

APRIL 2014 ISSUE 120

# forward



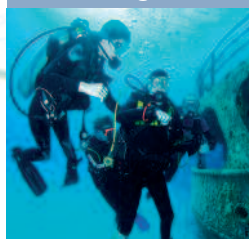
40 years of rebuilding lives after spinal cord injury



**Introducing**  
**SIA Healthcare**

see page 6

Scuba diving 24



Care in Tanzania 33



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APRIL 2014  
ISSUE 120



## forward message

The need for 'care' is something many of us with spinal cord injury have to address. Despite 'green shoots', we still live in a challenging economic climate and care funding is constantly under attack. How are those of us with SCI who need care and support supposed to think about returning to work or leading an independent life if we cannot get out of bed in the morning? We have come a long way in terms of pushing 'disability' as an equality issue but I think the revolution has really only just begun.

SIA is now well into its 40th Anniversary year. There are many ways in which members can get involved. We enjoy great support so please do get in touch with the fundraising staff at SIA House who would be delighted to hear from you.

Please also save the date of Thursday 16 October 2014 when WilliamsF1 will, once again, be hosting SIA's AGM at their conference centre. We are planning a conference day around technology. More details will emerge over the coming months but it would be great to see SIA members supporting the event.

Congratulations to all those who took part in the Paralympic Winter Games. Whether you won a medal or not, you are all winners!

Jonathan Fogerty, SIA Chair C5/6

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

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Find out more about us at [www.spinal.co.uk](http://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.

## Wheelchair Bowling

In the last edition of *forward* there was a Q&A regarding bowling – green or lawn as opposed to tenpin. As a long-time wheelchair bowler I have been fortunate to be involved, along with many other people, in the development of the game to the present day and I would recommend it as a great game, not just for oldies. Nowadays, most indoor clubs and many outdoor ones welcome wheelchair bowlers. Special buggies and adapted wheels are allowed onto the greens without causing any damage. A lot of clubs own one or more buggies for use, as do the British Wheelchair Bowls Association (BWBA) from whom buggies can be hired.

The quickest way to begin is to contact your local council to find your nearest green and to go along and check it out. They should be very helpful. If that is a bit daunting, join the BWBA and find out when and where their next training session is. There you will see all levels of the game and be able to try out a buggy and get all the information you need. Contact the Chairman, Ian Blackmore, email [blackmore@sky.com](mailto:blackmore@sky.com) or write to him at 6 Dingley Rd, Rustington, W Sussex BN16 3PY. He'll tell you all you need to know.

From April 7 -11 the annual Inter Spinal Unit Games will be held at Stoke Mandeville Leisure Centre. Each SCI Centre will be sending a team of in-patients who will be having a go at a large selection of wheelchair sports and taking part in competitions. There is great rivalry between the Centres! There is a lovely indoor green so if you are not already in a team, try to go along and have a look. Further details will be available from your SCI Centre physiotherapist.  
**Margaret Maughan T11**

## Praise for forward contributors

I felt compelled to write to commend *forward* on the feature on Travel and Holidays in the February edition. As a long-time supporter of SIA, the experiences shared by these members exemplified everything that is commendable about SIA. They were informative, honest and inspiring. Working as a solicitor bringing compensation claims for spinal cord injured people it is invaluable to have access to this sort of information to add value to our clients' claims and (hopefully) enjoyment of their lives. More strikingly, it demonstrates the value of SIA and its vital role as advice shop on the one hand and inspiration on the other. I shall remember this, as well as the other key aspects of the charity while trying to ignore any saddle sore on the forthcoming London to Paris bike ride in aid of SIA in May. I suggest you approach the travel sections of the weekend broadsheet newspapers and invite them to reproduce some of your articles – they could learn something from these SIA members on how to inspire, inform and educate in print.

**Cathy Leech, Partner**  
**Pannone Solicitors, part of Slater and Gordon**

## Constructive criticism

I would like to highlight a very rare occurrence where the CEO, Customer Relations Manager and the Accessibility Manager of a large public company actually paid heed to constructive criticism of their operation from a disabled person.

Having faced a particularly frustrating collection of my family from a flight at Luton Airport one evening, I contacted the CEO who, to my surprise, came back within an hour offering to meet me with his two key managers. I duly did so and had an unusually constructive conversation. As a result much is willingly being changed to improve disability issues.

The time of free parking in the short stay car park for Blue Badge holders has been extended to one hour, to allow time to get to the terminal and back. All the signs in the car parks and terminals are being dramatically improved and it is hoped that this work will be completed by Easter. They are looking into the technology of making it possible to pay for Blue Badge parking within the machines in the terminals, although this may take a little longer.

They have also requested that I talk to their handling staff collectively, to explain the user's point of view and give them some tips and advice about disabled people using their services.

It is so refreshing to find this attitude in a big business. Thank you Luton Airport.

**Mike Mackenzie**

## Free Life membership

At the recent SIA Trustees meeting, ten names were drawn for the free Life Memberships funded by the Gibbs Fund. These ten lucky people will, from now, receive a subscription to *forward* free of charge, for the rest of their lives.

The money for free Life Memberships was granted for five years so there will be a further opportunity for ten more SCI people to apply next year. SIA is grateful to the Gibbs Fund for their continuing support.

*The views and opinions expressed in forward* are not necessarily those of the Spinal Injuries Association. We reserve the right to edit letters sent for publication. The deadline for receiving contributions for the June 2014 issue is 1 May 2014.

**Q** Can you give me the dates and times of this year's Naidex Exhibition in Birmingham?

**A** Naidex 2014 will be held at the NEC Birmingham on 29/30 April from 10am - 5pm and on 1 May from 10am - 4pm. The SIA stand is C04 – come along and visit us! **For more information** please visit [www.naidex.co.uk](http://www.naidex.co.uk)

**Q** I feel really inspired by our GB winter Paralympic team. Where can I get information on taking up a winter sport?

**A** Whether flying down the ski slopes, taking part in a sledge hockey match or something a little less strenuous like curling, you can find out more about winter sports and clubs in your area by visiting the Parasport website [www.parasport.org.uk/winter-sports](http://www.parasport.org.uk/winter-sports)

**Q** I am going on holiday to the USA but I am having trouble finding travel insurance.

**A** This is a common problem for SIA members. We have produced an Insurance Factsheet which details the various insurance companies providing a service for disabled people. This includes cover for holidays and travel, wheelchairs, car and Life Assurance. Call the SIA Advice Line to request a copy on Freephone 0800 980 0501.

You can also download a copy from the SIA website. Please visit: [www.spinal.co.uk/page/downloads](http://www.spinal.co.uk/page/downloads)

**Q** I want to get away for a week or two but I cannot find any accommodation that has a ceiling track hoist. Can you advise me where I can find this information?

**A** The Ceiling Hoist Users Club has a selection of self-catering cottages and hotels with ceiling track hoists in the UK and abroad. Visit [www.chuc.org.uk](http://www.chuc.org.uk) Once on the website, you can also download the booklet *Accessible Holiday Accommodation*. A number of SIA members who advertise regularly in *forward* own self-catering properties

with ceiling track hoists. Check out the advertisements in the classified section of this issue.

**Q** Can you give me any details of where I might be able to buy a used wheelchair?

**A** Once again, the classified section of this magazine has advertisements for second hand equipment, including wheelchairs. Here are a few other popular websites to try: Disabled Gear: [www.disabledgear.com](http://www.disabledgear.com) Sport Mobility: [www.sport-mobility.com](http://www.sport-mobility.com) Ask DES: [www.askdes.org.uk](http://www.askdes.org.uk)



**Q** I would love to learn to fly an aircraft. Do you know who I can contact?

**A** Whether you want to take a micro-light flight or become a fully-fledged pilot, Aviation for Paraplegics & Tetraplegics (APT) Charitable Trust can help you get off the ground. Please contact APT on 01722 410744 or email them at: [admin@disabledflying.org](mailto:admin@disabledflying.org)

The office is not always staffed, so please leave a message. Flying Scholarship for the Disabled is another organisation that offers scholarships to teach disabled people to fly aircraft.

**For more information** please visit: [www.toreachforthesky.org.uk](http://www.toreachforthesky.org.uk)

**Editorial & Advertising** Lynne Punched | Tel 020 8361 6971 | Email [lynnepunched@btconnect.com](mailto:lynnepunched@btconnect.com) | **Next copy date** 1 May 2014 | **Published by** Spinal Injuries Association, SIA House, 2 Trueman Place, Oldbrook, Milton Keynes MK6 2HH | Tel 0845 678 6633 | Fax 0845 070 6911 | Email [sia@spinal.co.uk](mailto:sia@spinal.co.uk) | Freephone Advice Line 0800 980 0501 Mon-Fri 9.30am to 4.30pm | Text messaging Text SIA and your enquiry to 81025 messages will be charged at your standard network rate | Registered Charity No 1054097 **Chief Executive Officer** Paul Smith | **Design & print** TU ink [www.tuink.co.uk](http://www.tuink.co.uk)



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# SIA secures a **bright** future as we launch SIA Healthcare

We are delighted officially to launch the latest venture in the history of SIA – SIA Healthcare.

