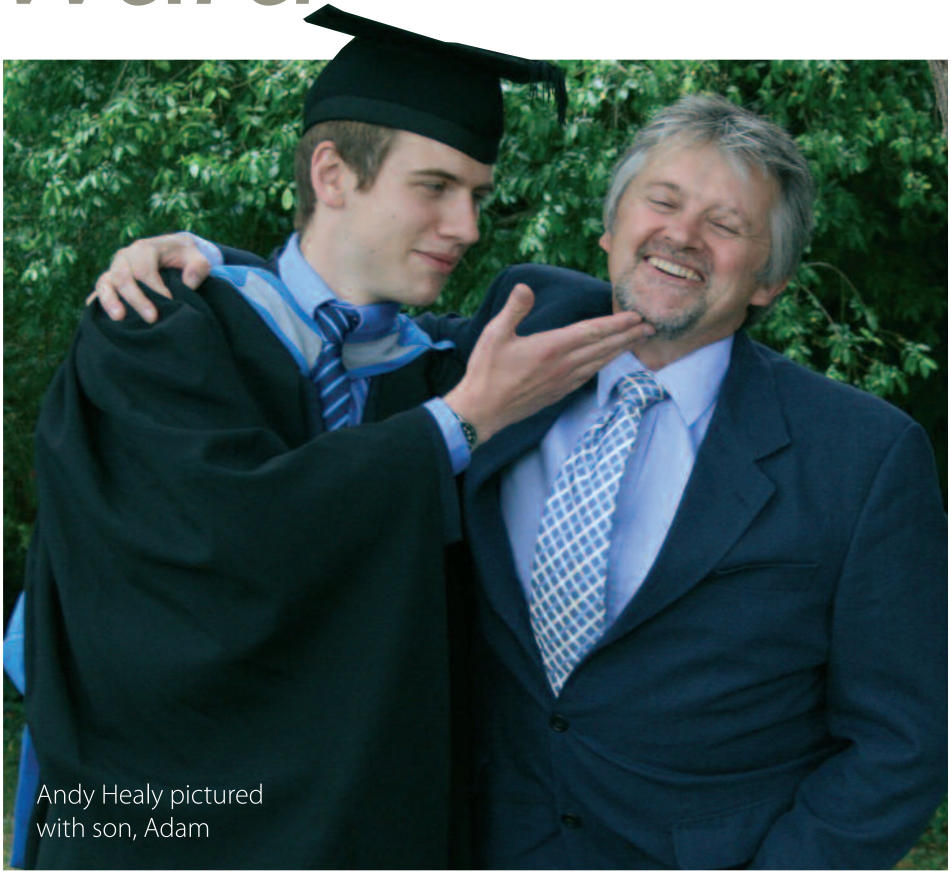

THERA TRAINER
0
Pulse: 0 1/min
0 RPM
Power: 0 Watt
Distance: 0,0 km
Duration: 15:00 min
STOP
START


THERA TRAINER


THERAvital
THERAlive
THERAfit
THERAfit plus
BALANCE TRAINER
BALANCE TRAINER

A rich vain

Vanity is one of my few faults, writes Andy Healy L1… I still check myself out in shop windows and eschewed the sport of wheelchair rugby due to the high risk of cuticle damage. I have small hands, you see, but they're beautifully formed.



Andy Healy pictured with son, Adam

Although I do walk, I'm more confident sitting down. If a good-looking woman is approaching I can sit up straight in the chair and hold my belly in. I will of course be invisible to her but you have to make the effort. I walk like an old man.

Back in the day, I used to stride out everywhere and the chair hardly ever left the house. It was never less than hard work and I remember once talking to a potential customer at a summer air show with sweat dripping off my nose. It was worth it, I felt, to give him the impression I was recovering from a skiing accident. I like to think he was convinced.

