Season’s greetings to all our readers
Origin’s live-in care services have been developed with your independence in mind.

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  - long term respite
  - university care support

- Providing first class services for those newly injured and those with existing, long term SCI

- Origin PAs can accompany you on holidays abroad or on business trips either in the UK or overseas

Specialist live-in spinal injury care

Owned and managed by Peter Henry, who has himself a C5/6 spinal injury Origin has a unique insight into how liberating, reassuring and life enhancing good quality live-in care can be. This guiding principle is at the heart of everything we do.
forward message

Next year in 2014, SIA will celebrate its 40th birthday and as Chair I want to use the occasion to reflect on the achievements of the organisation and look to the future. Part of SIA’s 40th celebrations will be to ‘Make 40 Matter’. We want members to pledge to do something to raise awareness of SIA. So have a think about what you could do and go to page 28 if you need some ideas.

I am pleased to report that the changes to SIA’s Governing Council were approved at the recent EGM and, at the AGM that followed, the Trustees had the opportunity to review the annual Impact Report. This Report highlights the great work that is done every day by SIA in supporting people affected by spinal cord injury. SIA is widely recognised as the leading provider of support services. I send my sincere thanks to all the SIA staff for their hard work and commitment in the past year.

I now begin my third year as Chair of SIA. I am confident that SIA can ride the storm of this challenging economic climate and I am looking forward to the year ahead and to ensuring that SIA is around for the next 40 years!

May I take this opportunity to send you all my best wishes for the festive season and wish you a Happy New Year.

Jonathan Fogerty
SIA Chair C5/6

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

The views expressed in forward are not necessarily those of the Spinal Injuries Association. Nor is SIA responsible for the use which might be made of the information provided. SIA does not endorse any commercial organisations and acceptance of commercial advertising or sponsorship, or editorial reference, should not be interpreted as an endorsement of the firms or products involved.
Wheeling over rough terrain

I should like to make a few comments about the excellent article in the October issue of Forward on choosing a manual wheelchair.

As the article says being able to change the wheels of a chair can improve the performance of the chair in different environments. In a wheelchair-friendly urban environment a lightweight, narrow-rimmed wheel with smooth high-pressure tyres will perform well, while on a rough off-road surface a stronger, wider-rimmed wheel with wide, deep, heavily-treaded tyres is preferable. Be aware that the differing depths of tyre will affect the diameter of the wheel which will have some effect on the chair’s geometry. If the wheels are parallel this should be of no significance, but if the wheels are cambered changing to a deeper tyre will cause the wheels to ‘toe in’ making the chair harder to push.

However, the major problem with using a wheelchair that is optimally set up for the urban environment is not the nature of the rear wheels but the nature of the casters. Normal sized casters are hopeless in the rough, and on a wheelchair with a standard setup it is not possible to fit casters with a large enough diameter to work well.

The best way to adapt a standard ‘urban’ wheelchair for the ‘rough’ is to fit a large single wheel to the front of the chair. I have such an adaption, known as the Rough Rider, produced by Da Vinci Mobility. Despite extreme use and numerous accidents it has enabled me to access the countryside with relative ease for many years. There are similar adaptations produced by other manufacturers but I have no first-hand knowledge of them.

It is best that the base wheelchair has either parallel wheels or an adjustable camber. I would also recommend that the base chair has the facility to fit push handles. No matter how strong you are, if you go seriously off-road you will occasionally get stuck and the handles will facilitate the efforts of those trying to un-stick you.

The other alternative is to choose a wheelchair with the large drive wheels in the front and the caster at the back, such as the Trekinetic. I have trialled this chair and been impressed by its versatility and the quality of its engineering. Both the Rough Rider and the Trekinetic have been reviewed in previous editions of Forward.

Further information can be obtained from the following websites: www.davincimobility.com www.trekinetic.com www.disabledramblers.co.uk

Roger Fitzwater T11

Pre-war survival rates

I am interested in the work of George Riddoch, the famous Scottish neurologist, who was responsible for treating spinal cord injured people at the London Hospital before the Second World War. I have come across an extraordinary story. It appears Riddoch’s sister became paraplegic following a road traffic accident on 13 July 1934. She qualified in medicine from Aberdeen University in 1927 but did not practise after her accident. I am interested in her career as she lived for over 30 years subsequently and must be the earliest record of a female paraplegic surviving prior to the opening of specialised spinal centres. I wondered whether any Forward readers know of other female paraplegics from before the war who might have survived their injuries? Please contact me via the Editor of Forward.

JR Silver MD
Fellow of Institute of Sports Medicine
Consultant in Spinal Injuries

Research study

I am looking for volunteers to participate in a psychology study I shall be conducting. My
Thanks

I am just taking the opportunity to thank all those who voted for me in the recent Trustee elections for another three-year term.

SIA is a cause very dear to my heart as I became paralysed two years before it came into being and it was a very, very difficult time in the lives of myself and my parents. It was impossible to get any information as there was no internet then.

Coming home was a very solitary and frightening time, with no friendly forums or chat rooms where you could air your concerns and problems and speak with someone who had a few more years experience under their belt.

SIA is approaching its 40th year and in that time it has helped tens of thousands of disabled people, families, friends, colleagues and health care professionals, both here and in other countries. In times of trouble and uncertainty the wonderful Advice Line staff have always been there to hold my hand till I get back to equilibrium.

Having been a Peer Support Officer at Middlesbrough Spinal Centre for nine years I like to think I was able to give a bit back and I always urge people to get involved.

I am greatly concerned at the lack of female PSO staff. Please ladies, if a vacancy does appear in your area, give some consideration to applying for it. Our female members need you!

Here’s hoping for another good three years making SIA better and stronger than ever.

Alison Lyon T10

Editor’s note: In addition to Alison, the following people were also elected: Jonathan Fogerty, John Borthwick, Raquel Siganporia and Judith Jesky.

Jonathan Fogerty has been re-elected as Chair of Trustees. Martin McLelland was co-opted to the Trustee Board and Michelle Howard will take over as Treasurer until such time as an external candidate can be identified.

UK Spinal Cord Injury Form

UKSCIF is a new networking and educational forum to facilitate research and the transfer of information between the voluntary, independent and statutory sectors.

If you work in the field of spinal cord injury and you want to make a difference UKSCIF would love you to join and be part of this exciting new Forum. Further details and a membership form can be obtained from lynne.carrick-leary@irwinmitchell.com
Can a stay in hospital affect my Disability Living Allowance?

Yes, most definitely. Four of the principal disability benefits – Disability Living Allowance, Personal Independence Payments and Attendance Allowance will stop after 28 days in hospital and Carers Allowance will stop after 12 weeks. In turn, this can affect your entitlement to any other means-tested benefits you are receiving. Consequently, you should let the DWP know if you, or a dependant, are admitted to hospital. If someone gets Carers Allowance for caring for you, they must tell the Carers Allowance Unit that the person they are caring for has been admitted. Once you have been discharged or given a discharge date, let the DWP and/or the Carers Allowance Unit know and these benefits will be reinstated, as long as you still meet the criteria.

What if I fail to notify the DWP or Carers Allowance Unit?

From October 2012 the DWP and local councils have the power to impose a fixed rate civil penalty of £50 on some claimants who have been overpaid a benefit. The overpayment of benefit must have been caused by a person’s failure to disclose changes by either:
(a) negligently making incorrect statements and failing to take reasonable steps to correct them, or
(b) failing, without reasonable excuse, to provide information or to disclose changes in their circumstances. So, falling under section (b), if you fail to notify the DWP or the Carers Allowance Unit that you are in hospital, they could impose a £50 new Civil Penalty and ask you to repay any overpayments. If your spouse receives Carers Allowance for looking after you and you haven’t informed the DWP you are in hospital, s/he could also be fined £50 and made to repay any overpayments.

For further information please visit: www.cpag.org.uk/content/claimants_lose-penalties or contact Ray Cross on the SIA Advice Line 0800 980 0501

I am going into hospital, how does this affect my Motability car?

The rules for this have recently changed. In the past, payments were not stopped for Motability customers, whose mobility component continued to be paid to the Scheme until the end of their Motability agreement. However, from April 2013 onwards, the DWP has started to treat all hospital in-patients in the same way, whether they have a Motability vehicle or not.

This means that, for disabled people with Motability agreements who go into hospital after April 2013, the DWP will stop paying the Disability Living Allowance mobility component to the Motability Scheme if you are in hospital for more than 28 days. Please note, as soon as you are admitted to hospital, you should notify DWP of your change in circumstance. If you are in hospital for more than 28 days, you, or somebody acting on your behalf, should contact Motability to discuss your individual circumstances. Depending on the expected length of your hospital stay, and of course your own preferences, Motability will discuss appropriate arrangements with you.

For more information please contact Motability on 0845 456 4566

I am keen to source details of holiday facilities where care is available in the UK. How do I find out what there is within easy reach of where I live?

SIA’s Advice Line staff have recently revised their list of wheelchair-accessible holiday accommodation where nursing care is available. These establishments have not been inspected by SIA but many have been recommended to us by members. Members who are interested in booking the accommodation should contact the owners direct to check the details and to ensure that their own requirements can be met before making a booking. Please contact the SIA Advice Line 0800 980 0501. Open Britain, part of Tourism for All, can help you source accessible accommodation and help source nursing care. For more information please visit: www.openbritain.net or Tel: 0845 124 9971

Holidays for All, a premier supporter of Tourism for All, may offer a similar alternative. It offers accessible holidays for disabled people with or without their friends, family or carers. For more information please visit: www.holidaysforall.org or Tel: 0845 124 9971

Holidays for All is a consortium of the UK’s leading disability charities and specialised tour companies which offer leisure activities and accommodation throughout the UK and abroad for people with sensory and physical impairments, their friends and families.
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"After months of struggling with other catheters I came across iQCath on a web search. I applied for samples & also received really good advice from their Helpline and now I find iQCath no problem whatsoever...thank you again!" iQCath user
Along with the new name, Rebuilding Lives after SCI Awards, we also have a new member of the judging panel for 2014.

In October we welcomed Claire Williams, daughter of Sir Frank Williams, to the Awards Committee. Claire decided to get involved due to the help that SIA gave her father when he became SCI in 1986. Claire has said “With the help of SIA and a strong support network, my father managed to rebuild his life and return to work as the Founder and Team Principal of the Williams F1 Team”

“I am honoured to be a member of the Rebuilding Lives after SCI Awards Committee, which is recognising individuals in the community, as well as the work of inspirational professionals who do so much to help those with a spinal cord injury lead long and fulfilling lives.”

Following the success of the Women in Spinal Cord Injury Awards in June, plans for a bigger and better event for 2014 are already underway. Along with the new name, Rebuilding Lives after SCI Awards, there are 16 new categories for your nominations.

The Awards
1. Outstanding Sports Achievement Award
2. Armed Forces Achievement Award
3. Inspirational Achievement Award for Young People
4. Inspirational Achievement Award for Adults
5. SIA Community Star Award
6. Inspirational Carer Award
7. Liz Martin Award for Achievement
8. Outstanding Nurse Award
9. Outstanding Physiotherapist
10. Outstanding Occupational Therapist
11. Outstanding Healthcare Assistants
12. Outstanding Consultant
13. Outstanding Case Manager
14. Outstanding Psychologist
15. Outstanding Team
16. Excellence in Legal Care Award

Nomination period
The wait is finally over. The Rebuilding Lives after SCI Awards nomination period is about to open!

We invite you to get involved. We all know someone who goes that extra mile. So why not recognise those achievements by nominating them for an award? Nominate a friend, a family member or a colleague, anyone who you know dedicates themselves to Rebuilding Lives after SCI.

The nomination period is open from 16 December 2013 to 28 February 2014, giving you all over two months to nominate!

Nominate online at www.spinal.co.uk/page/RLSCI or email RLSCI@spinal.co.uk and we will send you a Word version of the nomination form.

Gibbs Fund for Life Subscription Awards

Once again, SIA is pleased to offer 10 free Life subscriptions to forward following a very generous donation in 2010 from the Gibbs Fund. The fund allows us to offer 10 free Life subscriptions each year for a period of five years – this being the fourth year.

We will draw 10 names from amongst those who put forward their details for entry into a draw which is open to existing subscribers to forward magazine and new members. The draw is restricted to spinal cord injured people only. Names will be drawn by the Trustees at their February meeting.

If you are a spinal cord injured member and you would like to enter then please send us your name, address, telephone number and an email address if you have one, either by email to c.stribling@spinal.co.uk or by post to Life Subscription Draw, SIA House, 2 Trueman Place, Oldbrook, Milton Keynes MK6 2HH
Sarah Orr
Peer Support Officer for the London SCI Centre and North London

I am very pleased to have joined the SIA Outreach Services team. I have worked for a number of other SCI charities in various capacities, in the UK and internationally, in the twenty years since I broke my neck and I am very much looking forward to this new opportunity with SIA. During that twenty years I returned to high school to complete my Highers (I grew up in Scotland!), attained a BSc in Ecology and Environmental Science at Edinburgh University and more recently an MA in Human Rights from the University of London. I also love adventures and have travelled extensively since my injury, most notably spending eight months backpacking around Australia and New Zealand.

Understanding first hand, and through past professional experience, the many and varied SCI-related challenges that can crop up during time spent in a general hospital, and in an SCI Centre, I hope to be able to help anyone who finds themselves in this situation and I am looking forward to getting started in my new role!

Please feel free to contact me on 07535 774118.

Ellie Walsh
Trusts Manager

Before joining SIA as a Trust Manager, I was a Fundraising Assistant at a local grant making charity and a Trust and Legacy Fundraiser for a local hospice.

I thoroughly enjoy working in the charitable sector and I am excited about the new challenges of working for a national charity. Trust fundraising is a passion of mine and I look forward to working alongside the fundraising team, and co-working with Amanda Saville on Trusts and Legacies for SIA.