SIA Healthcare is a dedicated Home Delivery Service that will provide spinal cord injured people with all of their urology and stoma appliances and prescription medication and deliver it efficiently and discreetly to their door. It is innovative, and we have worked hard to develop a service that will be of real benefit to you and your family for the rest of your lives.

2014 is already a significant year for SIA as we celebrate our 40th Anniversary and continue to deliver the Pathway of

Support identified in our Strategic Plan. Both are significant milestones in their own right and the development of SIA Healthcare is another step forward, both in our ability to enhance the lives of spinal cord injured people and in securing financial stability for SIA.

SIA Healthcare was officially launched to our members and supporters on 20 March and the many benefits of the service are being experienced by those people who have already signed up.



**One SIA person who has shared his experience of SIA Healthcare is Jamie Rhind, from our Outreach Services team:**

"I didn't have any issues with, or complaints about, my previous home delivery service. I've been with the same provider since I left hospital 16 years ago and never really saw the need to change. I guess when you don't know what else is out there or how you can do things differently you just continue with what's familiar.

I decided to switch to SIA Healthcare because having my prescriptions delivered at the same time as my continence products will take away the hassle of collecting my medication from the pharmacy. Over the years there have been countless occasions when I've forgotten to order a repeat, suddenly realised I'm almost out of medication, or struggled to get to the pharmacy. With SIA Healthcare, they call you every month to check what you need and when you need it, and it also means you're not having to stockpile medication or continence equipment because they'll only send you what you require, it's really flexible.

Switching to SIA Healthcare could not have been easier, you make just one phone call and they do the rest: contact your doctor, get copies of all your repeat prescriptions, etc. The transition has been seamless.

I think when you become familiar with anything in your life, it's often hard to change. I did have concerns that the service would be the same, I would still get the same products, delivered at the same time, but the staff at SIA Healthcare have been so helpful, really



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going that extra mile to ensure that switching my home delivery service has been hassle-free.

My one piece of advice to anyone concerned about switching to SIA Healthcare is to give it a go. What have you got to lose? If you don't like it or feel the service is inferior to that of your previous provider, it's just as easy to

switch back. Whether you've had issues with home delivery in the past, or are perfectly happy with your current service, I guarantee you won't have had the convenience of having your continence equipment and medication delivered to your door together! Try out SIA Healthcare for a few months, I'm sure you won't want to switch back!"

**SIA Healthcare** is a collaboration between SIA and Bullen Healthcare, a 4th-generation, family-owned independent Dispensing Appliance Contractor (DAC) who are innovators in their marketplace. Their independence allows them always to put the needs of their customers first, allowing customers the freedom to choose whatever products suit them and their lifestyle without fear of products being switched.



## SIA Healthcare Benefits

- **ALL appliance and medication prescriptions delivered at the same time, discreetly to your door**
- **Your own dedicated, named personal adviser from the SIA Healthcare Customer Care Team**
- **One call, one order and one delivery every month and don't worry about finding the time to call us – we call you**
- **A flexible approach to placing your order each month – if email is better for you we will work with you to suit your needs**
- **Our regular monthly stock check means that you only order what you need – no more excess stock or unwanted boxes**

# Benefit Rates from April 2014 – March 2015

NON MEANS-TESTED BENEFITS	Old Rate 2013/14	New Rate 2014/15	MEANS-TESTED BENEFITS	Old Rate 2013/14	New Rate 2014/15
<b>Attendance Allowance</b>			<b>Income Support Personal Allowance</b>		
Lower Rate	53.00	54.45	18-24	56.80	57.35
Higher Rate	79.15	81.30	25 or over	71.70	72.40
<b>Carer's Allowance</b>	59.75	61.35	Couple (under 18 responsible for a child)	85.80	86.65
<b>Child Benefit</b>			both aged 18 or over	112.55	113.70
Only/eldest child	20.30	20.50	<b>Premiums</b>		
Other children	13.40	13.55	Family	17.40	17.45
<b>Disability Living Allowance</b>			<b>Enhanced Disability Premium</b>		
<b>Care Component</b>			Single rate	15.15	15.55
(Lower Rate)	21.00	21.55	Disabled child rate	23.45	24.08
(Middle Rate)	53.00	54.45	Couple rate	21.75	22.35
(Higher Rate)	79.15	81.30	<b>Disability Premium</b>		
<b>Mobility Component</b>			Single rate	31.00	31.85
(Lower rate)	21.00	21.55	Couple rate	44.20	45.40
(Higher rate)	55.25	56.75	<b>Severe Disability</b>		
<b>Employment &amp; Support Allowance</b>			Single, one qualifies	59.50	61.10
<b>Personal Allowances</b>			Couple (lower rate)	59.50	61.10
under 25	56.80	57.35	(higher rate)	119.00	122.20
25 or over	71.70	72.40	Disabled child	57.89	59.50
<b>Incapacity Benefit</b>			<b>Pensioner</b>		
Long term	101.35	104.10	Couple rate	109.50	112.80
Short term (lower rate)	76.45	78.50	Carer	33.30	34.20
Short term (higher rate)	90.50	92.95	<b>Permitted work earnings limit</b>		
<b>Industrial Injuries</b>			Higher	99.50	101.00
<b>Disablement Pension (100%)</b>	161.60	166.00	Lower	20.00	20.00
<b>Statutory Maternity Pay</b>			<b>Carer's Allowance earnings limit</b>	100.00	100.00
Standard rate	136.78	138.18			
<b>Retirement Pension</b>	110.15	113.10			
<b>Severe Disablement Allowance</b>					
Basic rate	71.80	73.75			
<b>Statutory Sick Pay</b>					
Standard rate	86.70	87.55			
Earnings threshold	109.00	111.00			



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# Welfare Benefits Advice

Over the last few years, both SIA and Aspire have actively reported back to the Government on their welfare reform plans. There is overwhelming concern about these changes and the significant impact they will have on the lives of spinal cord injured people. But, whatever we might think about these changes, they are here to stay and have started to be implemented.

There are a number of key changes, some or all of which will affect the majority of people with a spinal cord injury:

- Disability Living Allowance claimants will have to claim the brand new Personal Independence Payment
- Incapacity Benefit claimants will have to claim Employment Support Allowance and undertake the Work Capability Assessment
- Disabled people will not be exempt from the Under Occupancy Penalty ('bedroom tax')
- Employment and Support Allowance claimants will be transferring on to Universal Credits.

Just looking at that list is daunting, let alone managing the implications of the new systems. Over the past two years Ray Cross, Advice Line Officer at SIA, has been providing benefits advice as part of our Freephone Advice service, guiding people through the system and helping them complete benefit forms. We know that through this work Ray has been able to help people gain a better understanding of the benefits system and help them obtain the

assistance to which they are entitled. This service also provides links to more specialist advice from our Continuing Healthcare Adviser and Social Care Caseworker.

We are pleased to announce that there is now further help available for people seeking benefits advice. Aspire has a dedicated case worker, Nicola Lazare, providing a Welfare Benefits service tailored to meet the needs and requirements of spinal cord injured people.

For people seeking help with benefits advice both SIA and Aspire can provide:

- General information and advice about benefits, including a benefits check.
- Guidance and up-to-date information on how welfare benefit reform will impact on you and your family.
- Help in completing benefit forms and explaining letters and other information from the Department for Work and Pensions.
- Practical advice on how to have

a successful health assessment delivered by either ATOS or Capita. However, Aspire with its service can also:

- Provide a dedicated worker
- Monitor progress of your claim
- Prepare evidence and advocacy at appeals.

In addition, although predominantly a telephone service, the Aspire Welfare Benefits Advice Service will, in some cases, be able to arrange home visits and support you at tribunals. **Aspire Welfare Benefits service** can be contacted on: **020 8420 6711** or **welfarebenefits@aspire.org.uk**

To speak to Ray please call the SIA Advice Line on Freephone, **0800 980 0501** or email **advice@sia.org.uk**

If you are applying for NHS Continuing Healthcare, or having your NHS Continuing Healthcare reviewed contact Brian O'Shea, **b.oshea@spinal.co.uk**

To obtain help with problems with social services from your local council contact Simon Legg, **s.legg@spinal.co.uk** Both these services can also be accessed by ringing the Advice Line number **0800 980 0501**



## Make the most of your holiday

Nothing revitalises quite like a holiday, especially when your whole family can relax and concentrate on having a great holiday too. However when care packages designed for you at home are not flexible enough for trips away it can be frustrating.



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# Launching our new training programme

Welcome once again to the new SIA Academy training year! We are pleased to announce the 2014/15 training programme aimed at spinal cord injured people, and hope that there will be something here that will be of interest to you. Last year we held more courses than ever and enjoyed a great deal of success, so we are looking forward to the year ahead. The expansion of the courses continues at such a pace that we welcomed Sandra White to the team in January as Education and Training Assistant and she and Karen will be happy to help with any queries.

The courses are FREE for spinal cord injured people and we also welcome bookings from family members, carers/PAs and health professionals.