Today, a 20-metre stagger between executive shed and house is about as much as I regularly manage (ASOS please note. Oh, and I can't plan a meal either). As I lurch past the picture window from the lounge on the way to the loo, it's not a pretty sight. I always appear older and more stooped that I imagined. This may be something to do with my black flexi-splints, something I'm looking into with the help of the good folk at Stoke Man. But my old rigid pink ones made me stride like Wallace in The Wrong Trousers. Those latex ankle ones would be an improvement but I hear they make the ankle look so bulky.

I used to be fashion-conscious. Navy friends still remind me of a short-lived, leather trouser phase during the 80s and I feel that my current hairy slob phase is more down to poverty and absence of a social life than any decline in that interest. Indeed, if I had the money I'd commission a wardrobe based on a series of short-waisted jackets, as worn by military officers as evening dress but, in my case, suitable for every occasion.

As for now, unless I'm pitching for work I never wear a tie and I use the chair as an excuse for never, ever wearing a jacket. But at least I shave.

It should come as no surprise to learn that I don't consider my legs my best feature. They used to look great in tropical rig – muscled with just the right amount of hair – but several decades of only partial use have left them wasted, scarred, pock-marked and almost hair-free. I still wear shorts, although I'm never quite sure if I'm being defiant or deluded.

In spite of this, as far as body image goes my positive snapshots both come from my lower half. I am proud to have so far beaten foot-drop. Secondly, after all this time I still have a 34-inch waist and right now, I can do the top button up.

Lookin' good Mr H!

A dedicated follower of fashion

How my friends would laugh if I tried to claim I was that.

Shoes however, have been a big factor over the years. For over 20 years I was told my foot/leg problems were due to neuropathic pain from the incomplete L3 injury back in 1988, but recent x-rays organised by a new orthopaedic consultant revealed it's arthritic changes between my second and third toes. I realise I've had it from a year or two after the injury as the site of the pain hasn't altered.

I'd always gone for light, flexible soles as they seemed to help the pain. However, this has changed since a visit to the Surgical Appliances department to have 'rocker soles' fitted to my left shoe. This means a stiff sole (even the thought of this could trigger my pain) which acts as a sort of splint to the unruly metatarsals and stops the constant flexing of my foot in the troublesome area.

Friends loved asking if I was 'rocking around the Christmas tree', or 'around the clock' or if I was a 'heavy rocker' (the latter I am, but am trying to diet).

I was sceptical about the supposed benefit of these shoes and I also questioned whether my balance, never one of my selling points, could be adversely affected.

The first day wearing the modified shoe (my right shoe was not modified) seemed just to move the pain around to a different part of the foot. It also made the back of the shoe (called the heel cuff), knock into my Achilles tendon as I walked. This often happens with new shoes or ones I've not worn for a while, and gives me a bad night's sleep with a nasty burning sensation in the tendon area and calf. However, it's a sort of initiation rite as after that things are fine.

I persevered. The consultant had said if the rocker sole did not help, then the next option was to have cortisone injections into the offending joint and ultimately having the bones fused. I had a busy day at work, walking around the retirement housing scheme on various tasks. Sometime in the afternoon I realised I hadn't noticed the pain for ages.

Since then, the pain has improved markedly and the appliance department has modified three shoes in total. Beyond this I would need to pay for the service. There are 'rocker shoes' available online but, it's important that items are chosen carefully, as 'Rocker Shoes' also means a type of sports shoe with a convex sole which apparently take a while to get used to as the centre of balance is altered.

In the days when I bought shoes, I found a company in Germany, Bär shoes (search for Baer comfort shoes) which are expensive but are good for your feet and last for ages. You can choose the type of sole and shape and there's a good range; they don't look especially 'orthopaedic' which I know can be an important factor. Ecco and Hotter are other brands which are useful. Cosyfeet shoes I found less comfortable.

I'm not keen on going out in shorts. My drop-foot splint is obvious and I need socks so there's the classic British fashion cliché of Brits abroad (sandals with socks) to fall into.

The streets of Britain are safe from my knees! **David Wheeler L1**

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SPAIN

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