I am not spinal cord injured, but I am a staunch believer in equal rights and I am excited to be part of an organisation where equality plays such an integral role.

Although I grew up in Milton Keynes, I have lived in Edinburgh and Brighton. Whilst at university I specialised in gender politics and sexuality in late nineteenth century English and American fiction.

I love playing hockey, so I spend most of my weekend on a pitch, in the wind and the rain, chasing a small plastic ball with a stick; but I equally enjoy reading, going to the theatre and spending time with my friends and family.

We need your votes before 13 December

SIA is working in partnership with Aspire and Back Up to raise awareness and vital funds to support people with spinal cord injury. Earlier in the year we jointly applied to be London Luton Airport’s Charity of the Year for 2014 and we’re thrilled to announce that we have been successfully shortlisted!

In order to become their Charity of the Year we need YOUR vote! Anyone is eligible to vote so please spread the word to all your family and friends.

The voting period runs from noon 1 November to noon 13 December – votes will only be accepted during this period. You can vote by following the link on the front page of the SIA website www.spinal.co.uk

This is an amazing opportunity for our three charities so please support us. Thank you very much!

www.spinal.co.uk
PEER SUPPORT OFFICER –
GREATER LONDON (SOUTH)

SIA is seeking to appoint a Peer Support Officer to join its Outreach Services team, specifically to provide support within the Greater London area south of the Thames and surrounding counties. This post is in addition to that which already exists in the area covering north London.

The role of the PSO is to address the needs of newly injured people in non-specialist healthcare settings, working primarily within Major Trauma Centres and District General Hospitals and undertaking domiciliary visits in order to offer support to them and their families. Other key aspects of the role involve delivering in-service training and participating in Study days organised for Healthcare professionals. Due to the nature of the work we anticipate that the post holder will be spinal cord injured, will have excellent verbal and written communication skills and the ability to build strong relationships with key stakeholders. A confident and outgoing personality is essential, as is a willingness to travel. Previous experience in a support or information-giving role would also be advantageous.

The post is part-time (21 hours per week) and is offered on a three-year fixed-term contract at a salary of £14,134 per annum (£24,027 pro rata) plus pension scheme, Life cover and 28 days annual leave (pro rata and excluding Public Holidays).

Closing date for completed applications is Friday 3 January 2014
Interviews will be held at the SIA Office on Friday 17 January 2014

Visit the SIA website to download a Job Information Pack for either vacancy or e-mail c.pinches@spinal.co.uk to request a pack in Word format

PUBLICATIONS MANAGER

SIA publishes a range of literature on spinal cord injury and is currently seeking a Publications Manager to drive forward our publications programme and be responsible for the production of our magazine, forward, which is published six times per year.

Applicants will need to be good wordsmiths, have the ability to deal with authors, printers and designers, and all aspects of publishing copy from initial concept, through to proofing and published product. If you have experience of the publishing world, enjoy working with text and design, and can communicate effectively and persuasively with a range of stakeholders, we would like to hear from you. Based in our offices in Milton Keynes, the post is full time (9am to 5pm Monday to Friday) offered at a salary of £25,746 per annum plus pension scheme, Life cover and 28 days annual leave (excluding Public Holidays).

Closing date for completed applications is Friday 31 January 2014
Interviews will be held at the SIA Office on Wednesday 12 February 2014

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Thanks to the Big Lottery Fund Wales

Tony Stephenson, Regional Peer Support Officer, looks back on three years of delivering the service in Wales with the support of the Big Lottery Fund, Wales.

The last three years in Wales have been extremely interesting to say the least. I’ve supported over 200 SCI people and 150 family members and visited around 50 different hospitals. I’ve also given CPD-certified in-service training talks to over 200 healthcare professionals. Hopefully, all of those SCI people and their families have got something out of the regional peer support service and the support I’ve given them.

I was the first member of the regional peer support team to get an honorary contract with my health board, something that more and more members of the team are now getting. With the honorary contract I get an email address that health care professionals seem to prefer to use and an ID badge which really helps when visiting new hospitals or meeting staff that are new to me.

Wales is a real challenge. It’s a beautiful country (I’m probably a little biased) but the roads aren’t the best and with this job there’s a lot of driving. But I have supported SCI people the length and breadth of the country and it’s worth it. It makes a real difference, especially to those SCI people in areas where they think they would never get a visit from me as they are so isolated.

The Cardiff Study Days have been a particular highlight. The first one was held at Cardiff Metropolitan University and was very well received. In their feedback, professionals asked for a more practical day so that was what was given with the Moving and Handling Study Day held at Cardiff’s Millennium Centre this year.

Over the last three years, I’ve worked closely with Jakko Brouwers (Senior Service Improvement Programme Manager) at Rookwood SCI Centre and Sue Williams (Programme Manager in Nursing and Adult Lecturer at Cardiff School of Nursing and Midwifery) also at Rookwood. They have both been a great help. Jakko organised my honorary contract and Sue has attended some of my in-service training talks, giving her very knowledgeable perspective on SCI.

My main aim throughout the last three years has been, and still is, to support SCI people and their families. Initially this support was just for newly injured patients. But those newly injured patients rehabilitate and go home where they come across a whole new set of challenges and problems. So I carry on that relationship and support them for as long as they feel they need it. Over time that support is needed less and less, but they know if they have an issue I’m just a phone call away.

All this has been made possible with funding from the Big Lottery Fund, Wales. We are very grateful that they had the vision to support what has been a very successful three-year service, which I am looking forward to continuing to deliver in future.

Tony Stephenson T3
On 6 November 2013, The Court of Appeal upheld a legal challenge by five disabled people against the Government’s decision to close the Independent Living Fund (ILF) in March 2015. In an unanimous Judgment the court held that in December 2012, the Minister for Disabled People had breached equality duties when making the decision to close the ILF.

At the time of writing it is not clear what effect this Judgment will have on the future of the ILF and the long term implications for the people who rely on the Fund to provide (or part provide) their care and support. To keep abreast of developments on the ILF keep looking on the SIA website.

In the meantime, if you are experiencing issues with ILF and Local Authority Social Care Funding please contact our Social Care Adviser, Simon Legg, by email s.legg@spinal.co.uk or by phone on 07535 774135

Independent Living Fund

Secretary of State for Health, Jeremy Hunt MP, announced in his speech at the Conservative Party Conference that the Government would legislate in the Care Bill to give the Care Quality Commission statutory independence. He said “the care of our NHS patients is too important for political meddling – and our new legislation will make sure that Ministers always put patients first.”

Speaking at The Health Debate in Manchester, Chair of the Health Select Committee, Stephen Dorrell MP, said that in its current form the health and social care system was “not suitable or sustainable”. He said there was a need for change, and that the pace of change had fallen behind. He said he wanted to see the introduction of a system where families can prepare for the future and caring for their family.

Shadow Secretary for Health, Andy Burnham MP spoke at the Labour Party Conference on the same issue putting emphasis on the importance of ensuring that less pressure was put on a family member to be the lead carer for another family member. He described “whole-person care – for children and adults with disabilities too”. He said this country needed a service that looks after people who care. “For far too long, too much has been asked of family carers.”

Minister for Care, Norman Lamb MP, focused on care workers when he spoke at the Liberal Democrat Conference. He said that “delivering better care across our health and care system is something I am incredibly passionate about”. He spoke of a “horribly fragmented” health and care system and the solution being the more effective use of money and the joining up of care, “integrating health and social care, mental health and physical health, primary and secondary care”.

Mr Lamb said, “there is nothing that defines a society more clearly than the way in which it cares for the most vulnerable and for the elderly.”

The issue of care has been in the headlines frequently since the party conference season. Norman Lamb announced at the Westminster Health Forum in October that, as of April 2014, those in receipt of NHS Continuing Healthcare would be eligible to ask for a personal health budget. Prime Minister David Cameron said that “fitness-for-work” tests for disabled people must improve.

Bowel Management Survey

In 2004, SIA surveyed its members to gain a better understanding of their experiences of bowel management in District General Hospitals. The results gave SIA the evidence we needed to lobby for improvement in this area of SCI care.

The following year the Royal College of Nursing, in conjunction with SIA, produced revised guidelines for the digital removal of faeces. Amongst the recommendations, the guidance stated that the procedure should be undertaken by a trained practitioner, that if in doubt an SCI Centre should be contacted for advice, that each hospital’s Bowel Management Strategy should be regularly reviewed and that correct bowel management is the best way to prevent Autonomic Dysreflexia in SCI people injured at T6 or above.

Nearly 10 years on from our original survey, SIA has launched a follow-up survey to assess the impact of these guidelines and to identify examples of good practice where the guidance has succeeded in improving bowel care for SCI people.

SIA would like to hear about your experiences of bowel management, good or bad. The survey can be found on the Campaigning pages of SIA’s website. Alternatively you can request a paper copy by contacting SIA House.
**New SIA Social Care Advice Service**

**SIA** is pleased to announce our new Social Care Advice Service. This service is focused on the problems our members may have with their social care, which is support arranged after an assessment of need by their local council's social services team.

Since the Government announced massive cuts to local authority funding in the 2010 Spending Review, there has been a substantial increase in the number of calls SIA has received about social care problems. Many of these queries have been from people whose care packages are being reduced, and/or whose charges are being increased. Although the Government has said that there is no need for local authorities to cut social care budgets, this is not being reflected in practice.

There has also been a lot of queries from people who receive funding from the Independent Living Fund, and who were worried about what would happen to their support if the Independent Living Fund was dissolved into local authority budgets from 2015, as planned.

“flexibility in the way people are able to use their budgets has decreased, and it is harder than ever for disabled people to get their voices heard”

Simon Legg

There is a widespread process of change going on in social care, and more recently in health care as well. This is supposed to lead to disabled people having more control over the care and support they need, having more choices and to their services being flexible enough to support them to live the lives they want (rather than having to live their lives around the services they need). There is to be a shift in power, away from professionals and authorities and into the hands of individual disabled people and carers. This is sometimes called the personalisation of health and social care, or the personalisation agenda. These changes are not yet a reality for many disabled people (even though almost every social care user now has a “personal budget”, at least on paper, and Personal Health Budgets are expected next year). In many local authority areas it seems that bureaucracy has increased, flexibility in the way people are able to use their budgets has decreased, and it is harder than ever for disabled people to get their voices heard. At the same time the massive cuts to councils’ own budgets have made it much more difficult for positive change to happen.

In response to our members’ concerns, SIA has set up a new Social Care Advice Service, to try to provide the best possible advice and support to our members when they experience issues with their social care. It is closely modelled on the existing, very successful, SIA NHS Continuing Healthcare Advice Service, which has helped a great many of our members to obtain sufficient NHS Continuing Healthcare funding and to achieve a decent quality of life, living independently in the community.

The two services will work very closely together as jointly funded support from both health and local authority seems to be on the increase. SIA has also recently had more enquiries from members who have been put forward for NHS Continuing Healthcare funding by the local authority, as well as people who have had their NHS Continuing Healthcare funding reduced or stopped and been redirected to social care.

The new SIA Social Care Advice Service will support you to understand and take control of your social care, to get your support needs adequately met and to improve your quality of life. We can support you to prepare for assessments (both assessment of need and financial assessments); to gather relevant information and to challenge decisions; to understand the law, your rights and local authorities’ duties and powers; to look at alternative ways of meeting your...
What’s been happening?

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

CONSERVATIVE PARTY CONFERENCE

Fringe meetings
- Clinical Commissioning Groups: How are they working out?
- The Health Debate: A health and Social Care System Fit for the 21st Century
- Making the connection: Integrating Health and Social Care for the poorest
- Shirking or Working: Where next for Welfare Reform
- From Welfare to Work: Local solutions to a national problem?

Other meetings
- Meeting with SHINE
- Meeting with Spinal Injuries Ireland
- MASCIP
- Clinical Reference Group on SCI
- Personal Independence Payments (PIP) Implementation Stakeholder Forum
- Disability Rights UK AGM
- Integrated Health and Social Care Seminar
- Disability North exhibition
- Coloplast Symposium

The Social Care Advice Service is available on Tuesdays, Wednesdays and Thursdays between 9am and 5pm. Please contact Simon by phone, email or text on 07735 774135 or s.legg@spinal.co.uk with any issues, problems, questions or concerns you may have in relation to local authority social care. You can also contact the service via the SIA Freephone Advice Line on 0800 980 0501

What matters most to you?
In August’s edition of *forward*, SIA Member, Pat Barrett, wrote about his poor experience of having the RAC recover himself, his wife and his vehicle from the side of a motorway. In his letter, Pat highlighted two extremely important points as well as other minor ones. His two main issues were:

- Why were he and his wife left stranded on the hard-shoulder of the busy M25 for one hour and forty minutes?
- Why doesn’t the RAC have the provision to legally and safely recover a wheelchair user from a motorway?

Pat also wrote to the RAC highlighting these issues but after he failed to get a satisfactory response, SIA contacted the RAC on his behalf. Mark Cooley from the RAC Operations Executive, replied.

“Thank you for highlighting Mr and Mrs Barrett’s concerns about how we handled their request for RAC assistance recently. As a result, I have reviewed the circumstances of their complaint and contacted them directly with a more thorough response.

“That response includes clarity about how we will handle the recovery of a customer who is a wheelchair user. In most cases, when we have to recover a vehicle that has a wheelchair user as a passenger, if they are unable to travel in the recovery vehicle, then we will arrange for a suitable taxi, or utilise a private ambulance service, if necessary.

“The RAC would remain responsible for making whatever arrangements are necessary to ensure our members reach their destination. However, we would ask your members to bear in mind that the arrangement of all services are subject to availability and there may be delays in, for example, arranging a private ambulance.