You will receive a pack at the end of the course which contains the presentations and supplementary information, and we are, of course, happy to help with any subsequent queries. Most of our trainers are spinal cord injured themselves, so can speak from personal experience on many of the issues covered in the courses.

## Courses currently scheduled for April 2014 – March 2015

### Becoming a parent after spinal cord injury (1 day)

**Sheffield SCIC** 26 July 2014

**SIA House, Milton Keynes** November 2014 (date TBC)

**Southport SCIC** 7 February 2015

### Choosing your wheelchair (1 day)

**Rookwood SCIC** 15 April 2014

**Southport SCIC** 10 May 2014

**Middlesbrough SCIC** 14 June 2014

**Stanmore SCIC** 24 June 2014

**Sheffield SCIC** 13 September 2014

**Salisbury SCIC** 8 November 2014

**Stoke Mandeville NSIC**

22 November 2014

**Oswestry SCIC** 21 February 2015

**Pinderfields SCIC** 21 March 2015

### Funding and managing your care needs (2 days)

**Sheffield SCIC** 10 & 17 May 2014

**Oswestry SCIC** 6 & 13 June 2014

**Middlesbrough SCIC** 5 & 12 July 2014

**Stanmore SCIC**

23 & 30 September 2014

**Pinderfields SCIC** 4 & 11 October 2014

**Rookwood SCIC** 14 & 21 October 2014

**Southport SCIC** 15 & 22 November

**Salisbury SCIC** 7 & 14 February 2015

(date TBC)

**Stoke Mandeville NSIC** 21 & 28

February 2015

### Housing (1 day)

**Oswestry SCIC** 11 April 2014

**Salisbury SCIC** 31 May 2014

**Stoke Mandeville NSIC** 28 June 2014

**Pinderfields SCIC** 12 July 2014

**Southport SCIC** 19 July 2014

**Sheffield SCIC** 18 October 2014

**Middlesbrough SCIC** 15 November 2014

**Rookwood SCIC** 17 February 2015

**Stanmore SCIC** 17 March 2015

### Making a claim under the Equality Act (1 day)

**SIA House, Milton Keynes** November 2014 & March 2015 (dates TBC)

### Motoring and mobility (1 day)

**Harlow or SE England** (TBC)

### Options: Life and work after SCI (1 day)

**Stoke Mandeville NSIC** 5 April 2014

**Pinderfields SCIC** 24 May 2014

**Rookwood SCIC** 8 July 2014

**Southport SCIC** 6 September 2014

**Salisbury SCIC** 27 September 2014

**Oswestry SCIC** 24 October 2014

**Stanmore SCIC** 25 November 2014

**Sheffield SCIC** 28 February 2015

## Healthcare Professional Study Days

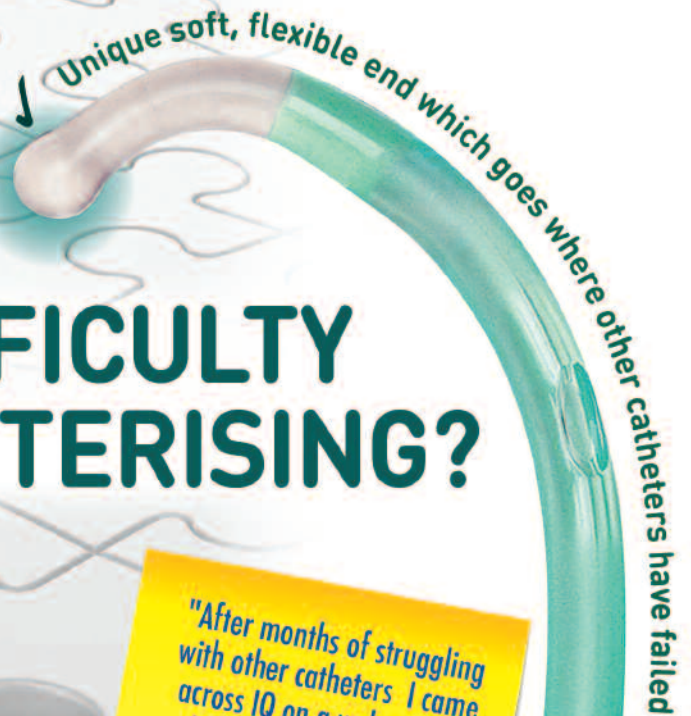
There are still a few places available on the Moving and Handling Study Day we are holding for health professionals in Leeds on 24 April 2014. The event is aimed at those who work in non-specialist rehab centres and district general hospitals to help them when treating spinal cord injured patients. Using a combination of presentations and group workshops, delegates will have the opportunity to practise log-rolling and positioning in order to maintain and maximise joint preservation, as well as learning techniques for moving patients safely in bed and getting a sling in place with limited rolling and staff involvement. Places are FREE to NHS professionals, but hurry if you would like to come, as numbers are limited!

A new training brochure, with information on the courses we offer for SCI people, healthcare professionals and members

of the legal profession will soon be available to download from our website, or contact Karen or Sandra if you would prefer a hard copy.

We are always interested in identifying new subjects of relevance to our members, and we are currently working on a new course which will look at the issues SCI people face as they get older. If you have any ideas for future courses, please let us know.

**To book or for more information** on any of the Academy Training Courses, please contact Karen Mikalsen, Education and Training Co-ordinator, at [k.mikalsen@spinal.co.uk](mailto:k.mikalsen@spinal.co.uk) or on 0845 678 6633 ext 221 or Sandra White, Education and Training Assistant, at [s.white@spinal.co.uk](mailto:s.white@spinal.co.uk) or on ext 218. [www.spinal.co.uk/page/training-education](http://www.spinal.co.uk/page/training-education)



# DIFFICULTY CATHETERISING?

"After months of struggling with other catheters I came across IQ on a web search. I applied for samples & also received really good advice from their Helpline and now I find ISC no problem whatsoever ...thank you again!"  
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# Government announces their intention to continue with the closure of the Independent Living Fund (ILF)

Minister of State for Disabled People, Mike Penning, announced on 6 March 2014 that from 30 June 2015 the Independent Living Fund (ILF) will close. Funding will be transferred to local authorities and the devolved administrations. Current users of the Fund, which was first set up more than 20 years ago, will then receive support through the mainstream adult social care system.

Mike Penning, said:

*"Our understanding of disabled people has changed over the past 20 years, and along with it there have been significant developments in how we*

*provide social care to disabled people so they can live independent lives. We continue to spend £50 billion a year on disabled people and the services provided to them, and as part of the Government's long-term economic plan, we want to make sure that disabled people are given the support that allows them to fulfil their potential."*

#### SIA Comment:

Approximately 1,000 spinal cord injured people in the UK rely on full- or part-funding from the ILF to meet their care and support

needs. This has allowed them to take a full and active role in society and family life. We are greatly concerned that if users of the ILF (and others who have been denied access to ILF since it was closed to new applicants in 2010) have to rely solely on local authority funding in the future they will see a noticeable cut in the care and support they

should be receiving, especially if local council budgets continue to be slashed.



Mick Hutchins C4/5

## All Party Parliamentary Group on Spinal Cord Injury

**The All Party Parliamentary Group on Spinal Cord Injury (APPG) met on 26 February 2014. Shadow Secretary for Health, Andy Burnham MP, attended the meeting where members of the group and observers were invited to ask questions. Andy Burnham spoke about Labour's policy of 'whole person care' and improving the specialist gap as well as answering various questions from the group about health care for SCI people. Here is a selection of some of the questions raised and Mr Burnham's responses:**

**Q** Can improvements be made with the number of beds available for spinal cord injured people on ventilators?

**A** I will take this question on board. I think the picture of specialised commissioning is still settling in the new NHS. It is a bit disruptive let's say.

**Q** What are your views on delays in discharge whilst people wait for suitable Continuing Healthcare packages?

**A** We don't do the simple things that get people out of the door to the places where they want to be and where it will be much less

costly. This problem is created by the way in which the funding works. The policy I am looking at is to deliver a 'year of care tariff'. This would provide an incentive for prevention to keep people out of hospital.

**Q** With this ambition for 'whole person care' is there anything that can be learnt from private sector activity in terms of pulling together disciplines from right across the board?

**A** It does imply very big professional change if you were to have a service that is personalised to each person in their home. That is the kind of change

that I feel the system is going to have to make. Whole person care is about removing the barriers to people working in the most integrated way possible.

**Q** Will your policy of 'whole person care' merge health and social care budgets?

**A** The 'year of care tariff' only becomes possible when it comes from a single budget for physical, mental and social care. I am talking about commissioning with one budget.

**Q** Will there be a Care Pathway specific to children with a spinal cord injury?

**A** Whole person care is as relevant to the start of life as it is the end of life. If you do the right thing at the start of life the savings can be vast. At the moment the system doesn't think enough in that way. If you have fully integrated commissioning for children I think

you would start to get the different pathways for services that you describe.

**Q** If the NHS is a national service should it not be possible that, when staying with relatives, I can access the same services that I receive at home?

**A** The 'N' in NHS means that entitlement is broadly the same everywhere. The trouble is that isn't the case when it comes to community and social care support. Whole person care for me means ending that. The 'N' in NHS should be an entitlement that it applies to everybody everywhere.

**Q** How can the Government break down silos between the Department of Health and the Department for Communities and Local Government to make a more joined-up approach to how local services work?

**A** I think that post-war Government had a clearer understanding of the linkage of people's living environment and their health and how the two were connected. That alignment is not there yet in terms of health and housing and I think your best hope at local level is the health and wellbeing boards.

**Q** Can we address the issue of SCI children on ventilators facing delays in discharge due to a lack of arrangements being made for them at home?

**A** The hospital is increasingly not the master of its own destiny. It can't move people through and do what's best for them and get them home because factors outside of their control are preventing that. In my model of a new generalist care pathway I see the GP as funding a much broader range of social support because if you get people what they need quickly, the chances are they aren't going to struggle and fail and cost the system a lot more money.



**Catherine Stribling**  
Public Affairs  
Communications  
Officer

## Public Affairs Diary February/March 2014

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

- All Party Parliamentary Group on SCI
- Parkinsons UK 'NHS Continuing Healthcare: failing to care' campaign meeting
- NHS Continuing Healthcare stakeholders group
- Social care reform and resource allocation conference
- NICE Spinal Trauma
- Clinical Reference Group: Access and Capacity
- Trauma Programme of Care Strategy Event
- Clinical Reference Group



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# Martin McLelland

SIA Honorary Consultant and Trustee, Martin McLelland, retired last year and we felt it fitting to acknowledge his achievements on behalf of SCI people...

I have had the privilege of knowing and working with Martin McLelland since 1999, interacting with him in various capacities. Over this period of time, he has been a wonderful teacher, mentor, colleague and good friend.

Like many of his contemporaries, Martin initially trained in orthopaedic surgery before moving into the field of spinal cord injury management. He did his SCI training at the Oswestry SCI Centre before returning to Sheffield to take up a consultant post at what was then the Lodge Moor Spinal Unit. He spent the next two and a half decades of his working career at Sheffield, for the most part working with his colleague Mr Ravichandran (Ravi), with whom he formed an outstanding clinical partnership and friendship. This relationship and the collegiate working environment that it engendered was to set the ethos for the new spinal centre that was built at the Northern General Hospital on the closure of

Lodge Moor. The new centre was among the first of the modern purpose-built SCI Centres. Together, Martin and Ravi developed new services and were able to take the Centre to new levels of excellence. Martin served as the clinical director there from 1999 to 2009. The consensual and participative approach he adopted to management was vital in managing the difficult challenges faced during this period.

## Patient focus

In everything that he did during his professional career, the patients he cared for remained at the centre of his focus. His patients held him in very high regard. Towards the end of his NHS career, when changes within the NHS and the accompanying resource crunch started affecting the functioning of the SCI Centre, he fought many a battle within and outside the organisation to protect the services at the Centre. He actively supported SIA and worked very closely with it on many local and national issues. Since his retirement, he has continued this work for the cause of his patients, by regularly sitting on disability appeal tribunals.

Martin has always been an excellent and passionate teacher. He has inspired many young doctors and has been active in the efforts to have spinal cord injury medicine recognised as a separate clinical specialty in its own right. As a young doctor, when I made the decision to move into SCI training, I was very strongly influenced by Martin's enthusiasm, his passion for the specialty and his warm personality.

He has been an active proponent of the concept of what he described as 'surgical rehabilitation', the use of surgical techniques to aid the rehabilitation of people with spinal cord injury. His initial training in orthopaedics and the subsequent

surgical slant to his training laid the foundations that enabled him to advance this concept. The Sheffield SCI Centre came to be nationally recognised for the surgical work it carries out in areas such as pressure ulcer management and Baclofen pumps for spasticity management. Together with colleagues from other clinical specialties, Martin regularly lectured internationally as part of the Sheffield spinal course, which attempts to increase awareness and knowledge of SCI-related problems.

## Man of influence for SCI

Martin has been the president of BASCIS (British Association of Spinal Cord Injury Specialists) and treasurer and council member of ISCOS, roles in which he influenced and strengthened the cause of spinal cord injury care. He was the chairman of the organising committee of the highly successful and much-praised 2012 ISCOS meeting in London, one of the most successful meetings that ISCOS has organised. He was also very closely involved in many of the important national developments in SCI care pathways during the period 2008 -2012.

Above all, most people who know Martin will recognise him as the warm and wonderful person who can be relied on for advice, support and encouragement. His ability to bring people together and to bring out the best in people is exceptional. Martin's wide interests outside of medicine and his desire for new information and knowledge are especially striking. His love of new technology is well known to those who have interacted with him.

He has served the cause of spinal cord injury admirably for the last three decades and I anticipate he will continue to do so. I am sure readers of *forward* will join me in wishing him many more years of productive retirement and very good health.

**Pradeep Thumbikat**  
Consultant in Spinal Injuries



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# GET INVOLVED

## Raising Funds...



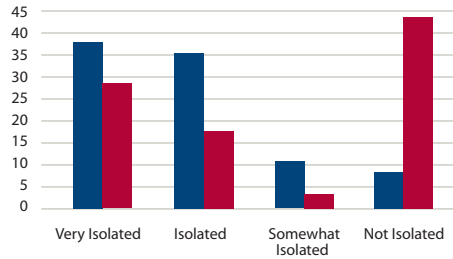
## Big Lottery Fund

In 2011, SIA celebrated being the beneficiary of a phenomenal three-year grant of £347,912 from the Big Lottery Fund. The grant funded the launch of our national Community Peer Support Service, which provides peer-led support for those newly injured patients who are not receiving treatment in a specialist Spinal Cord Injury Centre.

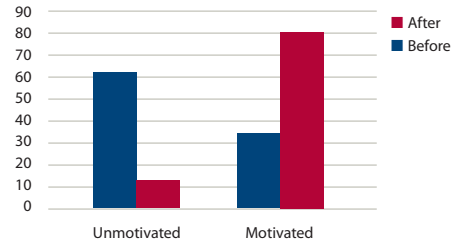
SIA decided a service of this type was required after a research report showed 41% of spinal cord injured people were not being admitted to a specialist spinal centre within a month of their injury and 10% were never admitted at all.

This led to SIA's pilot Community Support Service in 2008, which began with one dedicated officer who established links with the District General Hospitals in England. Thanks to funding from the Big Lottery, several charitable trusts and corporate sponsors, the team now consists of ten officers who provide support to newly injured people across England and

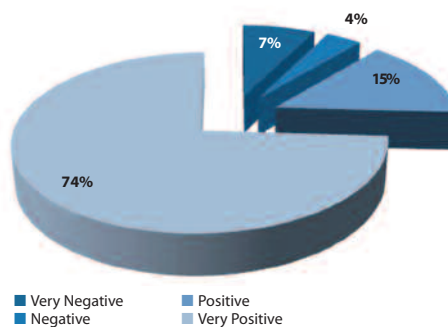
### How isolated did you feel before/after meeting the Regional Peer Support Officers?



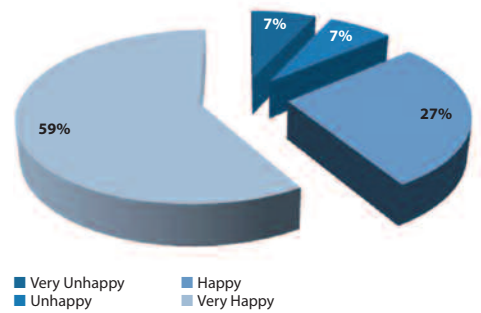
### How motivated did you feel about your rehabilitation before/after meeting the Regional Peer Support Officer?



### How positive was your outlook for life after discharge after meeting the Peer Support Officer?



### Were you happy with the level of care and support you were receiving from staff within the hospital after your visit from the Peer Support officer?



Wales, as well as a dedicated Armed Forces Officer.

We have just come to the end of the second year of funding from the Lottery and, as part of our evaluation of this service, we conducted a telephone survey of individuals and their families who have been supported. The results have been pleasing and an overview is shown above.

This is just a snapshot of the results

of our survey and highlights the difference that support from a peer can make. If you would like to know more about the Peer Support Service please visit our website [www.spinal.co.uk](http://www.spinal.co.uk) and find the officer working in your region.

We would like to thank the Big Lottery Fund for their support as well as the many Charitable Trusts and Corporate Sponsors who fund the Peer Support Service.



## Thank you!

National complex care provider The Complete Group recently handed over a donation of £750 to support the work of SIA.

Complete specialises in providing complex care to adults and children with spinal cord and brain injuries and other disabling conditions, enabling them to live independently at home.

The company is a long-term supporter of SIA and Simon Sinclair, Head of Commissioning, and Commissioning Manager Nicola Reilly presented the cheque at a meeting to discuss the work of the organisation in supporting SCI people in hospitals, specialist centres and in the community.

The donation was made up of £250, a sum that Complete has been able to donate for the last three years as a result of sending e-cards at Christmas instead of conventional cards.