“However, as you imply, this may not be immediately possible if the vehicle is on a motorway hard shoulder, or somewhere else where it is not safe to carry out the transfer of a wheelchair user from one vehicle to another. In these circumstances, it is not illegal to allow that passenger to remain secured in the broken down vehicle whilst it is transported to a place of safety, such as a motorway service area, where alternative arrangements can be made for the onward journey.

“As breakdown service provider to Motability drivers, RAC is clear about this issue and it was uncertainty on the part of a driver working for our contracted recovery agent who gave incorrect information to Mr & Mrs Barrett. I have taken steps to ensure that driver is updated on this point, as well as reiterated our position to colleagues within our operation.

“The RAC has been the service provider to Motability drivers for several years and is pleased to have recently renewed the partnership. Therefore, our teams are skilled in responding to the needs of customers with mobility issues and we will continue to ensure we provide outstanding service in this respect.”

SIA is keen to hear from any other wheelchair user who has recently had experience of being recovered by the RAC or any other breakdown service, to see how their policies on vehicle recovery for wheelchair users work out in practice.

If you have any such recent experiences please either email m.hutchins@spinal.co.uk or phone 0845 678 6633 ext 206.

Mick Hutchins C4/5
SIA Public Affairs Officer
Here are just a few ideas of how you can raise money for SIA over the festive season…
So easy you could do it with your eyes closed…

- Collect the stamps from all Christmas cards you receive over Christmas. Send them to SIA and we can convert them to cash. Tell all your friends and family to do the same.
- Instead of sending Christmas cards, donate the money you would have spent to SIA.
- Ask your office to hold a dress down day just before Christmas and donate the proceeds!

With just a little more preparation…

- Take an SIA collection tin to any clubs or societies you belong to.
- Hold a Christmas themed quiz at your local pub. Most pubs will be happy to help you organise a quiz on a Tuesday or Wednesday – a great way to boost their mid-week business and raise money for SIA at the same time.

- Have a pre-Christmas clear out and hold a car boot sale to get rid of unwanted items and donate the proceeds.
- Celebrate the festive season by inviting friends round for a coffee morning with cake and charge a small fee.

A little more thought but a whole lot more rewarding!

- Kick start your New Year’s resolution by signing up to the London to Paris Event in 2014, just one of our cycling events. Visit www.spinal.co.uk/page/londonparis40 for more information
- Organise your own New Year’s Ball and invite all your friends and family to donate funds to SIA
- Help SIA to Make 40 Matter in 2014 by signing up to complete a minimum of five pledges (see pledge form on page 29.)

More and more people are now using the internet as a means of commemoration and a memorial website can help you to share valuable, personal memories and thoughts about your loved one.

As well as sharing words about your loved one you can upload pictures, music and even videos. The site is also an invaluable way for family and friends, wherever they are in the world, to send their thoughts and contributions, maybe by adding a photo you’ve never seen or sharing a special story you’ve never heard.

A memorial website enables friends and family to come together, not only in sharing memories and thoughts, but in supporting each other during the long and painful grieving process. Some people will also use their site to pass on information to family and friends about funeral arrangements and later on anniversaries and other important milestones.

A growing number of memorial websites are now being used to help raise money for good causes in memory of a loved one. To find out more, visit the memorial charity website www.cornflowerfunds.spinal.co.uk

Memorial websites can be kept online indefinitely, meaning that you can create a lasting record and legacy to be kept in perpetuity for family and future generations to see.

For further details please contact Elizabeth Wright on 0845 678 6633 ext 229 or email e.wright@spinal.co.uk

London Legal Autumn Drinks

Over 150 guests enjoyed SIA’s London Legal Autumn Drinks in October. Great fun was had by all who spent the evening networking, bidding in the silent auction and enjoying a drink or two.

A huge thank you to everyone who attended, particularly Hilary Meredith Solicitors (who were celebrating their 10th Anniversary!) and Temple Garden Chambers, who both sponsored the event.

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Legacies: A momentous year

Last year was a momentous year for SIA during which we received an unprecedented level of donations from legacies. We were left significant gifts from several individuals which totalled over a million pounds. Due to the nature of legacy fundraising, it is not something which can be easily predicted or budgeted for and we have been completely overwhelmed and in awe at the immense generosity shown to us.

The last year included several legacies of a substantial size, but also many more of varying amounts, all of which are gratefully received and all of which enable us to continue providing services to spinal cord injured people and their families.

We have recently published our Strategic Plan for 2013-16, Pathway of Support, and the high level of legacy income we received last year means we are in a secure position to start implementing this plan and developing the support we provide. The individuals who remembered SIA in their Will have made a real difference to the lives of those we support for many years to come.

One of these individuals was Elizabeth Martin, pictured, or Liz as she was known to SIA. Liz sustained a high level injury (C3/4 complete) in an RTA in 1991, which eventually required her to be permanently ventilated. Despite this, she lived a very full and active life, which included serving as an SIA Trustee for seven years. Independence was very important to Liz and she acquired a vast knowledge of her impairment and how to manage it. This was knowledge she passed on to her PAs enabling her to live her life in her own home and in her own way.

Liz’s generous legacy to SIA will help us to continue delivering and developing services, such as our new Social Care Project which supports SCI people to get the care they need to live independently and our Master Classes which educate on a variety of SCI-related topics.

Every legacy left to SIA, no matter how big or small, helps us to make a real difference to SCI people and their families.

For more information on how you can include SIA in your Will, and to see SIA’s list of solicitors who provide a free ‘Will Writing’ service to SIA members, visit the legacy section of our website or contact Amanda Saville on 0845 678 6633 ext 222 or email a.saville@spinal.co.uk

Spotlight on The James Tudor Foundation

SIA is very fortunate to benefit from the support of many different Charitable Trusts and Foundations. We would not be able to deliver our services without this support. This new ‘spotlight’ feature will enable us to demonstrate the impact Trust funding makes to our service delivery.

One such funder is The James Tudor Foundation. Established in 2004, its main object is the relief of sickness. The Foundation’s first donations to SIA, in 2010 and 2011, launched the Community Peer Support service in the North West. This service has since gone on to support over 300 spinal cord injured people and their families and covers 50% of District General Hospitals in the region.

This year the Foundation has renewed its support to SIA with a two-year pledge to support the Continuing Healthcare project. Due to the current economic climate this service is in high-demand and the support from the Foundation will ensure it continues to be available to those who need it. Rod Shaw, Chief Executive of the Foundation said: “The James Tudor Foundation is pleased to continue its support of the Spinal Injuries Association with funding towards the post of the Continuing Healthcare Adviser. It is essential that disabled people receive the support they need to receive the quality of care they deserve.”

The difference The James Tudor Foundation has made is immense and we are very grateful for their on-going support. To find out more about the Foundation visit their website www.jamestudor.org.uk

Charity of the Year

Be part of our big Anniversary!

2014 is going to be a really exciting year for SIA as we celebrate our 40th anniversary. It’s not too late to become part of the celebration and make SIA your Charity of the Year for 2014! We have a full fundraising and promotional campaign running throughout the year. It’s a great opportunity for your company to get involved and get some exposure whilst joining in the fun.

For more information contact Stephanie Potter on s.potter@spinal.co.uk or call 0845 678 6633 ext 232
“I can’t wait for the next Fish and Chip night! Can we have one every month?” asks our 4-year-old nephew every time we see him. We have held a Fish and Chip night to raise money for SIA for the last three years and the event seems to have captured his imagination so much that he is always seeking new games, songs or costumes.

Preparations start weeks in advance as SIA invitations are sent to friends with the order to ‘wear something fishy’. Efforts so far have included dressing up as pirates (complete with inflatable parrot and a bottle of rum), wearing fish ties, flippers, homemade anchor necklaces, fish facemasks, fish swimming hats and fishing nets. The less adventurous wear normal dress and claim to be cruise-ship passengers.

Our home is decorated with SIA balloons, posters and collection boxes. A shower curtain covered in fish creates a “river” on the floor, and pirate cups, plates and napkins adorn the table. Then the games begin! The SIA quiz tests all abilities; the children enjoy guessing the number of shells in the jar or number of fish oil capsules in the bottle; there is a race to complete different parts of a fish jigsaw puzzle and we play ‘Pop-up Pirate’. The highlight this year was the unveiling of a super hand-knitted lifeboat-man and we all had to guess his name (Clive).

Once the fish and chips and the ‘Phish food’ ice cream (complete with chocolate fish) are eaten, the sing-along begins! We have a CD of the hearty Filey Fishermen singing hymns such as ‘Take the Lifeboat’ and ‘Will your anchor hold in the storms of life’ and we pass around hymn sheets and join in (points awarded for the best singing). The grand finale is when my nephew joins me on the organ and we play a medley of tunes. With a full stomach and the joy of friendship, fun and song, donations readily come in. And one very excited 4-year-old boy then cannot wait to tell his classmates of the great time he has had, whilst also learning about giving.

Helen Cowan, SIA Supporter

SIA’s Fish and Chip supper event is held every year to coincide with Spinal Injuries Awareness Day. This will be held next on 16 May 2014, but it’s such fun you can hold one at any time of the year and SIA will offer all the support you need. Telephone 0845 678 6633 ext 229 for more information.

Bristol Barristers support SIA

Members of the Personal Injuries Team of St. John’s Chambers, the largest barristers set in the South West, hosted an evening drinks reception at Bristol Marriott Royal Hotel, sponsored by Frenkel Topping. This was followed by a full-day conference sponsored by Irwin Mitchell LLP on behalf of SIA. The two events raised over £5,000 in total.

Key-note presenters addressed a range of current hot topics, including rehabilitation, disability and employment risks. Consultant Surgeon in Spinal Injuries, Brian Gardner FRCS FRCP was the headline speaker who addressed clinician reports in spinal cord injury claims.

Back Row, from left: Paul Scrutton, Frenkel Topping; Sarah Tennent, SIA; Derek Jenkins, Chief Executive St Johns Chambers; Steve Ashcroft, Frenkel Topping; Glyn Edwards, St John’s Chambers

Front Row from left: Steve Hodges, SIA Peer Support Officer (South); Peter Hutchings; SIA Peer Support Manager (West); Tony Stephenson, SIA Peer Support Officer (Wales)
Are you ready for the Zombie Evacuation?

Calling all friends and family!

On Saturday 5 October, Sarah Tennent, Business Development Manager for SIA took part in the Zombie Evacuation 5K Run in Cambridge, to help raise money for us.

“I cannot recommend this event enough. It was an absolutely fantastic day. If you want an event with a difference, this is definitely the one to choose. My friend and I did not stop laughing (and screaming) the whole way round the course,” said Sarah.

“The zombie costumes were fantastic and the volunteer zombies even have to go to zombie school to learn how to move and sound like a zombie, which all adds to the brilliant atmosphere on the day. The course is full of surprises along the way with zombies hiding in long grass and jumping out and chasing you, a pitch black house you have to quickly run through, zombies squirting you with fake blood, rooms with dead ends where the zombies can trap you, obstacles and much more. We loved it so much we are doing it again next year with a big group of friends, but in one of the night time running slots rather than a day-time slot, so it will be even scarier and more adrenalin charged.

“Whilst it does make you scream and jump, it is also extremely funny. I am a scaredy-cat anyway when it comes to jumpy horror films so if I can do this anyone can! You will not regret it and will be talking about it for days afterwards and telling all of your friends how amazing it is and that they have to do it too.”

For more information about future Zombies Evacuation events please contact Elizabeth at e.wright@spinal.co.uk

Or maybe the Colour 5k?

Helen Chapman, SIA’s Communications and Marketing Officer has also been running to raise funds for SIA. She writes...

“I signed up to take part in the Colour 5k run after seeing an advert on Facebook. The photos of previous Colour 5ks looked fantastic and I thought it sounded like an interesting twist on a 5k run, and boy was I right!

On 31 August I parked my car in a field in the village of Little Houghton, Northamptonshire, and was led into an adjoining field where organisers warmed us up and explained the 5k course. We were to run round a 1k loop five times to complete our 5k. Half way round the 1k loop was a water sprinkler system that would suitably drench us so when Colour Bandits threw powder paint at us, at the end of the 1k loop, it would stick.

The hooter sounded and some 100 runners, including me and two friends, were off. At the end of the first 1k loop I nervously entered the first Colour Station...“No Andrew! Don’t chuck the paint in their mouths!” shouted one Colour Bandit as I coughed and spluttered my way through, with my face and front now dripping with red paint. Note to self. Must remember to keep my mouth closed next time!

The second, third, fourth and fifth lap continued in a haze of blue, orange, green and purple and at the end we all looked like different versions of the same running masterpiece.

The run was a great giggle, one I would definitely recommend, and for me, the best bit was finding out that I raised over £110 in sponsorship for SIA.

Find out more about the Colour 5k runs at www.colour5k.co.uk

www.spinal.co.uk
Conveen Optima has a new look and...

Conveen Optima is the leading sheath designed to make life with incontinence as trouble-free as possible, giving men back their independence and sense of control.

We have been listening to what you tell us and have made some improvements to the Conveen Optima packaging!

The compact Smart Pack now has a turquoise touch point with an arrow, on the top right hand corner, which makes it more intuitive to open. The colour on the size label has also been enhanced making it easier to identify sizes. Finally, the double-strip applicator on the sheath itself has also changed to a turquoise colour from white.

By listening to your feedback and comments we have been able to incorporate some of these into the product, which in turn makes it easier to use. So, whenever you see a turquoise colour touch point on Conveen Optima then this indicates an action.

...Peristeen has a new lid!

Peristeen now has a new and improved lid making it intuitive to open and more discreet.

At Coloplast we are always looking for ways to improve our products to make life easier for our Customers.

Over the past 2 years Healthcare Professionals and people who use Peristeen have made us aware of improvements that could be made to the lid of the Peristeen water bag. We have listened and responded. As a result we have redesigned the lid making it more intuitive to open and much more discreet.