The remaining £500 came through the activities of Complete's in-house Fundraising Group during 2013. This included a head office event in which supporters of the group, dressed as James Bond, took and delivered breakfast orders in return for donations and prize draws.



# Community Stars light-up our lives

SIA's Community Stars programme has now been running for over four years and we have 300 Stars. These individuals have raised over £200,000 by holding fundraising activities in their local community, ranging from dress-down days to coffee mornings, school fetes to quiz nights.

These community events provide invaluable income for SIA and we are keen to recognise the massive effort made by our dedicated fundraisers and provide the support they need to ensure their activity or event is a success. Therefore, we are delighted to launch a new recognition scheme for our Community Stars, awarding badges to acknowledge the hard work and effort that goes into raising money for SIA.

So far we have awarded Gold Community Star Badges to Cathy Leech and Gerard McDermott QC for raising over £5,000 and Silver Community Star Badges to Linda and Tracey Hartley for raising over £2,500. Congratulations to all! We will be awarding more badges over the coming months, so watch this space.



**If you have an idea for an event do get in touch. We will send you a fabulous fundraising pack crammed full of ideas and goodies such as balloons, T-shirts and banners to help you publicise and promote the event. You could hold a sponsored silence, a curry night, have a car boot sale or come up with a completely new fundraising idea.**

**For more information about SIA Community Stars, please contact Elizabeth Wright: [e.wright@spinal.co.uk](mailto:e.wright@spinal.co.uk)**



## Make the Batter Matter

### Register now for your Fish and Chip Supper pack

Get together with friends, family and colleagues on Friday 16 May and support SIA by holding your own Fish and Chip Supper. You can hold your supper at home or at work or in a local community venue. You can even hold it at lunchtime!

By inviting eight other people and asking them to give a £5 donation you will raise at least £40. But, we can give you even more fundraising ideas by sending you a fundraising pack full of all you will need to organise an event.

**To request your pack** please go to [www.siafishandchips.co.uk](http://www.siafishandchips.co.uk) or email [fundraising@siafishandchips.co.uk](mailto:fundraising@siafishandchips.co.uk)

## Prudential Ride London-Surrey 100

The Prudential Ride London-Surrey 100 is set to be even bigger for 2014. On 10 August cyclists will travel 100 miles along a modified version of the Olympic Road Race, seeing the best sights that London has to offer.

### Own Place

If you have won your own place in the ballot, we would love you to join TeamSIA. By being on our team, you will receive support and advice in the run-up to the event. We will also be there to support you on the day and will provide you with a TeamSIA cycling vest.

### Golden Bond places

We have a number of Golden Bond places in 2014. Please fill in the registration form on our

website [www.spinal.co.uk/page/ride-london-100](http://www.spinal.co.uk/page/ride-london-100) Registration fee: Holding Donation £100 Sponsorship target: £750

### How we will help you

We understand the commitment that our cyclists have to make in order to complete this challenge, and in return for this amazing dedication we will provide you with:

- Fundraising pack, tips and advice
- Regular emails and updates
- TeamSIA Cycling shirt
- Training advice
- Support on the day

**For more information** contact Elizabeth on 0845 071 4350 or email [fundraising@spinal.co.uk](mailto:fundraising@spinal.co.uk)

## Adidas Half Marathon

Thank you to the 34 people who took part in the Adidas Half Marathon at Silverstone on the 2 March 2014. The runners and wheelchair participants braved the very cold weather and travelled 13 miles around the racetrack – so far the team has raised £5,000 with the money still coming in.





**B**efore I was paralysed I enjoyed a varied career as a nurse working in pre-Hospital Emergency Care. In 2008 I was accepted to Medical School at the University of Dundee, where my aim was to qualify as a doctor and continue working in the same field. However, after a period of serious illness I was diagnosed with widespread Vasculitis which ultimately resulted in a spinal cord injury at T12/L1.

It's fair to say that I thought my life was over at the start. Adjusting to life in a wheelchair was a big task, and the associated continence issues were things I had never even thought about until it became a personal reality.

I had previously led a very active lifestyle, enjoying watersports and travelling, alongside a busy job. There was also a huge concern that this spelled the end of my hopes for a career in medicine – I had never heard of a doctor in a wheelchair before!

It soon became clear that with the support of family and friends my life post-injury was the same as before,



# All set to go!

Elizabeth Ferris overcomes her biggest hurdle.



I just had to live it sitting down. I was able to return to medical school to continue my studies and threw myself into sport. It was a huge honour to be selected to play for Scotland at the Wheelchair Rugby League World Cup in 2013, four years after I had started out on this new chapter of life.

Undoubtedly, one of the biggest hurdles for me to overcome was getting used to the new way of managing my bladder. I was determined to continue to be out and about, and I have never let the fact that I need to catheterise interfere with going to places where the facilities are less than accessible. It can sometimes be a hassle though, and I did find it pretty embarrassing that the catheters I used were in great big bulky packaging which left no doubt as to what was inside!

Excitement isn't usually the first word that springs to mind when thinking of a catheter system, but that is honestly how I felt when first introduced to the SpeediCath Compact Set from Coloplast. It is so discreet and compact; no-one would ever know what is contained inside, banishing the awkwardness associated with the product I was using previously.

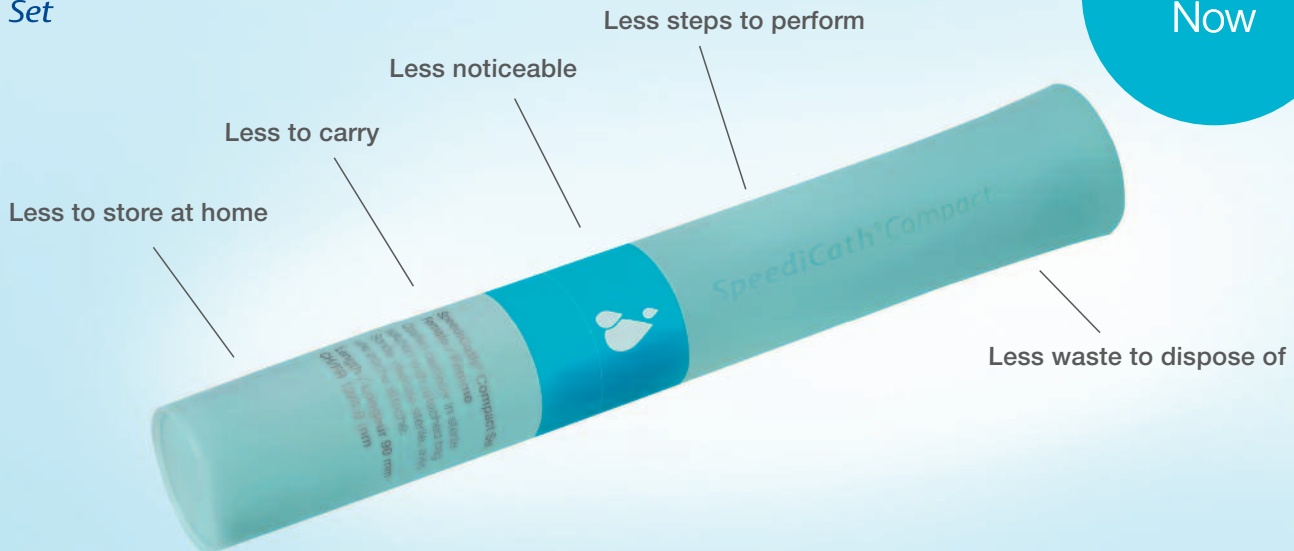
It's no exaggeration to say that the SpeediCath Compact Set has changed my life. I know that I can go anywhere, anytime and never have to worry about having a large bag in which to hide all the catheters I need for the day. The catheter itself has a sturdy feel, it is very easy to use and disposal is no trouble at all.

Knowing that I can rely on the SpeediCath Compact Set to cope with the demands of my busy lifestyle means that I can have the confidence to get on and enjoy staying busy.

Top: Elizabeth before her SCI.  
Left: Playing wheelchair rugby for Scotland

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# Travelling with Confidence

## Tips from the Bladder and Bowel Foundation

**Debbie Gordon, Clinical Manager at the Bladder & Bowel Foundation says...**

**T**here should be no real reason why you can't go on holiday as long as you prepare carefully and plan everything well in advance.

Ask your GP to provide or help you with the following:

- A letter outlining your medical history. Certain items are more tightly controlled in other countries than they are at home. If you carry syringes, medicines, appliances and devices, or have an implant or are ventilated, you will need a medical letter from your doctor explaining their use to show at customs. If you're on medication it's also advisable to keep your medicine in its original packaging if travelling by air. A GP letter can also help explain your condition to a doctor in a different country if you need to get a prescription there.
- A written management plan outlining what you should do for mild, moderate and /or severe symptoms, and when you should seek medical attention.
- If you are going away for a while, ensure you are able to take with you enough of your normal medication, devices or appliances to last the duration of the trip.
- A contact number for your GP or Spinal Cord Injury Centre, in case you need medical advice while you are away. It can be very reassuring to know that you can call your GP if you have any medical problems.



### Tips

- Public toilets are few and far between in some countries. It is often easier to find an accessible toilet in a hotel, bar or restaurant, or in a shopping centre.
- When flying, remember to split up your supplies between different bags, in case one is lost!
- Remember to pack in your hand luggage a supply of all the items you are likely to need during the journey and waiting periods at each end.
- A portable washing line (or just a piece of strong cord which can be stretched across a room or balcony) and a few clothes pegs can make drying a lot easier.
- Take a supply of all the items you will need – catheters and bags, sheaths, gloves, pads, wipes, etc.
- Think about a convenient time to travel – depending on what time of day you carry out your bladder and bowel management routines.
- For more information go to [www.bladderandbowelfoundation.org](http://www.bladderandbowelfoundation.org)

# Now fitted with side Air-Bags

## Life with a colostomy

I hesitate to use the m-word, but I never thought I would be *moved* to discuss, in public, bowel management for people with spinal cord injury. However, my own arrangements may be worth sharing. I have had the benefit of a colostomy for ten years now. There is no shying away from the fact that twenty years of manual evacuation had taken its toll; my bowel could, at best, be described as sluggish. Regularly spending over an hour each day in the bathroom, I was experiencing bleeding, profuse sweating, terrific headaches, fatigue – I have to say, not the most fun I have had with my trousers down. No end of laxatives seemed to alleviate the difficulties – I suspect my GP was beginning to think I had set up a sideline dealing in Sennakot (other brands of herbal laxative are available).

The problem came to a head when I was diagnosed with Colitis, otherwise known as Inflammatory Bowel Disease – no, not just irritable, but inflamed. All very glamorous stuff. Received wisdom suggested that an elective colostomy would ease the symptoms and reclaim my evenings for my family and my social life. Elective colostomy – it sounds like the sort of phrase used when opting for cosmetic surgery, but the term elective really just means ‘not performed as an emergency measure’.

### No going back

Some colostomies are reversible, but not mine. Presumably, they tie knots in your plumbing in a different way to make it reversible. The operation was performed under general anaesthetic in a local general hospital (rather than a specialist spinal centre) and involved a stay of about five days. A couple of months off-work was probably not quite enough time to get over the operation and become acclimatised to the idea of managing the bags and adjusting to life around a colostomy but, sooner rather than later, you need to get on with your life again.

Ten years on, I think I have trialled it for long enough to conclude that it was probably the best thing I ever did. The



health problems have improved tremendously and, whereas previously I might spend up to ten hours a week on bathroom-duty, these days I might spend just ten minutes a day. I still take more Senna than you can shake a stick at, but now just to regulate when the stoma is active. I tend to take a few laxatives in the morning and the colostomy is active for about an hour in the evening, when I can deal with it in the comfort of my own bathroom.

### Side effects

For the sake of balance, a colostomy is not without its problems. Leaks are commonplace, although hopefully not too traumatic (for both me and those around me!). The amount of planning and preparation is not to be underestimated. The bags are easily available on prescription and are delivered to my door three or four days after placing an order.

Perhaps the biggest drawback of having a colostomy is the noises it makes from time to time. These can vary from gentle gurgling noises to full blown comedic parps. Some days I am like a whoopee cushion on wheels! Paying close attention to the diet does help. It varies from person to person but some foods, notably lentils, onions and any sort of beans for me, tend to cause wind.

Amongst friends and family, this is easy enough to laugh off, but it is also where careful planning is vital – if you are

invited to propose a toast at the local photographic society dinner, the last thing diners want to hear is ‘My Lords, Ladies and Gentlemen ... parp!’

One issue I have yet to resolve is when do you tell people you have a colostomy. Not every person you meet needs to be fore-warned about the potential flatus, but if you spend long enough in my company, eventually the noises will be noticed. You can hardly greet people for the first time, shake hands and announce proudly ‘I wear a colostomy, me, you know’ – on reflection, perhaps I should get that mantra made into a badge. One useful observation: young children and pets can be very useful when deflecting the blame for some of the sounds. I once found myself in a crowded lift with my fourteen-year-old daughter when my plumbing decided to play its infamous ‘party trick’. Blowing raspberries very much louder than a girl of her age generally should, to my delight, my daughter covered for me. She would rather be perceived by strangers as ‘having problems’ herself than see her flatulent father embarrassed. Perhaps that is the real reason they play music in the lifts in posh department stores.

**Name and address supplied T5/6**

**If you would like to speak about any aspect of life with a colostomy with the author of this article, please contact the SIA Advice Line**

# The Mult/Cath Study

## Important new research into Intermittent Catheterisation

Intermittent catheterisation (IC) is an important management option for people who cannot empty their bladder naturally. Incomplete bladder emptying may be a consequence of neurological disease affecting bladder muscle contraction or, in men, an enlarged prostate causing outflow obstruction. People needing IC are taught how to insert a catheter, drain the bladder, and then remove the catheter. Single-use, disposable catheters are the most commonly used option in the UK. When IC was introduced to the UK in the 1970s, plain, uncoated catheters were routinely washed and re-used and this is still practiced by some people in the UK and, more extensively, in other countries.

Over the years new types of catheter have been developed, for example, with special coatings designed to make catheterisation easier and safer. Such innovations have increasingly been

associated with the commonly held belief that using a sterile catheter for each catheterisation causes less urinary tract infection (UTI) but recent reviews of the research do not support this conclusion.

Using a combination of re-usable and single-use catheters is called 'mixed use'. This option is attractive to some because, for example, it reduces the number of catheters required when away from home, and may have environmental and cost benefits.

In order to establish if mixed use of both sterile and re-usable catheters is safe and acceptable to people using IC, we will be undertaking a major piece of NHS research over the next five years, culminating in a clinical trial; but first we must do some preliminary work to:

- Investigate ways of cleaning and storing catheters that are effective and acceptable, coming up with clear guidance on a range of easy-to-use methods.

- Understand the factors that are important to people doing IC; for example, how to manage when away from home.
- Identify the signs (what your doctor can see or tests reveal eg bacteria in the urine) and symptoms (what you complain of eg pain when passing urine) of UTI. We will need to be confident that re-using catheters is not more likely to cause UTI than using a sterile catheter each time.
- Identify factors that would influence the acceptance of mixed use IC by both manufacturers and those teaching IC.
- We will be seeking people willing to take part in various phases of the research. If you think you may be interested in being involved and would like to know more, we would be very happy to talk to you. Please contact us if you:
  - Are over 18
  - Using IC for bladder emptying – especially if you clean and re-use your catheters at least some of the time.

We are particularly interested to hear from you if you live in London or the southern counties, or near Bristol, Glasgow or Newcastle. Please contact Margaret Macaulay, Research Nurse, for an informal chat. Email: [m.macaulay@ucl.ac.uk](mailto:m.macaulay@ucl.ac.uk)  
Tel: 020 3549 5417.

Thank you, we look forward to hearing from you!

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# Celebrating 20 years!

The Transhouse housing charity in Oswestry, Shropshire is celebrating its 20th anniversary this year.



Transhouse was established in 1994 by Prof Waghi El Masri from the Midland Centre for Spinal Injuries, who is also President of the charity.

Transhouse provides short-term accommodation and independent living support to patients newly-discharged from hospital or SCI Centre and who are waiting to move into more long-term accommodation.

Transhouse has two large bungalows in Oswestry which can accommodate

up to eight disabled people at any one time. Since its inception the charity has successfully assisted over 200 disabled people make the move into independent living.

**Prof El Masri said:**

*"I am very pleased and gratified that Transhouse has become such a wonderful success story. The charity has enabled many people with spinal cord injuries to live independent lives after their discharge from hospital and to retake their place in society."*

Transhouse is planning an open day on 10 June 2014 to celebrate its 20th anniversary.



Above: Mr El Masri  
Other pictures show the facilities at Transhouse



If anyone would like to visit the open day and to hear more about the services that Transhouse provides they are asked to contact the manager, Fae Dromgool, on 01691 404359 or 07702 094819



# Have a go at scuba diving!

Dive Ability was set up to make as many disabled people as possible aware of the benefits scuba diving has to offer and to have a go at it...

We started off as a group of friends experienced in scuba diving (some with a disability) diving monthly in a swimming pool together, we became a charity in early 2011 and we are now registered with the Charity Commission.

Our charity is user led, consisting of

disabled and non-disabled committee members and trustees. Our monthly pool sessions near Alton in Hampshire are accessible and we can offer try dives and Open Water and Advanced Diving Qualification Courses to all abilities, taught by our highly experienced and qualified instructors. We also hold numerous social

events throughout the year and arrange accessible dive holidays abroad. This enables our members to discover the amazing array of sea life that places like the Red Sea have to offer.

We know from experience that scuba diving gives you something to look forward to, a goal to aim at and a great sense of achievement, all of which are important in anybody's life. This leads to a greater sense of well being and higher confidence levels, which will enhance other aspects of your life. Most importantly, all this is achieved whilst having fun!

I am a C4/5 tetraplegic and have now been diving for over six years. Thanks to the amazing bunch of instructors and volunteers that have helped me, I have managed to do over 50 dives in the Red Sea and shark diving in the Bahamas.