Peristeen is a simple solution that empties the bowel effectively.

If you would like to receive further information and/or a DVD about Peristeen or Conveen Optima, then please contact Charter Healthcare on freephone 0800 220 622, or visit www.coloplast.co.uk
Many people with spinal cord injuries live with severe symptoms of constipation. If you live with chronic constipation, you may have tried to improve the situation by modifying your diet and even taking medication but with limited success. However, there is a different approach. Peristeen is an effective and predictable system, which can be used routinely at home. It’s available on prescription from your doctor.

For an information pack call: 0800 307 7975 or visit: www.my-bowel.co.uk

Putting you in control with Peristeen

Coloplast Ltd, Nene Hall, Peterborough Business Park, Peterborough PE2 6FX
Christmas with the PA

A really effective client / PA relationship is one in which the PA understands the wishes of the client and supports him/her to live their life their way. Conversely, the client should understand the needs of the PA and ensure a safe and secure working environment.

Often the relationship evolves over a period of time to suit both parties. Whilst the PA is there to meet the needs of the client, we understand that in order for this to work effectively the PA needs to ‘fit in’ with the client’s wider family. We cannot divorce the client from spouse, children, parents and friends; indeed these people are important for the emotional health and well-being of the client.

This brings me nicely to Christmas. It is a time of year when most of us re-connect with our extended families. Happily, this can be a very rewarding experience, though speaking from personal experience emotional strains are sometimes just under the surface.

This is difficult enough when dealing with members of one’s own family – it is doubly challenging if an ‘outsider’ is also present. For this reason I would encourage clients and PAs to prepare for Christmas. Firstly, it is worth remembering that it is Christmas for the PA too. S/he is working and not with his/her loved ones. Secondly, there will inevitably be changes to the usual routine and it is helpful to discuss what this may entail. For example you may not want bowel management at a particular time or on a particular day. You may want to be left for extended periods. Finally, the client should be aware of any eccentricities and tensions in their family. Forewarning the PA of a great uncle’s tall stories or a cousin’s (embarrassing) signature party piece would be especially helpful!

Many clients choose not to have a PA at all over the Christmas or New Year period, leaving it to the family to support them. This is, of course, perfectly OK. However, before going down that route it may be worth asking, ‘Do they (and you) have the capacity and skills to support you? Do they really want to?’ Again a discussion beforehand may save any embarrassment later.

In the final analysis, it is about enjoying the festive season safely. So, I would like to take this opportunity to wish all forward readers a very joyful Christmas and a happy New Year.
The Convenience of not needing a Convenience.

The VaPro Plus Hydrophilic Intermittent Catheter offers all the benefits of the standard VaPro Catheter, with the added advantage of an integral 1000ml collection bag, delivering catheterisation on-the-go.

- **Protective tip** helps shield the catheter from contact with bacteria in the distal urethra. This reduces the risk of carrying bacteria further into the urinary tract to help support well-being.

- **No additional water is necessary** - sterile water vapour molecules are already inside the foil packaging. They activate the catheter’s hydrophilic coating, making the catheter lubricated, smooth, and ready for use right out of the package.

- **Touch Free** protective sleeve helps assure confident handling and helps reduce the risk of possible bacterial contamination during catheterisation. The sleeve also makes the catheter easy to grip and thereby easy to use.

Now you can experience all the benefits of VaPro on-the-go.

To receive a sample, or to find out more about VaPro Plus, please visit [cathetersample.co.uk](http://cathetersample.co.uk) or call 0800 521 377

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I was recently appointed a Trustee of the charity and am keen to spread awareness of the grant programme. Thirteen years ago, I was a patient in the Salisbury SCI Centre when an accident left me with a high level spinal cord injury. My experience means that I have a good understanding of the needs and challenges faced after SCI.

SSIT’s aim is to assist people with SCI, enabling greater independence and quality of life. Over the years the charity has funded a wide range of equipment including powered wheelchairs, handbikes, specialist mattresses and beds, physiotherapy, speech equipment and fertility aids. We have even part-funded a boat!

One recent beneficiary is Bruno Hansen who has a T12 spinal injury following a road traffic accident in 1998. A former charter yacht captain, Bruno continues to lead an active life in Cornwall. He applied for a grant from SSIT for a Freewheel this year, which he says “has revolutionised his life” allowing him to get out and about with ease. He commented, “Rough terrain is no longer a barrier and I am so much more independent”.

Part-funding for IVF is another important area of our funding programme and it’s heart-warming to receive news of the birth of a baby. Steve and Sally Hodges now have two children born following IVF treatment. Steve contacted us to say thank you: “We feel complete as a family and this would not have been possible without SSIT’s generosity.”

If you have any equipment needs, and live in our region, we encourage you to apply to SSIT. The Trustees meet four times a year at which time applications are reviewed by a team of spinal injury specialists. Should you have any questions you can contact me by phone or email. We are there to help you in any way that we can.

Paul Smart C4/5
Email paul.smart@ssit.org.uk
Tel 07935 054 622
Website www.ssit.org.uk
I survived a horrific car crash back in March 2008. Not only did I sustain a spinal cord injury, C5/6/7, but I also scalped the top of my head which meant that I was left with a massive bald patch. So you can imagine what that did to my self esteem and confidence! At the time I did not realise the extent of my head injury.

During the first eight weeks post accident, I spent my time in three hospitals, where my appearance was the last thing I actually thought about! Eventually, I was moved to the SCI Centre at Salisbury Hospital, where I knew that I was in for the long haul. However, my head injury took priority over my spinal cord injury. I was lucky to meet the most amazing plastic surgeon, who after three head operations, has managed to restore most of my hair again. She was so knowledgeable and professional, and with the use of tissue expanders she managed to stretch my skin with hair follicles and I now have an almost full head of hair again.

When my rehab at Salisbury was complete and I moved into my new adapted home, I started to worry that I would never get a decent hairstyle again. Luckily Tanya, my previous hairdresser, came to the rescue! She kindly offered to cut and colour my hair at home, even though she’s extremely busy and owns her own hair salon. We had to carefully consider the problem of my incredibly stiff neck, so initially we found a way to bring me forward in my wheelchair and tip me over the bath, with of course the assistance of my wonderful carers! It’s a rather tricky manoeuvre as you can imagine, but great care was taken of course.

However just recently we have tried another approach and I can now tip my head backwards over the bath as I have gained more control and flexibility over my neck, which makes life a whole lot easier.

Due to those head operations I now have thinner hair compared to before the accident, so great skill is needed to cover any bald patches which are lurking underneath! Tanya has passed on some useful tips to my care team, which creates the illusion of fuller hair. For example, back combing is amazing for cover ups, but obviously it has to be smoothed over to give a sleeker look. Also I have discovered a product called ‘Fullmore’ - coloured hair thickener, which can be found on the internet for approx £20. It can be devastating for a woman to have a bald patch, so hopefully my tips will help others who may have encountered similar problems.

Thanks to the skills of her plastic surgeon, Peggy has almost a full head of hair again.
Having become paralysed in 1993 (age 11) at T6/7, it wasn’t until I left home to attend Southampton University that I first began to recognise the sudden, unpleasant symptoms of what I would come to recognise as Autonomic Dysreflexia (AD).

However, I initially put these feelings down to my enthusiastic participation in Freshers’ Week, as the symptoms of AD are comparable to a particularly awful hangover. However, the effects would come on far more violently and disappear far more rapidly than any other hangover I had experienced previously.

Concerned there was a deeper issue than my inability to tolerate alcohol, I consulted my university doctor but was met with a shrug of the shoulders and an unhelpful ‘well you’re paralysed, your whole body is messed up, or soon will be’ attitude.

Reassured by this stunning level of medical insight and convinced that this was yet another of the hurdles to overcome in becoming paralysed, I resolved to lay off the tequila and continued with university life in blissful ignorance.

I was in my mid 20s before I even heard about AD. Following an MOT admission at Stanmore SCI Centre, I recognised the symptoms as they were described to me almost immediately. It turns out my sudden pounding headache, shivers, goose bumps and sweating could be a result of AD and not a tequila-induced stupor. It seemed I owed Señor José Cuervo an apology!

So what is it?
The medical definition of Autonomic Dysreflexia is that of a syndrome characterized by a sudden exaggerated reflex rise in blood pressure which is sometimes accompanied by bradycardia (low pulse rate), in response to a stimulus originating below the level of the spinal cord injury.

The stimulus could, for example, be pain below the level of paralysis or an overfull bowel or bladder. AD can affect anyone with an injury level of T6 or above. If the excessive rise in blood pressure is left untreated it can result in haemorrhage, stroke, seizure or potentially death.

So AD was soon added to the growing, spinal cord related, lexicon my friends and family had to learn. A whole new, exciting world of ‘spasms’, ‘catheters’ and ‘pressure management’. It became part of our everyday life and was all the more manageable because of that familiarity.

In fact I was glad of that familiarity, when I fractured my knee during a skydive some years later. The AD I experienced afterwards was the main reason I knew I had caused myself an injury and was ‘in pain’.

I knew what it was, I knew to tell someone about it, and I was not afraid to tell the non-spinal doctors treating me why they should take this seriously!

But therein lies the problem. Healthcare workers, at least those who are not spinal cord injury specialists, have rarely heard of AD. It’s perhaps unsurprising then, that many fail to appreciate the significance of such a condition, even in the face of the protestations of their patients.
One day last year, Ian noticed that he was beginning to feel unwell and passing blood through his catheter. This had happened a few times and on each occasion he was diagnosed with a UTI. After several hours, he started to experience the early symptoms of AD such as the skin becoming flushed and a tingling sensation. His symptoms became worse and he started sweating and developed a pounding headache. Ian called 999 and told the operator he thought he was experiencing AD and must be treated with urgency.

The operator proceeded to ask Ian a barrage of unrelated questions whilst the AD continued to worsen, to the point of becoming intolerable. The pain from the headache was impeding Ian’s ability to answer questions and contributing to his anxiety, as he knew full well that the situation was serious. The operator was not listening to Ian and insisted on following standard procedures before dispatching the ambulance. Eventually an ambulance arrived, but Ian had to go through the rigmarole of questions and differential diagnosis again before they were allowed to take him to hospital. This included performing an ECG test and testing him for diabetes. Despite Ian telling them he had AD and showing them his GTN spray which he had used, the paramedics simply said they hadn’t ever heard of AD and insisted on working through their standard checklist, thus overruling Ian’s knowledge and experience.

Fortunately Ian’s symptoms of AD had begun to lessen at this stage and when he was eventually transferred to hospital, A&E staff diagnosed him with a blocked catheter and UTI, as expected. Driven by his harrowing experience and a desire to prevent others from having to endure this unnecessary distress, Ian has sought to raise awareness of AD amongst paramedics and collaborated with a medic to draft an article for a paramedic industry magazine. Moreover, through his job at SIA, Ian continues to impart his knowledge and experience to those who are newly injured and supports them through the incredibly difficult period when they first become paralysed.

Being able to articulate your needs and having the confidence to do so with conviction are all part of the learning curve when you become paralysed. Being able to discuss this with people like Ian is an invaluable resource, as is the work he is doing in bringing AD to wider public attention.

**So what can I do to protect myself?**

### Special Patient Register

Contact your GP and ask about the Special Patient Register. To join, you simply ask your GP to complete a form, which outlines the conditions you are at risk of developing; the idea being that when you call 999, your name should be flagged up and you are automatically taken to hospital. Once there, you will be treated promptly for your potentially life-threatening condition, thereby avoiding unnecessary delays.

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**Top Tips**

1. **Tell friends and family that you may experience AD so they know what it is and can tell others should you not be able to experience it in the event of an emergency.**
2. **If you are concerned about experiencing AD, speak to your treating spinal cord injury specialist for more information about possible medications and how to manage AD.**
3. **Carry a completed SIA Emergency Card with you.**
4. **Ask your GP to complete the form for the Special Patient Register so you are on the list.**
5. **Stand your ground!**

**Symptoms of AD**

- Feeling flushed or a tingling sensation in your face.
- Excessive sweating or shivering.
- Sudden onset of a pounding headache (as though your head is about to explode).
- Extreme anxiousness, adrenaline or a sense of impending doom.
- Nasal stuffiness or possible blurred vision.

---

Raquel is Vice Chair of SIA and works as a clinical negligence solicitor at Bolt Burdon Kemp. Bolt Burdon Kemp are proud sponsors of Ian Younghusband, Peer Support Officer for the North East
Make 40 Matter in 2014!
by raising awareness and funds for SIA.

“When mum was diagnosed with Transverse Myelitis our lives changed overnight. SIA has always been there, offering advice, information and support.” Tracy Hartley, SIA Community Star.

In 2014 the Spinal Injuries Association (SIA) will be celebrating 40 years of rebuilding lives after spinal cord injury. We are looking forward to kicking off our programme of 40th Anniversary activities with our Make 40 Matter pledges! And here's how you can help...

We are looking for committed Make 40 Matter pledgers to undertake a minimum of five pledges (from a list of 40) during 2014. Pledges range from something as easy as wearing an SIA wrist band or retweeting an SIA message, to organising fundraising events of your own. The aim of the Make 40 Matter pledges is to raise awareness of, and funds for, spinal cord injury and SIA’s vital services.

As a committed supporter, Tracy has already pledged her support to SIA next year, “In 2014, I will Make 40 Matter by cycling in SIA’s London to Paris bike ride”. If you think you can help us to Make 40 Matter, please email fundraising@spinal.co.uk

To read about the events planned for our 40th Anniversary year, please turn to page 11.

A time for sharing
“In July 2004, after enjoying a day at the park with friends, we all decided to head back to my brother’s place. A few people got in his pool and I decided to go in too. I dived in not thinking about what I was doing, and my body just shut down. After doing a pathetic doggy paddle and trying not to drown, my friends soon realised I wasn’t messing around and pulled me out.

I was taken to the local hospital where I was put into halo traction for about six weeks. I was then transferred to Rookwood Spinal Cord Injuries Centre where I spent a further ten weeks rehabilitating. I left using two sticks to help me walk.

When I look back I’m really proud of myself and how I dealt with it all. I met some amazing people in hospital who I am still in contact with today. The nursing staff, physio team and OTs were all fantastic. I think my dad and brother found it difficult to talk about my injury or accept it at first but things got easier for them when I got home. My mother was fantastic. I owe an awful lot to her, she is my rock!

Whilst in Rookwood SCIC I received advice from Tony Stephenson, who was volunteering for SIA. Tony taught me to try and think things out before I make a choice.

Tony later moved on to become the Peer Support Officer for Wales, and I was lucky enough to secure the post of Peer Support Officer for Rookwood SCIC. I am really proud of that.”

Paul, C6 Incomplete

The sharing of experience is at the heart of everything we do. Sharing personal thoughts and feelings, as well as ideas and motivation for rehab can help others come to terms with their injury and motivate themselves to push forwards.

Every day next year we aim to share a different person’s experience of SCI.

Help us to raise awareness of SCI during our 40th Anniversary, share your story at www.spinal.co.uk/page/My-Story
To Make 40 Matter in 2014 I pledge to... (please select at least one option in each section)

### Raise awareness by...
- Wearing my SIA pin badge every day
- Wearing my SIA wrist band every day
- Using my SIA trolley token key ring every time I shop
- Wearing SIA clothing items at fundraising events
- Signing up 40 people as new SIA members
- Emailing 40 contacts about SIA’s tribute fund
- Getting 40 contacts to write to their local MP using our campaigns tool kit
- Promoting SIA’s Royal Dinner ballot 40 times
- Emailing my company about SIA’s Ruby Corporate Partnership
- Adding SIA’s Make 40 Matter slide to any work powerpoint presentations
- Voting for my company to make SIA our Charity of the Year
- Subscribing to forward to keep up to date with the 40th Anniversary news

### Join the digital revolution by...
- Joining SIA’s Linkedin group
- Following SIA’s Twitter feed
- Liking SIA’s facebook page
- Recommending SIA’s facebook page to 40 facebook friends
- Updating my facebook cover photo to SIA’s for 40 days
- Updating my Facebook status to “Make 40 Matter with SIA” 40 times
- Using the hash tag #Make40Matter in 40 tweets
- Reposting 40 SIA social media messages

### Be an SIA Community Star by...
- Attending a Great British Fish and Chip Supper
- Organising my own Fish and Chip Supper
- Distributing 40 Fish and Chip Supper posters

continued overleaf...
Promoting the Fish and Chip Challenge to my local chippy
Baking and selling 40 cakes to friends, family and colleagues
Holding a ruby themed mufti day at work or school
Organising a 40 sponsored pub crawl
Holding a 40 stop relay challenge
Holding a forties inspired tea party
Celebrating your 40th with SIA

Show my support by...
- Distributing 40 donation boxes in my community
- Donating £4 a month as a committed giver
- Donating £40 to the Make 40 Matter online fund
- Texting DSIA01 £4 or £40 to 70070 to make a one off donation
- Donating £40 to SIA Xmas Star appeal
- Buying 40 SIA Christmas cards

Join Team SIA by...
- Promoting London to Paris bike ride to 40 contacts
- Joining Team SIA on for the London to Paris Bike Ride
- In 2014 swimming at an event with Team SIA
- Running with Team SIA at an event in 2014

Please provide your contact details so we can assist you as you take on your 2014 40th Anniversary pledges!

Your details...
Name
Address
Postcode
Telephone
Email

Please return your pledge form to...
Make 40 Matter
Spinal Injuries Association
SIA House
2 Trueman place
Oldbrook
Milton Keynes
MK6 2HH

40 years of rebuilding lives after spinal cord injury

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- We can also provide assistance on a live-out basis in and around Lancaster/Lune Valley area.
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For further information call us on 01539 730777
email
enquiries@spinalhomecare.co.uk
or visit
www.spinalhomecare.co.uk
Recent technological advances have certainly improved things. The arrival of internet shopping has enabled people to access a much wider range of products than was previously available. Someone in Sweden has invented a new doohickie that makes life easier for people with reduced dexterity. A few clicks (and perhaps a large bank balance) can see the product racing to your letterbox.

This improved access to potential customers provides more opportunities to turn a 'niche' item into a successful product. Indeed, one lives in hope that this will bring costs down as many 'access products' tend to be very much more expensive than those with wider applications.

Designed2enable.co.uk is an example of how this technology can be used effectively. Born out of frustration, the site was launched by SCI wheelchair user Katherine Pyne and her husband John to make it easier for people to find 'assistive products that look good'. With a range of products that include contemporary shower seats, grab rails and bathroom accessories, designer walking canes and ergonomic gardening tools, Designed2enable.co.uk also contains this stirring mission statement.

“Our environment has a huge impact on our state of mind and we believe that if we surround ourselves with good design, then we will thrive.”

Another company that seeks to challenge the institutional aesthetic so common in adaptive products is Motion. In 2005, Motion co-founder, James Taylor, broke his neck diving into the sea in Portugal. After eight months in Stoke Mandeville, James returned home to his flat in Battersea, South London, to find a range of equipment had been installed to make his life ‘easier’. James and his wife Katherine suddenly found their home full of all-too-familiar grey padded shower seats, white plastic support rails, inaccessible showers and depressing furniture.

Together with close friend Ed Warner, James and Katherine set up Motion to provide an alternative so that other people could avoid the same frustrations. The company regularly brings together a group of 'Range Architects' with a diverse range of disabilities. Meeting every three months with the co-founders, they provide feedback on what really works, and what needs to be improved before products are added to the range and made available to buy. Motion also offers free expert advice (online and by phone) from Occupational Therapists to make sure that the products recommended are fit for purpose.

www.motionspot.co.uk

While technological improvements in logistics are helpful and personal experience invaluable, advances in computer-aided design (or CAD) provide some really exciting opportunities for innovative ideas to reach the marketplace. CAD enables a home computer to be turned into a powerful design and prototyping tool, and can even give the user insight into the properties of different materials for manufacture.

Access to powerful tools means that, now more than ever, resourceful individuals who have found innovative solutions to everyday problems have the potential to realise their idea and bring it to market.

A recent example of this process is
The widely publicised development of the Carbon Black wheelchair. Designer Andrew Slorance set out to make a wheelchair that is, “More desirable technology than it is medical device.”

Slorance’s wheelchair design uses carbon fibre to produce a sleek product with a very different appearance to the standard ‘box’ and ‘z frame’ wheelchairs we are used to. Along with other carbon-fibre wheelchairs like the Panthera X, Carbon Black is a good example of how digital design tools can maximise the potential benefits to be gained from materials new to wheelchair manufacture. The expensive testing and development processes of the past would have been virtually inconceivable before the emergence of CAD. Designs can now be tested virtually, without the need for costly prototypes.

Another useful tool that has advanced in recent years is 3D printing. This allows the user to ‘print’ a unique three-dimensional object in a matter of minutes. This technology is already seeing applications in medicine, with metal or ceramic prosthetic implants being designed by surgeons using MRI and CT scans to tailor the item to the individual patient’s requirements. And while this ‘top end’ use of technology is very expensive, the cost of desktop 3D printers that produce plastic items has come down significantly, which could change the way that personalised products such as splints and other everyday tools are produced.

Perhaps the most exciting potential consequence of these developments is their ability to make designers of us all. Back in 2010, then RSA Director of Design, Emily Campbell organised a series of events to test the idea that design as a discipline, or structured thought-process, can address the dramatic loss of confidence and diminished motivation that can result from a sudden physical impairment, and contribute to independence. Campbell argued that design’s potential today was to make people and communities more resourceful and self-reliant.

Designers are very resourceful – practical, good at improvising solutions, comfortable with uncertainty and brave about sorting out complexity and disorder. The RSA programme looked at the potential of developing a new model of design-training, focused on self-reliance and creative resourcefulness.

Besides an inevitable personal interest, Campbell (whose brother is T4) chose spinal cord injury as a focus for the project for two reasons: firstly because it is possible to argue that spinal cord injured people have experienced a sudden and dramatic loss of resources and furthermore, the point of rehabilitation is to regain self-reliance or independence.

The response to the project was universally positive; Glasgow, Stoke Mandeville and Sheffield SCI Centres all set up Design & Rehabilitation projects with elements of the programme continuing. One hopes that thinking about design can become an important element of the rehabilitation process, inspiring recently injured individuals to think of their environment as something they can shape to suit their needs.

In the future, while the advance in technology puts ever more sophisticated tools within reach of more of us, the most exciting potential offered by design could lie in building confidence and inspiring more of us to find our own solutions to the problems we face every day.

Tim Rushby-Smith T12
A user’s perspective

Why 'less is more'

Tom Nabarro is a software engineer. While he was an undergraduate at Brunel University in 2007, he had a snowboarding accident which resulted in tetraplegia. He was in Stoke Mandeville for 15 months rehabilitation before leaving to take up his current job.

We asked Tom to look back at the various forms of assistive technology that he has experimented with in the six years since his injury, from the early days in the OT department at Stoke Mandeville in a manual chair and a neck brace, to his latest explorations of available hardware and software that can be used to assist those of us who are less mobile. Tom writes...

I am a C4 tetraplegic with no functional use of my limbs. So the assistive technology that I use requires the use of the head or neck. It is hugely important to be able to access digital media – a central component of life for our generation. So one of the earliest challenges for a tetraplegic who has grown up using manual input devices such as a mouse or keyboard or joystick (and of course a mobile phone) is to locate and learn how to use alternative input devices.

At Stoke Mandeville in 2008 I started by using the SmartNav head-pointing device. This was intuitive and very responsive and meant I could get back to web browsing on a computer for the first time since my accident. However, compared with a manual mouse, the ‘dwell-click’ function on SmartNav was a bit hit-and-miss, which was frustrating.

There are various options for cursor control and ‘clicking’, including a physical switch. I guess it’s worth experimenting with these to find what works best for you.

The OTs at Stoke Mandeville also offered sip/puff devices – you can achieve very precise muscular control via lips, tongue and mouth, so these can be used as alternatives to hand controls. I didn’t spend much time experimenting with sip/puff as I had my eye on voice-activated software from an early stage (see below).

A visiting representative from the ACE Centre first introduced me to Eye Gaze technology back in 2007. This was a revolutionary idea; the machine tracks your eye movements, and you move the cursor by sweeping your eyes across the screen. Back then, however, the immaturity of the technology implied limited functionality as far as I was concerned. This sort of limitation is common with emerging technologies; the new idea is great, but the first-generation machines barely do what it says on the tin.

I’m glad to say that Eye Gaze technology has come a long way. Successful open source experiments include the ‘camera mouse’ and ‘gaze’. There are products that relate to computer gaming interfaces, such as ‘Kinect’ and the proprietary Tobii ‘PCEye’. These are currently expensive, but they are reliable and do offer an impressive level of functionality. I now use the ‘PCEye’ with a desktop PC, particularly in order to use graphical tools and for browsing the web and reading documents. The effortless scroll function, following your eyes automatically, is great.

Next up, I am looking forward to playing with Google Glass. Apparently it’s the best way of recording live video when you’re on your bike...

I’ll digress here to point out the obvious: most technologies have a specific remit when it comes to functionality. Gaze and pointing devices are great for pointing and clicking, so you need these for using graphical tools, for web browsing or scrolling through documents. But they are not efficient or slick when it comes to inputting data. It’s early days for Google Glass. I would expect great things to emerge in this field, and I am sure that ‘smart glasses’ and other ‘wearable’ computing devices will soon become the norm.

Through years of personal exploration of alternatives, I have become an advocate of the ‘less is more’ philosophy when it comes to equipment. The fact of being dependent on others for handling equipment is pretty crucial here. I need to mitigate against the lack of manual dexterity (and computer skills) of some of my assistants – and the risk of accidental...
whether or not you are looking to retain employment post-
injury, or are unemployed and trying to find work, if you have a spinal
cord injury you may need additional support or equipment to help you
carry out your role. Access to Work (ATW) is a Government scheme that
can help fund the additional costs of being a disabled employee or
entrepreneur. These costs may be transport to and from work,
personal assistance in the workplace, adaptations to your working
environment, or in the majority of cases, specialist equipment to enable
you to do your job. Richard writes...

"There was a moment in Stoke
Mandeville, looking out of the window,
I realised I needed to get my act
together. I had no big insurance claim
coming my way, the Government had
told me I would have to pay for my
own care, and I had a wife and three
kids to support. I also had a
photography business to run which
employed three other people.

As I started to get my act together,
the SIA Vocational Clinic, held at Stoke
Mandeville, really helped. I wasn't sure
how I'd be able to return to my job,
until I heard about the Access To
Work scheme.

I had my first meeting and
assessment with ATW, in my studio,
within weeks of leaving Stoke
Mandeville. I prepared for the meeting
with the hope of securing funding for
all my needs. If you don't ask you don't
get, I soon found out. I also learned that
you need to haggle, in two areas, what
they think you need and the price/
percentage they are prepared to pay.

When the decision came through
I was amazed. Access To Work were
willing to pay a huge chunk of the cost of:
• A three-storey lift within my studio.
• A frontal scissor lift and entry
system to my studio.
• An electronic camera stand that
I control from my computer desk.
• A video camera I designed to look
through the viewfinder of my
camera, displaying the image on
a second screen at my computer
desk, enabling me to see all that
my camera sees.