Diving is now my main hobby, I am one of Dive Ability's committee members, and very committed to making disabled people aware of the amazing sense of freedom scuba diving offers. I'm also very keen to show interested new instructors and volunteers how to take me into the water and to teach them the skills required to enable a disabled diver, such as myself, to dive safely with their help; more often than not I find that they get as much out of it as I do!

So what's stopping you? If you would like to have a go at scuba diving then get in touch – we have the right equipment and experienced and qualified instructors to make it happen!

**Matt Colliard C4/5**

**Dive Ability Access Officer**

**For more information tel Andy Wood,**

**Dive Officer on 07721 890058**

**Web [www.diveability.org](http://www.diveability.org)**

**Email [trydives@btinternet.com](mailto:trydives@btinternet.com)**





# Upwards and onwards!

## Ann Turner re-kindled her love of horses when she took up carriage driving

To begin I must tell you about my first pony. She was called Dolly, about 14 hands high, excellent temperament, no need to shoe, cheap to keep. She had a neat head which consisted of an oak post attached to a gate; a wall which was also attached to the gate was her body, with a hessian sack for a saddle. The reins were baler twine (the old type) the bit was a skewer from the kitchen drawer.

My father worked on the local farm estate which had a heavy horse called Dolly for ploughing etc. When they needed a new harness for Dolly, Dad would bring the old harness home for my Dolly!

It wasn't until I was about 18-years-old that I had my first riding lesson. When I was a child my parents could not afford it and there was no riding school nearby at the time. So, in between times, I used to ride friends' ponies (appallingly).

Not long after I married we moved to Warminster (a garrison town) as it was nearer to my husband's job with the army.



*"She had a neat head which consisted of an oak post attached to a gate; a wall which was also attached to the gate was her body, with a hessian sack for a saddle"*

It was there I started riding lessons with the Infantry Saddle Club. When the head of riding asked if I would like to work towards taking my British Horse Society qualifications I jumped at the idea (excuse the pun).

It was at an Equestrian Centre in Chelmsford where I spent a fortnight to brush up on all aspects of horse care that I took the exam and passed.



Ann being assisted into the carriage



Ann in her new seat, driving independently

> In the year 2000, I was diagnosed with breast cancer. During chemotherapy I still kept up my teaching which helped me to overcome the effects. I thought that was my share of problems over and done with but, once again, tragedy reared its ugly head. In 2003, I was escorting a hack when I was thrown from the borrowed horse I was riding (my own horse was lame at the time). I was airlifted to Salisbury SCI Centre with a severed spinal cord and this is where I spent the next eight months, paralysed from the chest down, having only the use of my arms.

So, after eight months, I went out into the big wide world wondering what on earth I was going to do with myself now. My good friend came one day with a cutting from a Somerset newspaper describing the Somerset Levels RDA (Riding for the Disabled) Carriage Driving Group with a contact number. The rest is history! I have been driving for six years and, having recently gained my RDA

*“Once I am in the seat I replace the arms and then I feel that my horse, my back step and I can compete with any non-disabled person and take on the world!”*

Grade 3, I can drive independently and can also compete with non-disabled people. The competitions include dressage, fastest times through a cones course and a timed cross-country course which includes driving through water, gates and obstacles as well as ‘showing’ classes.

I recently had a special driving seat made for me. It is a quality seat made by a wonderful craftsman and it has removable arms enabling me to slide across from my wheelchair into the carriage seat. Once I am in the seat I replace the arms and then

I feel that my horse, my back step and I can compete with any non-disabled person and take on the world!

It’s not just the carriage driving that I enjoy, it’s the smell of clean harness, saddle soap, hay and straw and of sweaty ponies! Also the fun we have within the group. We always have cakes and wine at the top of the essentials list when we go away. The group runs solely with a wonderful band of dedicated and enthusiastic volunteers. We constantly have to fundraise which is an enormous task.

I now feel I have had three different lives: life before my accident, my life of eight months in the SCI Centre and my life now. So, I would like to say to disabled people out there that there is life after an accident, you just have to take a different path to the one you were on originally. I am lucky to have such wonderful family and friends, especially the Driving Group, who support me in every thing I do.

**Ann Turner T4/5**

**To find out more** about Carriage Driving in your area, take a look at the website [www.rda.org.uk/taking-part/carriage-driving](http://www.rda.org.uk/taking-part/carriage-driving) or contact your nearest branch of Riding for the Disabled.

You may also like to read Ann’s book *Reflections from the Somerset Levels* which is available from [www.somersetlevelsda.org](http://www.somersetlevelsda.org) and costs £13 incl. p&p. All the proceeds go towards the upkeep of the ponies, vets’ fees, bedding etc.

# Ruby Corporate Partner Anthony Gold Solicitors

I am known as one of the UK's foremost serious injury solicitors. I am not known as a concert pianist.

So how on earth do I find myself signed up to play 20 minutes of Schubert on a Steinway piano, on a stage in Kings Place, alongside professional musicians and in front of 200 of my peers?

I wanted a tough challenge is the answer.

Most fundraising I hear about involves physical challenges. A team of my colleagues took part in the 24-hour Three Peak Challenge for spinal cord injured people.

Sounds gruelling indeed. As I prepare for my fundraising concert what climbing three peaks lacks in comfort it makes up for in privacy. It's the public performance of my concert that is the terror!

But that's the point of

a challenge isn't it – to really take something on? I have been lucky in my life. I have interests that I have been able to follow. Since childhood, music has been one of them.

For 27 years – most of my adult life – I sang on and off in the London Symphony Chorus. I had to stop when I developed vocal chord palsy. There's nothing that can be done about it; I just couldn't keep singing. So I took up the piano again.

It wasn't easy but I worked hard, practised a lot and have a wonderful teacher – Linda Nottingham. Linda is joining me on stage in that Schubert duet.

Through my work as a catastrophic injury solicitor I have been privileged to meet incredible people, some of whom have spinal cord injury. I fight to get the maximum compensation for them, to do everything



in my power to help them get the best support to make the most of their lives.

I feel supported knowing that SIA is there for my clients. They know the people they help; they know how to help and they fight tirelessly to make things better. I can relate to that and that's why I'm inspired and very proud to be taking the stage for SIA's 40th Anniversary.

**Jenny performed her concert** on 2 April 2014. You can check the fundraising results on [www.justgiving.com/JennyKennedySIA](http://www.justgiving.com/JennyKennedySIA)



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# What's happen

**1 April**

## Members' photo competition

Highlight SIA's 40th Anniversary merchandise in a unique way! Take them on holiday with you, on days out or give them to a celebrity to wear. Then get snap happy with your camera and email your photos to [h.chapman@spinal.co.uk](mailto:h.chapman@spinal.co.uk) by 29 August.  
[www.spinal.co.uk/page/shop](http://www.spinal.co.uk/page/shop)

**11 April**

## 'Make the batter matter' in 2014

*Hold an SIA Great British Fish and Chip supper with your friends or colleagues, to raise money to support our vital services.*  
[www.siafishandchips.co.uk](http://www.siafishandchips.co.uk)



**16 May**

## SCI Awareness Day

Share your experience of SCI with your local press to raise awareness. Contact Helen at [h.chapman@spinal.co.uk](mailto:h.chapman@spinal.co.uk) to register your interest.

**15 May**

## Sip for SIA

London Legal Professionals' Drinks Reception.  
Join SIA for an evening of networking and fundraising at 9 Gough Square. Email [m.bloedorn@spinal.co.uk](mailto:m.bloedorn@spinal.co.uk)

**29 April**

## Naidex Exhibition Birmingham NEC

Come and visit us on stand C04 to pick up a 'Make 40 Matter' pack and chat to us about our activities.



# ing? April-July 2014



**6 June**

Who has been commended at the Rebuilding lives after SCI Awards? see the list of award winners at [www.spinal.co.uk/page/RLSCI](http://www.spinal.co.uk/page/RLSCI)

**Rebuilding Lives**  
after spinal cord injury

**16 June**

## Family DVD launch events

See how SIA supports families. Visit [www.spinal.co.uk](http://www.spinal.co.uk) to find an event near you!

**30 June**

## Donate

to our 'Make 40 Matter' fund at [www.spinal.co.uk/page/make40matter](http://www.spinal.co.uk/page/make40matter) as we strive to reach our online donation target of £40,000.

**7 July**

Join Team SIA at the Ride 100 cycle in Surrey. To take part email [fundraising@spinal.co.uk](mailto:fundraising@spinal.co.uk) or register on line at [www.spinal.co.uk/page/ride-london-100](http://www.spinal.co.uk/page/ride-london-100)

**2 July**

Motor forward with SIA at our exclusive Williams F1 Dinner. Dine with Sir Frank Williams and meet the Williams drivers. Just 40 places available! Email [m.bloedorn@spinal.co.uk](mailto:m.bloedorn@spinal.co.uk)



# Merchandise

We have produced three pieces of branded merchandise for you to use to help promote SIA in its 40th Anniversary Year. Each piece could be yours in exchange for a donation of £1. Please complete the form below or visit the online shop on SIA's website – remember to have your payment card handy.