All this equipment has enabled me
to return to work. I love being able
to contribute again and support my
family. I'm back running a successful
business with all its ups and downs. I
love the challenge of my job, creating
images I'm proud of. It's a great feeling."

If you'd like more information
on the Access To Work scheme, or to
book an appointment in a Vocational
Clinic at a SCI Centre near to you,
contact Jamie Rhind, our Vocational
Support Officer, at
j.rhind@spinal.co.uk
or
07800 854605. You can check
out some of Richard's work at
www.richardfoster.com

Damage to delicate electronic devices.
And it's a hassle carting cumbersome
equipment about. I am pretty
ambitious about using technology,
but substituting for a lack of biological
autonomy is never going to be easy.

Where am I at now?
I'm a software engineer by trade,
working mainly in Unix domains.
For the last six years my accessible
technology of choice has been
voice recognition software.

Thanks to Moore's Law (predictive
model of the evolution of ever smaller
but more powerful computing devices),
we can now run extremely accurate
voice recognition software on mobile
devices (laptops now, and
notepad/tablet/mobile phone apps
in the pipeline). I use voice recognition
for dictation, and for cursor control
and browsing.

Here I am referring to 'locally
processed' speech – not audio that
is processed 'on the cloud' like Siri.

With inexpensive voice recognition
software (I use Dragon NaturallySpeaking
12.5), all I need to carry around is a
microphone/earpiece. I can control a
PC with my voice (I use lots of keyboard
shortcuts and voice macros). Text input
is very efficient; mouse operation is
only moderately efficient.

There is an online community of
people who use computers solely
through voice. We use software tools
for extending the productivity of voice
recognition (eg Dragon Professional,
NatLink, Dragonfly, Unimacro) by
specifying custom commands.

As an example of these expandable
software interfaces, I now use my
iPhone through voice recognition on
my PC. For accessing my phone/digital
media I also use environmental controls
and a 'Perrero' switch adapter from
RSL Steeper.

My website has more details.
www.tomnabarro.com

In conclusion
Our generation is characterised by an
exponential increase in the use of digital
media. We need access to evolving
assistive technology in order to be
productive members of a digital society,
to interact productively in social,
academic and business circles.
Tom Nabarro C4

www.spinal.co.uk
Keeping warm this winter

using simple battery technology

Gerbing Heated Clothing is a company that know a thing or two about keeping warm. They are the oldest established heated clothing company in the world and have their roots set back in the USA over 30 years ago when the founder, Gordon Gerbing designed and sold heated apparel to the US Military. Since then Gerbing have gone on to design and develop heated clothing for tens of thousands of individuals who feel the cold. Their range includes, amongst other items, eleven different types of glove, jackets, gilets, socks and hand warmers.

Individuals with limited mobility may have difficulty maintaining a comfortable body temperature. This is especially so during the winter months, leading to many, who would otherwise enjoy outdoor pursuits, staying indoors rather than face the misery of getting too cold. With this in mind, Gerbing decided to concentrate their efforts for their new 2013/14 range on 7 Volt products. These are items of clothing that are heated by a powerful rechargeable lithium battery, making them ideal for those of us who want to take on the challenges that winter brings without having to wear layer upon layer of clothing making mobility even more difficult. Every item is supplied with a battery pack together with a UK/EU charger. Extra batteries can also be purchased for those who may need ‘back-up’ power. The heat given from all the products can be regulated by a push-button panel on the garment giving you between 25 and 100% power. The length of time that the battery can power each garment will depend on the setting chosen. As a rough guide, a garment set at 100% will give you two hours of heat. Set at 75%, it will give you three hours, at 50%, four hours and at 25% up to 10 hours.

When considering purchasing heated clothing, it is important that you are able to regulate the temperature yourself using this button. You must not use any heated item near to your skin if you do not have sensation in the areas you wish to heat. There are two gloves that could be particularly useful to disabled users; the first is their C-7 glove. Originally designed for cyclists, it is a thinner glove allowing the user more dexterity, particularly useful for wheelchair users. The other glove is the S-7, which is more of a winter ‘ski-type’ glove. The 7 Volt jacket is designed to wear underneath a coat, and has removable sleeves. It is fabricated from a lightweight but hardwearing material and is not too bulky. Set at low heat, this jacket/vest would be ideal to wear indoors too. The vast majority of garments are unisex and sizes range from XXS to XXXL.

Gerbing also supply a highly successful 12v range that can be powered directly from a mobility scooter battery through a battery hook-up system. Rather surprisingly the drain of power is smaller than you might think. In fact a pair of gloves only draws 2.4amps and a jacket 6.4amps.

So maybe you needn’t dread the cold weather after all! The entire range of heated clothing can be found on the Gerbing website www.gerbing.eu. Gerbing are offering 10% discount to SIA members. The telephone number is 01580 200212 or via email uk@gerbing.eu
Over the years I’ve got used to being hauled up and down flights of stairs by family, friends and passing strangers but, as I notice my own physical abilities waning, I’ve noticed that my friends and families are struggling more too... and I now take the heavy breathing in my ear as a warning that the exertions I am putting them through could be causing them some considerable harm.

It was, therefore, with some trepidation that I went out to stay with my best friend, Jill, in her beautiful new home in Austria. She and her husband had thoughtfully chosen the property with me in mind as it has a sizeable ground-floor bedroom and en-suite bathroom, with plenty of room for moving around the living areas of the kitchen and lounge. However, in order to get into the house there was a lengthy flight of stone steps up from the driveway which I would have to be hauled up and down every time we wanted to venture out. Not ideal, as my friend has a heart condition, a shoulder that dislocates at the drop of a hat and a knee that buckles for no reason! (I have thought about trading her in for a fitter model but we’ve known each other since we were 16 and it seems a little harsh).

Now Jill has always been the planner – the one to do the research – the one that I have relied on to find the easiest way to do something, so I wasn’t particularly surprised to find myself dragged off to Naidex to have a look at the stair-climber that she’d seen on the internet. Unfortunately the demo model that they had there wasn’t suitable for me to try, but Jill could. She tried it out on my behalf, questioned the rep until his eyes started to cross and took all of the information home to Austria to check whether it would cope with the depth and width of their steps. Her subsequent discussions and negotiations all went well with the company, AAT GB Ltd (www.attgb.com), and, when they next visited the UK she and her husband were given full training on the ex-demo model that they’d bought.

Having booked myself into their busy, unofficial B&B/spa at the end of the summer to recharge my batteries in the clean mountain air, I couldn’t believe how easy it was for them to get me up and down the ‘Eiger’ steps at no physical cost to themselves. It’s an incredibly simple system which can be operated by one person, with the ‘scoop’ system fitted it will adapt to fit most wheelchairs, and takes up very little room so is easy to store.

It may not be as quick as they once were in heaving me up and down whole flights of steps, but it does feel safer and I am much relieved that I’m not about to cause them a serious injury... and now, with a bit of luck, my visits to stay with them will be able to continue well into our dotage.

Jackie Bailey T3
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Getting a grip on life

The term ‘assistive technology’ can be defined as ‘any device or system that allows an individual to perform a task that they would otherwise be unable to do, or increases the ease and safety with which the task can be performed.’

This includes a wide range of devices from simple ‘low-tech’ items such as pushing gloves to more ‘high tech’ items such as powered mobile arm supports.

Shown below are two examples of typical ‘low-tech’ equipment made by Occupational Therapists at the NSIC, Stoke Mandeville.

In addition to the physical benefits of using assistive technology, there are the positive psychological benefits of having greater independence and being able to achieve more in your daily life.

Assistive technology can help to facilitate:
- functional independence
- communication and verbal independence
- preservation of privacy
- independent mobility
- communication and computer access
- active participation in sport, recreation and leisure activities
- exercise and fitness
- return to work

One of the major issues following tetraplegia is the inability to control movement and function in the upper limbs. Recent advances in restorative rehabilitation and exercise of the hand and arm have involved technology such as the use of robots and exoskeletons to move the arm, electrical impulses to activate muscles, and a variety of splints, supports and orthoses to aid function and to reduce tightness and spasticity in paralysed muscles.

It may be simpler to consider Assistive Technology as an umbrella term that includes assistive, adaptive and rehabilitative devices for disabled people.

Adaptive devices

These are items which promote functional independence in every day tasks to compensate for a loss of movement (ie they provide an alternative means for completing a task). For example: **Gripability**

The Gripability E3 is a device which enables the user to independently handle utensils like drinking vessels, cutlery, brushes and toothbrushes, pens and pencils and lot more in terms of daily living activities.

This grasping aid allows people with limited hand function to grab things, use them in a stable hold, and then put them down again.

To use the device, an automatically powered gripper is adapted to the hand to give control in reaching and handling items. The opening and closing of the gripper is controlled by a switch specific to the individual user. The system is powered by a mobile pneumatic air compressor.

**Assistive devices**

These are items which help to make use of limited or restricted movement and to assist in the completion of a task by activating that movement or maybe reducing involuntary movements. For example: **Bioness H200**

The Bioness H200 is an upper limb device which uses functional electrical stimulation to activate muscles in the forearm and hand.

The outcomes and therapeutic goals achieved, can be broadly set out under 3 categories:

- Reduction in tone through both the use of pulsed stimulation and the enhanced ability to weight bear through the affected limb
- Stimulation of gross grasp and release as well as lateral pinch allowing for functional ability and enabling independence in activities of daily living such as feeding, drinking, writing and brushing teeth
- Stimulation of specific muscle

*Royal Commission on Long Term Care – 1999
activity and muscle groups to build on recovery, with the effect of additional ‘carry over’

Rehabilitation devices
These devices help facilitate, improve and capitalise on changes in upper limb movement, which can then be translated into functional activity.

For example: Tyromotion Amadeo

The Tyromotion Amadeo is essentially a Continuing Passive Motion (CPM) device, which provides intensive repetitive training for the fingers.

It takes the fingers through the full available passive range of movement, but also allows and encourages the individual to use any available active movement.

The fingers are held in place using magnets, which allows for safe management of any spasticity or involuntary movement, whereby the fingers are quickly released with no risk of trauma.

This system is interactive and encourages participation through the medium of competitive game playing and on-screen virtual rehabilitation.

There are further devices with this system which can work on different upper limb patterns of movement.

The system can be used in an inpatient, outpatient or the home environment, and at all stages of rehabilitation, whether that be during the acute stages, when on bed rest, in a hospital environment, or beyond discharge out in the community.

Tyromotion Amadeo provides intensive repetitive training for the fingers

For any individual with complete or incomplete tetraplegia, assistive technologies that support any hand or arm function are vital to the success of rehabilitation. By the very nature of a high level spinal cord injury each person tends to have unique hand and arm function capabilities. This means that equipment available on the open market ideally needs to be capable of modification to individual needs.

Unfortunately, there are sometimes issues in terms of gaining access to these devices:

- lack of expert and/or professional and impartial advice (ie regarding the suitability of specific equipment to the needs of individuals)
- difficulty gaining access to resources (eg gaining access to an Occupational Therapist who has specialist skills with regards to fabricating splints or orthoses to aid upper limb function)
- limited finances (ie many of the high tech assistive technologies are extremely expensive and it may be difficult getting support when accessing funding or applying for grants)

At one time, most Occupational Therapy departments had their own workshops and employed specialist technicians to help make custom-made equipment to fulfil the needs of individuals. Today, there are very few of these facilities left, if at all.

There are design charities such as MERU, DEMAND and BIME, and voluntary organisations such as REMAP, which may help with designing, engineering, advising and making bespoke items for individuals who have been referred to their service. There are also some specialist design companies such as Such & Such Design Ltd and Really Useful Things who may be able to support with potential design and product manufacture.

In summary, the development and provision of upper limb technologies requires the application of sound engineering principles, strong design concepts and good problem-solving skills in order to achieve greater standards in daily living and functional independence for SCI people, whether that be in a home, work or recreational environment.

Ruth Peachment
Occupational Therapy Clinical Specialist, National Spinal Injuries Centre
Stoke Mandeville Hospital
With thanks to Christa Dyson
Assistive Technology Conference

Alex Rankin, Aspire’s Director of Services writes...

You can hardly escape technology these days. If you’re not sitting at a computer for work or study, the chances are you are using one to update your facebook page or carry out your shopping. Tablets are increasingly taking the place of books, as well as providing a handy alternative to laptops when you want quick access to emails and the internet. And phones are ever more like mini-computers, with users almost as likely to use them for emailing or surfing the web as they are for making calls. But what do you do if you can’t use a standard keyboard or mouse, if you don’t have the dexterity to manipulate a touch screen?

The Aspire Assistive Technology programme exists to ensure that everyone, regardless of the level of their injury, has independent access to a computer. Based in the SCI Centres, Aspire provides computers and the necessary technology, along with a dedicated team of volunteers, to ensure inpatients get the most out of what is available.

We’ve just run our fourth Assistive Technology conference; attended by NHS staff, Aspire volunteers, and other interested parties, the focus is on exploring how best to get the most out of the technology available and looking at new developments in this fast-moving field.

In conjunction with Stoke Mandeville, we’re already testing the effectiveness of using Eye Gaze technology in the early stages of hospital admission. The conference gave delegates the opportunity to see developments in the technology, with two different models of Eye Gaze system on show. Whilst it’s still a relatively expensive solution, Eye Gaze does give users with no head movement control of their computers. As the systems improve, and as the prices of the units fall, this is definitely a technology that we’re going to see ever-increasing numbers of people using.

Also on show were a couple of options for connecting switches and joysticks to tablets and phones. For those with little or no hand movement, this opens up the possibility of accessing the internet, books, sending texts and even to make calls. Both solutions could be linked up to a powerchair, with the user making use of the wheelchair controls to access the technology.

But it’s not always about high-level technology. Occupational Therapists from a number of SCI Centres presented case studies; the lessons learned were often that providing access to an individual’s existing technology – their own laptop or iPad, for example – was at least as important to the user as the ease with which access could be achieved. Looking at how technology could be stably mounted in suitable positions, and making use of more basic implements such as mouth sticks, was covered in several sessions. Whilst giving access to technology that the patient is comfortable with has psychological benefits, particularly in the early stages of rehab, it’s not always easy for the trainer; our conference looked at the access options – and problems – with Apple’s iPhone operating system and with Windows 8.

Assistive Technology offers huge scope to increase the independence and opportunities for SCI people. As one of the users featured at our conference said, “I was using my iPad and a mouthstick within days of arriving in hospital. From there I learnt to use headmice and voice recognition software. And now I’m using the computer every day, it’s part of my routine. Basically, it’s my window to the world.”

For more information on the Aspire Assistive Technology programme, see www.aspire.org.uk. If you are interested in becoming an Aspire volunteer and working to help give patients access to this technology, please email andrew.kell@aspire.org.uk for more information.
Robin Gibbons has been involved in the investigation of health and fitness following spinal cord injury for over five years.

His studies have been centred on people with tetraplegia who are typically at the lowest end of the activity spectrum. The two themes being investigated are reducing the risk of cardiovascular disease (CVD) and improving bone mineral density (BMD) following a specialist training programme. Functional Electrical Stimulation-rowing, or FES-rowing, was the exercise activity chosen as the training activity in these studies.

The bone study is being conducted in collaboration with UCL Institute of Orthopaedics and Musculoskeletal Science.

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What is the Tobii Eye Gaze system?

Eye Gaze has been mentioned several times in this Technology section. It is a device to allow people with high-level spinal cord injury to operate a computer using an eye gaze system. This allows people who would otherwise not be able to use a computer by any other means, to communicate.

Essentially the eye gaze is a software package which enables the user to control the computer screen by eye gaze alone. The set-up involves calibration of a patient’s eyes, which takes approximately two minutes, which is then stored and used for future logins. The system can be used with pre-programmed interfaces including symbols, a keyboard, pictures, phrases and word prediction. This enables someone to communicate with nursing staff, friends and family or simply lets them access a computer to use social networking sites, Skype, mobile phone, texting, email, internet and play games.

The user looks at the computer screen and makes a choice by ‘gazing’ at the item chosen. A choice can also be made to write the word on the screen or be voice activated so the word is spoken out loud.

Who needs it?

High-level SCI patients admitted to ITU or the acute wards in an SCI Centre are often unable to speak because of the presence of a cuffed tracheostomy. No air can move over the vocal chords and therefore they are unable to achieve a voice. This can be a temporary or a long-term situation. Without a voice a person is unable to use any voice activated system of communication. Also, as they are unable to move below their level of injury, they are usually unable to use any sort of media system. The head movement of these individuals is often limited in the acute stage of recovery, making other means of computer of communication, such as a head switch, Integra mouse or mouth stick, impossible.

The Eye Gaze system can enable the user to make choices about their own care, communicate at a social level with friends and family whether using the mobile phone, email, social networking or simply ‘speech’ when visitors arrive.

Establishing communication for high-level SCI people is essential if the negative effects of isolation are to be overcome. Already people in intensive or acute care settings are deprived of many things we take for granted, including daylight, a day and night pattern of living, movement and the ability to communicate with friends and family. Using an Eye Gaze system is a way of empowering people to take control of their situation, communicate their fears and anxieties and give an opinion on their care regime.

Eye Gaze systems are expensive – in the region of £25,000 each, but there is strong evidence that investment in this piece of kit at an early stage of rehab can prevent the negative effects of social isolation and reduce the overall time an SCI person stays in hospital.

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FES and

We take another look at the research being conducted at Brunel University by SIA member, Robin Gibbons.

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CVD and disuse-osteoporosis are now the most serious secondary and health threatening consequences of spinal cord injury (SCI). The overriding reasons for this are a lack of physical activity and paralysis, especially in the lower limbs. Activities such as arm crank and wheelchair aerobic training, swimming and weight training, are the
only exercise choices for many people with SCI. These activities rely on the exclusive use of the upper body, which severely limits the volume and intensity of exercise when compared to whole body exercise. In addition, these activities do not load the lower body. For these reasons, scientists have been investigating the use of FES-assisted exercise in an attempt to increase the amount of active muscle mass being exercised, as well as a means of increasing lower limb loading.

Initially, FES-cycling was the exercise activity of choice. However, the effect of FES-cycling per se on cardiovascular health and bone mineral density has been disappointing as a consequence of the lower than expected aerobic training effect and lower limb loading. This has resulted in a re-focus towards exercise activities that combine concurrent voluntary upper limb exercise with FES-assisted lower limb exercise. FES-rowing is one such activity. Robin found that FES-rowing not only resulted in an increased aerobic training effect but also increased lower limb loading when compared to the FES-cycling.

Whilst the study’s findings are still being confirmed, Robin has already identified some exciting trends. All participants with tetraplegia have shown an increase in heart mass and cardiac output, likely due to improved circulation. In conventional upper body exercise, blood tends to pool in the lower limbs. In FES-trained lower limbs rowing assists the return of blood to the heart. The increased pressure of blood returning to the heart results in better filling and therefore increased output. Essentially the heart is working harder, and as a muscle, increases mass in much the same way as a skeletal muscle does. Stronger hearts, and improved circulation, are key factors in reducing the risk of CVD, and in particular coronary heart disease.

Whilst investigating cardiovascular health, it became evident that FES-rowing also resulted in large forces in the lower limbs. Robin began simple measurements of these forces, which showed marked increases over a 20-week FES-rowing training programme. Whilst the underlying mechanisms behind loss of bone are still the subject of international investigations, it is widely accepted that muscle-induced force concurrent with weight bearing are essential factors for healthy bone mineral density (BMD). However, this is only true if the force is greater than body weight and, the force is repeated a sufficient number of times. FES-rowing appears to deliver forces that are greater than body weight and at a rate which results in improved BMD. Preliminary results with a small number of subjects suggest that FES-rowing does indeed have a positive effect on BMD, but these results need to be confirmed when all participants have completed their training programme. In addition, the pulling actions when rowing have been shown to have a skeletal health benefit. Although rowing involves a pulling action in the upper limbs, the associated muscle activity results in a compressive force in the associated bones. It is highly likely that the pulling action of rowing not only balances upper limb forces, but also improves BMD in these limbs too.

Robin will be formally publishing the FES-rowing study’s findings in the near future. In the meantime, he and his colleagues are seeking to obtain further research funding for a more detailed study on the cardiovascular and skeletal benefits of FES-rowing.

Robin Gibbons and his team wish to gratefully acknowledge the considerable funding support from the INSPIRE Foundation, without which these studies would not have been possible.
How FES is being used in the UK SCI Centres
– an encouraging picture

When muscles are affected following a spinal cord lesion, Functional Electrical Stimulation (FES) can be used to help the weak or paralysed muscles to contract. Gentle electrical impulses activate the nerves to help the muscles to function in response. With incomplete injuries, the stimulation travels along the spinal cord to the brain to potentially help with the recovery and relearning of movement. Sometimes the muscle is denervated, so the nerve does not respond. In these instances, the Ottobock Stiwell or the FES Cycles can make the muscle work directly.

FES is used during rehabilitation, but also longer term once the person goes home. It can be used to exercise, or during functional tasks such as walking, cycling, or daily living tasks such as eating and drinking.

FES can be delivered:
- through pads that are positioned on the skin and are wired into a stimulator (Odstock Microstimulator, Ottobock Stiwell, Saedo Myotrac, Restorative Therapies RT200/300)
- through wearable devices that use a splint or cuff to position electrodes such as the Bioness L300 and H200, Ottobock MyGait, walk Aide.
- in some cases, electrodes can be surgically implanted. This tends to happen when a person is using FES long term, for instance at home (Ottobock Actigait, Odstock Stimustep)

FES works via a timer, a trigger, or in the case of the Saedo Myotrac and Ottobock Stiwell, via EMG – the patient’s own muscle activity.

Benefits
FES can maintain and improve muscle bulk / strength, range of movement and circulation. FES cycling can provide a cardiovascular workout and can help with pressure sores. FES can also help to manage spasticity, reduce muscle spasms and may also help to reduce pain. Certain devices can improve walking and hand function.

In practice
Most spinal units use some form of FES with their inpatients. Occupational Therapists (OTs) at Pinderfields have been working with the Bioness H200 for hand rehabilitation. The system (pictured) stimulates the muscles that open and close the hand to allow users to pick up and release objects; it can be used for therapy as well as functional tasks. Belfast have been using this system along with the Bioness L300 Plus with patients progressing their walking. The L300 Plus picks the foot up when the leg is swung forwards during walking, and then helps the thigh muscles to contract to keep the knee and hip in a more stable position when standing on the weaker leg. Using the system helps patients to walk faster and more safely; this 2-channel approach is also used by Ottobock My Gait and Odstock Dual Channel systems. In most centres, Physiotherapists work with the FES bikes, such as the RT300. Kirsten Hart from Stoke Mandeville has designed a very good programme for adults and children to deliver routine and efficient FES cycling to patients.

The clinician’s perspective
Sarah Leighton, Physiotherapist at Sheffield stresses the importance of goal setting. Users have basic FES 5 days per week, with goals reviewed every four weeks to ensure the treatment is effective. Jackie Bevan, OT at Southport, reports that “FES is a great help for strengthening, and since the introduction of the H200, functional task training. Patients value gaining new movement and functional abilities, however small, but these changes may take months to develop so patience is important”.

Matthew Dale
BSc (Hons) Physiotherapy
Clinical Sales Specialist: United Kingdom & Ireland, Bioness
On the road to recovery with Bioness
functional electrical stimulators

Are you trying to regain your mobility, independence or hand function following a Spinal Cord Injury (SCI)? Function, freedom and mobility are now within reach thanks to the advanced functional electrical stimulators from Bioness.

The NESS H200 Wireless System activates the nerves that control the muscles in the hand and forearm, enabling you to open and close your hand. The system may help you regain function in your hand and wrist and so help to recover your independence.

The L300 helps people with drop foot to reduce trips and falls and improve their walking speed. With the addition of the L300 Plus thigh system we can also improve knee control and stability during walking.

By stimulating nerves to produce movement we can strengthen muscles, increase movement, reduce muscle tightness/spasticity, improve hand function and walking. Contact us to find out more today.

Contact us at: 0800.411.8100
Email: info@uk.bioness.com

Bioness
www.bioness.com
What I found there was quite extraordinary. The place was full of youngsters dressed in tin foil suits with glass bowls on their heads and strange contraptions in their hands. “What’s that?” I asked a passing youth, pointing to the slim piece of plastic he was holding. “That’s my smart phone, Daddio,” he replied, changing his suit from silver to crimson velour with a nonchalant swipe of his finger. All around me the kids were doing amazing things with these little devices, from designing skyscrapers or conducting virtual orchestras to calling their mates and texting and that.

If they could go back in time (apparently they can do this now) and see me tapping line after line of meaningless code into a ZX Spectrum so that a small, digital spider would walk across my computer screen, they’d laugh in my stupid, Cro-Magnon face. The ZX Spectrum? I may as well be banging two rocks together in an attempt to make it rain.

Of course, society’s great advances don’t stop at self-service check outs and automated phone lines. Technology is moving at such a pace our wheelchair users are less conspicuous than rolling around on four wheels, but quite how this is achieved by imitating Robocop is anyone’s guess.

Tired of people looking at you for a few disinterested seconds before returning to their conversation? Infuriated by the fact you’re now a unique individual rather than the humdrum no-mark you were before your accident? Then why not simply trade in your wheelchair for a half tonne pair of robotic legs? You can enjoy great benefits like not being able to get into a car, frightening small children and reaching land speeds of up to 20 metres per day! Most of all, we promise that you won’t look like a refugee from a nightmare future where humanity has finally been enslaved by their overlords, the machines.

That said, whilst I’m not interested in walking around like Robocop, I’d take his machine-gun-dispensing-thigh any day of the week. Then we’d see some real equality on the streets.

“No, we haven’t got a ramp.”
BLAM-BLAM-BLAM!
“Sorry mate, you’re a fire risk.”
BLAM-BLAM-BLAM!
“Hi, I’m Robbie Williams.”
BLAM-BLAM-BLAM!

Yes, I say leave that Spinning Jenny alone – the machines are our friends. Forget about Frankenstein, Battlestar Galactica and The Terminator and give me my silver foil suit and a rocket propelled wheelchair. I’ll gladly offer the hand of friendship to our computer allies and join them in the 21st Century... just as long as they promise not to kill me first.

Dan Burden T5
More Aids and aggravations
(or Can you have one without the other?)

Barry Brooks C6 writes about his ‘technology’ recommendations

Over the years I’ve tried loads of different aids. My policy is to try to be as equipment-lite as possible. Anyone who’s been in a chair for more than a quick demo knows that equipment reliance is a hazard to beware of.

It seems that everywhere you look there’s an expensive gadget, a high tech ‘get-you-on-your-feet again’ gizmo just waiting to remedy the situation for you.

However some bits of equipment are absolutely essential if life is going to go on with any degree of ease. Chief among which is all that goes into making a wheelchair sit-able on in the long term. I never understand why people refer to a wheelchair sit-able on in the long term. Among which is all that goes into making to go on with any degree of ease. Chief are absolutely essential if life is going waiting to remedy the situation for you.

‘get-you-on-your-feet again’ gizmo just there’s an expensive gadget, a high tech is a hazard to beware of. Knows that equipment reliance chair for more than a quick demo as possible. Anyone who’s been in a already hold formidable reputations.

The New Stimulite Cushion
After but a day of sitting on this new cushion option for the posture-and-pressure-management-challenged amongst us, which just about includes us all, I discovered that there’s life in the old rear yet.

I’ve struggled for year to find the holy grail of a cushion that both protects me from the daily discomfort of sitting and answers the equally permanent desire to just sit a little better: to balance, sit straighter and stop me from slowly turning into Quasimodo. My bottom, back and belly have paid a heavy toll in keeping me and my wheelchair on the road.

The Stimulite was originally designed for people who are at high risk of skin breakdown but quickly realised comfort by itself was not enough. A good functional cushion has to provide stability too, and a great cushion has to do both exceptionally well if it’s going to succeed where J-Cushions, Vicaire and a host of other seating solutions already hold formidable reputations.

Stimulite’s secret is layers of honeycomb cells. Three layers of honeycomb, each cell layer with a different firmness. The whole cushion only weighs in at a little over three pounds. So you don’t have to be a weightlifter to manage your cushion. Take note J-Cushions.

I’ve been both a J-cushion and a Vicaire user over the years. I find the three layers of honeycomb a lot softer to sit on than the single pocket of air offered by the Vicaire and while I’m grateful for J’s shaping power it is heavy and the gel pockets do seem to get harder with every hour and they do tend to trap you in a bucket-shaped position. Besides they are damned heavy.

The contoured Stimulite is my current choice. It holds me with a lighter touch than the J but it’s somehow secure and freer; keeps me in a good position while encouraging me to work a little to hold my new habit.

Stimulite has a well-thought-out range of different cushions and covers. It certainly added to my rear-racked days, or rather it’s taken away a noticeable amount of the ache and agony.

You can even get sheets of Stimulite to drape over your easy chair or car seat. Expensive it is but then every manufacturer thinks that being in a wheelchair makes us a lottery winner. As if it wasn’t bad enough not to get a mighty compensation package, everybody assumes that’s part of the deal and the more movement you lose the more cash you gain.

The Oswestry Standing Frame
The Oswestry Frame is the Coca Cola of standing frames. The classic which we all met, dreaded and grew to depend on (if we were lucky), in our early rehab days. Since their introduction there’s been a host of new competitors. Most have been gleaming high-tech metal machines with lots of options, which in my view people rarely use. The basic idea of a standing frame is to get you standing, securely and in comfort.

The frame is made of light wood; the design looks just as organic. It’s timeless: three, wide, sheepskin-covered, heavy-duty leather straps and a lectern to grip on to, lean on or curse from. The only change they’ve made over the years is to add a ‘raise you from your chair’ option. I’ve always found being hoicked up by a willing pair of hands is enough.

My frame has served me well for years. I’m sure all that weight bearing has kept me fitter than I would have been left slumped to my own devices. The beauty of the Oswestry system goes deeper than its beautiful design and build, it has no working parts to go wrong. The only part that is supposed to work is the one who’s standing there, busy going nowhere but bracing him or herself for the best that’s left.

www.gerald-simonds.co.uk
www.theodavies.demon.co.uk
We wanted to identify the functional effects of ageing with SCI and having done so, try to advise people on how best to alleviate some of the growing challenges they face on a daily basis.

We also wanted to research health and social issues that affect ageing partners and carers as they do such an important, often unrecognised, job.

We recognised, importantly, that newly injured people should be given up-to-date information so that they can make informed choices about the daily activities which will affect their long term health and welfare.

Ageing Well survey
The original Ageing Well survey was carried out in 2007. The response was tremendous. The top three health priorities identified were bladder, bowel and skin care issues. No real surprise there. These were closely followed by weight management and physical fitness. In conjunction, we invited the views of carers, so they could express their experiences of long-term caring and the effect it has had on them and their life.

Looking Ahead
We will be repeating the Ageing Well survey at the beginning of 2014. If you completed the survey in 2007 we would very much appreciate your input again.

Visits to the Spinal Cord Injury Centres (SCICs) in the UK began this year and will continue in 2014. The Ageing Well Project will be rolled out to health professionals in the SCICs to encourage them to discuss elements of ageing with SCI people. When you visit your SCIC for annual MOT check, you may wish to discuss any ageing concerns you have.

If you have a special story to tell related to your experience of ageing with an SCI, I would be glad to speak with you either face to face or chat to you over the phone. Sharing your experiences may help other people cope with their issues.

Alternatively, you can contact me to discuss, in confidence, any issues to do with ageing. These can be issues that are affecting you now or maybe you are thinking ahead in terms of planning adjustments to your daily activities. If there are any topics you would like me to cover in this column, then do please let me know.

Joy Sinclair, Ageing Well Adviser
Freephone 0800 980 0501

Steps to Ageing Well
Steps to Ageing Well are information sheets, currently being developed, to offer tips on how to adjust to the challenges of daily living as you age and the main health priorities of ageing. Topics covered so far are Bladder Care, Bowel Care, Skin Management, Care of Shoulder Joints, Nutrition, Physical Activity, Posture. Further topics to be covered include fatigue, women’s health and men’s health. The Steps to Ageing Well information sheets can be downloaded, free of charge, from the SIA website www.spinal.co.uk/page/Ageing-with-SCI

Project update 2013
The SIA Ageing Well Project commenced in 2006. This was in direct response to SIA members expressing concerns about ageing issues. What followed was a three-year project, financed by the Big Lottery Fund. Here we update you with further developments to the project.
Being different in the extreme!

Many people said that our second child would be totally different to the first, but I never expected the differences to be so extreme writes Emily Clacy C6.

"Every chair user knows that carpet is our nemesis, so we have hard stone and wood floors everywhere and her poor head is suffering some bumps”

W ell, you guessed it, she's off! After five weeks of being on all fours, rocking, moving backwards and rolling and at just six months old, Lydia has mastered the art of crawling, climbing and standing, and she did it all within a week! She is even trying to take steps and starting to ‘cruise’ around the furniture! I’m finding this all rather scary to be honest. Freya didn’t move until she was nine months old and didn’t walk until seventeen months! At the time I remember comparing her to my friend’s babies and feeling mildly anxious that she was lagging behind, but in hindsight I realise that it was a blessing in disguise.

Lydia is into everything and is totally fearless. Whereas Freya applied a careful thought process to her approach to standing, Lydia just grabs whatever is nearest to pull herself up; whether it moves or not is of no interest to her. She then likes to let go with both hands whilst trying to grab the object of her desire, thus toppling over on most attempts. It wouldn’t bother me so much if we had nice soft carpet everywhere, but every chair user knows that carpet is our nemesis, so we have hard stone and wood floors everywhere and her poor head is suffering some bumps. I feel totally helpless when she falls too, being unable to react quickly or pick her up to comfort her without help. We are at the mercy of my helpers who are perhaps not so mindful to her daredevil instincts.

My wheelchair has become Lydia's climbing frame and I have to try and hold her once she’s on her feet without falling out of my chair. On the plus side, as she is still so tiny and able to stand at my legs, I’ve been able to pick her up off the floor a lot earlier than I could with Freya. My strength has built up over the last four years of picking Freya up and I suppose with this being second time around, my confidence is better too.

Six months is also the magic age for weaning. I actually started Freya on solid food at four and a half months, but the guidelines have changed once again and the health visitors urge you not to try solids until six months now. In fact most things I did with Freya are all supposedly wrong now, but she turned out all right so it can’t be that bad! Freya took to purees fairly well, probably too well as she was averse to lumps for some time. I’ve tried the same approach with Lydia who promptly gags on a mouthful of puree and brings up her milk. I'm now attempting the baby-led weaning approach (basically just offering finger foods and letting the baby decide how much and what they want to eat). She seems quite happy to chew on a piece of vegetable or whatever I offer (usually tit-bits from my plate, cheese, bread, meat, fruit, etc.). It is a much slower process though and they don’t take much at all at first, but it is a lot easier all round to be honest. My biggest concern is her weight gain, with her being so mobile she hasn’t gained much weight at all in the last two months and with the baby-led weaning being very slow, I don’t think her weight will pick up that quickly either. But she is thriving in every aspect of her development and I have to remember this as reassurance.

The night-time raspberry blower
With all this development going on, Lydia has started waking in the night around 3am and stays awake for up to two hours most nights. She’s quite happy after a feed, cooing away and blowing raspberries. It is frustrating for Tim and I as she is still in our room and as he has to help me with all the night feeds, we are both awake and suffering disrupted sleep. Lydia will just drop off again and then Freya is up around 6am, so we feel like zombies most days. With Lydia’s weight gain being slow I’m not prepared to cut any night feeds yet, so there is no point putting her into her own room until we can establish weaning better and feel confident that she is taking enough food throughout the day. I’m hoping that by Christmas everything will settle down and we can have our room and bed back to ourselves. Watch this space!
Motocross

Getting back ‘on yer bike’

In a change from motor racing we look at Motocross in this issue, inspired by a meeting with SIA member Spencer Watts from Tiverton in Devon. Eighteen-year-old Spencer writes...

“I have done Motocross from a young age. I started at the age of eight years but sadly it came to an end in June of 2011 when I was 15 years old and had a motocross accident at a track in Worcestershire. I was left paralysed from the waist down, T10. When I was told by my consultant I’d never walk again and I’d never ever be able to ride a motorbike again my response was ‘no matter what it takes I will be back on a bike and doing the sport I love.”

I proved them wrong! Two and a half years down the line I’ve had a Motocross bike adapted for my needs, with an adaptive back brake raised onto the handlebars, along with an adaptive clutch and a metal frame around the bike which holds my legs in place to stop them from falling away from the bike sides.

I have no use of my legs from the waist down so someone has to catch me when I come to a stop along with someone holding me as I pull away! I rode my first meeting at a track in Yarley, Wells, Somerset on the 20 October 2013, what a success that was! It never felt so great to be back on a bike. I managed to complete the whole track all on my own with no help! Once I was out on the track I realised how different it was but it was still just as amazing as before!

I was competing against non-disabled Motocross riders and everyone was very interested in how the bike had been adapted and thought it was clever how it worked for me. As far as I know there is only one other disabled Motocross rider competing in this way.

I hope to do a lot more events and raise money for spinal cord injury charities in 2014. If it wasn’t for my family and friends I certainly wouldn’t be where I am today!

The reason for telling my story is just to show you that no matter what your injuries are, as long as you stick to it, you can do almost anything you want!

I may be in a wheelchair but that’s never going to stop me carrying on with what I want to do in my life! Never think for a minute that just because you’re in a wheelchair you can’t follow your dreams! Everything is possible if you fight for it.”

We look forward to following Spencer’s progress and bringing you regular reports throughout 2014.

If anyone is interested in finding out more about the adaptations to Spencer’s bike, the best person to contact is Andy Watts at the South West Motocross Club on 07798721897

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FLYING SCHOLARSHIPS FOR THE DISABLED

APPLY NOW!

There is still time to apply for a 2014 Flying Scholarship
Anyone wishing to apply for a 2014 flying scholarship with Flying Scholarships for Disabled People should submit their full application form to them by not later than Tuesday 31 December 2013.

Details of the scheme are available on the Charity’s website www.fsfdp.org.uk where a preliminary application form is also available. To obtain a full application form please contact Julie Bull, FSDP General Manager, Douglas Bader House, Horcott Hill, Fairford, Gloucestershire GL7 4RB Telephone: 0844 578 4 578 Email: info@fsfdp.org.uk Website: www.fsfdp.org.uk
All enquiries to Julie Bull (contact details as above)
A n eventful few weeks since the operation, which went OK, thanks very much. Apparently, much against character, I behaved rather aggressively in the recovery room and I later discovered a mystery cut on my cheek. I put it down to all that flailing against the tubes and wires that festooned my forearms but, I wonder, did I become such an aggravation that, to shut me up, one of the theatre staff landed a crafty one on me? I quite like the idea of that.

Anyway, as I write, the spine once more feels lovely and straight, the drain is long gone and the wound is healed. But more than two months down the line, two factors continue to trouble me.

I could not have expected the pain to go away immediately – you have to expect some sort of reaction after burly medics have been digging around your Central Nervous System for seven hours. The two weeks I spent recuperating in St George’s Ward were, shall we say, stimulating? But if anything it’s got worse, especially if you measure it through the more objective filter of sleep deprivation. I will know when it happens (or rather, after it’s happened and I’ve noticed the benefit over several months) but in the meantime, the intensity of sensation is now exacerbated by a touch of panic. It will ease eventually, surely?

What I also didn’t expect was that, as a result of only a fortnight’s bed-rest, my leg muscles would lose so much strength. As an in-patient my first wheelchair transfer, much to my disgust, was carried out using a goddam hoist and, when I later tried it for myself, my legs felt as weak as a baby’s. Even now, when gripped by a pain shot, I can grasp what feels like an entire hamstring within my fist.

Back home, flying physio Anna told me that for every day spent in bed, to rebuild my strength I should allow a whole week of rehab. That now sounds on the optimistic side; after all this time I can barely stand and can manage only a few steps on crutches. My sticks are gathering dust alongside a couple of broken umbrellas.

It’s particularly annoying to be back, almost, to square one. I went through this learning-to-walk-again routine a quarter of a century ago, at a time when I had more energy and was frankly a lot more motivated. I didn’t anticipate having to do it all over again.

I wonder though, if there’s a psychological aspect to that conclusion? Back then, I was at this same stage when I fell over and, such was the weakness in my bones after two years in a chair, broke my left tibia quite badly. I remember one orthopaedic surgeon telling me, rather pompously as I recall, that I was lucky to escape an amputation. This time, although I think I’ve ‘banked’ enough time on my feet to have escaped the condition, I’m not about to test the veracity of the notion. So I’m not only being a lot more careful when doing it, but find myself easily distracted from doing it at all.

So, dear reader, although I do try to at least end my columns on an upbeat note, I don’t have one for you this time. Except to note that, right now this minute, I am not in pain. I just want to sleep, please.

Andy Healey L1
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