**Pin badge**



**Key ring (including token for supermarket trolley)**



**Wrist band**

Item	Quantity required	Donation per item (min £1)	TOTAL
<b>Pin badge</b>			
<b>Key ring</b> (including token for supermarket trolley)			
<b>Wrist band</b>			
<b>I would like to make an additional donation to support SIA's work in the 40th Anniversary Year</b>			

Please enclose a cheque made payable to **Spinal Injuries Association** or complete the form below with your card details.

**TOTAL AMOUNT**

I wish to pay by: Mastercard / Visa / Maestro / Switch (\*delete as appropriate)

Card number --- Issue number

Name on card ..... Signature .....

Card Start date / Card Expiry date / Card security number

Name .....

Address .....

Postcode .....

Telephone ..... Email .....

*giftaid it*

**Gift Aid**

Tick here if you would like the tax reclaimed on this and future donations.

I confirm that I am a UK taxpayer, and the amount of tax I pay exceeds the amount I would like SIA to claim. This action will enable SIA to recover a further 25p for every pound you donate.

# Ruby Corporate Partner

## Fentons Solicitors

Part of Slater & Gordon

Deborah Johnson, a principal lawyer at Fentons (part of S&G), has supported SIA for a number of years and *forward* magazine recently caught up with Deborah in her Manchester office to talk about her work, SIA and care for those with SCI.

### So tell us about your work?

"I work on a daily basis with people who have sustained spinal cord injury. When calculating the value of a personal injury claim, I have to look at different areas of an individual's life



and how their injury has affected them. For example, I look at their accommodation needs, rehabilitation requirements, loss of earnings and past and future care."

### So how important is care?

"Care is a hugely important issue for everybody to deal with. The cutbacks have affected the funding of local authority care provision right across the country. It is more important than ever that a person's care needs are properly assessed and valued as part of the personal injury claim process."

"Until someone has a proper care regime in place, how can they even think about returning to work, going on holiday or starting to live independently? Care should fit in around the person's activity rather than the person fitting their activity around care."



There is a big difference!

"Take for example a recent client of mine. He is an incomplete tetraplegic and his case settled recently. He is a

very active individual and he has rehabilitated to a very high standard. The issue for him was that he would need more care as he got older. I had to use expert care evidence to demonstrate

to the court his current and future care needs and the significant cost of this. In the end, we succeeded and secured for him a financial settlement that will ensure his care needs are met for the rest of his life."

### And you and SIA?

"I am delighted to know that SIA is celebrating its 40th Anniversary this year and proud that Fentons is a supporter of SIA's work and services."

Fentons Solicitors (part of S&G) is one of the country's leading claimant personal injury solicitors, recovering tens of millions of pounds worth of damages every year.

To read more about Deborah and her work and to contact her go to [www.fentons.co.uk](http://www.fentons.co.uk)



A mid-wheel drive like no other.

## M400 CORPUS HD

Having launched the first mid-wheel drive platform to the wheel-chair market nearly 30 years ago, Permobil honors that rich tradition with the addition of the M400 to its product line. Developed by Permobil Senior Designers, Mehdi Mirzaie and Bo Engman, the M400 features the ground-breaking, Climbing and Traction Link system. With its compact size, the M400 has a tight 510 mm turning radius, comes with PG 120 amp R-Net electronics and offers two speed packages: 10 mph standard and 12 mph optional. The M400 also features stylish easy-to-replace swing arm covers made of scratch resistant material, which protect the swing arms from unsightly chips and scrapes. Easy to maintain, the M400 provides quick access to components and requires no special tools for servicing. To arrange a free, no obligation demonstration of this M400 or any of the extensive range of Permobil powerchairs, please contact Permobil UK head office using the details below.

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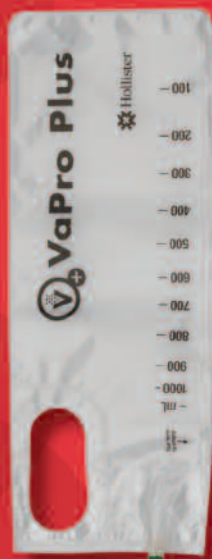
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# Tanzania partnership



**Tim Rushby-Smith tells of a successful partnership between Stoke Mandeville and a medical centre near Mt Kilimanjaro.**

While it can feel as if the NHS moves at the speed of a glacier when it comes to accessing some essential services, and we wonder how many of these will buckle under a Government onslaught that bears all the hallmarks of a privatisation agenda, it is worth taking a moment to consider life after spinal cord injury for those who live in the developing world.

In countries where multidisciplinary rehabilitation is unavailable, typical life expectancy after SCI can be as low as two years. Cervical injuries have a very high mortality rate due to a lack of skill in initial life support at the scene of any injury and a shortage of intensive care facilities.

With devastating mortality rates largely due to preventable complications like pressure sores and urinary tract infections, and with a poor quality of life after injury, a spinal cord injury can be viewed as a death sentence for many.

Often, the resource most lacking is knowledge among healthcare professionals. The forging of a special relationship between the National Spinal Injuries Centre (NSIC) at Stoke Mandeville and the Kilimanjaro Christian Medical Centre seeks to provide vital support in tackling this knowledge gap.

Kilimanjaro Christian Medical Centre (KCMC) is a 560-bed hospital serving a regional population of 2.5 million in Northern Tanzania. It has 16 clinical departments, as well as faculties of medicine, nursing, occupational therapy and physiotherapy.

For a number of years now UroLink, the charitable arm of the British



Michelle Clarke and Jane Stanbridge with SCI patient, Daudi, experiencing his first day in a wheelchair

Association of Urological Surgeons (BAUS) has supported KCMC's efforts to establish a urology department. As part of staff training UroLink has run a workshop for East Africa every two years. In 2011 Urology consultant John Reynard attended this workshop along with Dr Alison Graham and Jane Stanbridge, a nurse specialising in SCI, from the NSIC.

*"The attitude we witnessed two years ago seemed very harsh, almost brutal"*

The focus of the urology conference included spinal cord injury patients.

The hospital receives between 60 and 100 cases of spinal cord injury every year. The team from the NSIC was also introduced to the current SCI patients. SCI care is managed on a busy orthopaedic ward, which operates at 120% capacity. The care provision witnessed by the NSIC could best be described as pre-Guttmann; no bowel care, only indwelling catheters and with pressure sores in abundance.

Following a formal invitation from KCMC, a working group was set up at the NSIC to develop links with the Tanzanian

hospital so that knowledge and expertise could be shared between the two institutions.

In October 2012 another small team from the NSIC, including operational manager David Griffiths and physiotherapist Jo Armstrong, visited Tanzania to carry out a needs assessment and have discussions with key staff at KCMC about how they wished to develop SCI care.

Jo's previous work with Motivation enabled her to set up meetings with the charity's peer trainers in Tanzania who began to carry out hospital visits for 'survival skills' training. This working relationship continues to play a vital role, as the peer trainers also help to promote positive attitudes to SCI amongst KCMC staff.

In 2013 staff from the NSIC went to Tanzania to train the multi-disciplinary staff team. With a focus on aspects like bowel management and regular turning of patients to prevent pressure sores, this sharing of knowledge and expertise will have a profound effect on patients' survival rates and long term health.

Jane describes the challenges they faced.

"The most important thing we

*“It will be good for trainers to go and visit my family so that they can see people who are in a wheelchair but are very active and happy – I want to be happy just like others”*

> brought to KCMC is a change in attitude among the staff toward the patients. The attitude we witnessed two years ago seemed very harsh, almost brutal. There is now a genuine fondness and care directed towards the peer support workers when they come for weekly visits.”

As well as the challenges offered by social attitudes, there are practical differences in training, as OT Michelle Clarke explains,

“It is amazing what you end up doing – you need to be able to think laterally, teach on a variety of subjects and fabricate equipment out of locally available materials.”

KCMC is keen to shift their spinal patients into a dedicated spinal unit to be housed in new buildings financed by charitable donations, but there have been a wide variety of challenges to overcome. There wasn’t even a path connecting the new building to the rest of the hospital. More nurses are needed to staff the sixteen beds and a sluice is

Faustina Urassa, Peer Support Coordinator with John Reynard, Urology Consultant



Michelle, left, and Rachel Harrison, Physio, working with Daudi T4 on dressing practice

also needed, along with some security provision. Progress is gradually being made towards resolving these issues.

Jane remains resolute about the future of the partnership between the NSIC and KCMC, especially when she considers the alternative.

“If we don’t provide training and fund peer support, then patients will remain in pre-Guttmann conditions for another 30 years with a lot of suffering, no quality of life and early mortality. So we are determined to continue with this project until they can move into a purpose-built Centre and have become self-sustaining in education.”

In keeping with wider perceptions outside hospital, an SCI patient who doesn’t recover is seen as a burden and is often abandoned by their family.

Pius Hamisi Saria was 28 when he sustained a spinal cord injury three years ago. He was admitted to KCMC hospital and was an inpatient for two years.

On discharge Pius went to live with his mother for two months, until the family decided that he would live with his brother in a remote farming district with no bus services.

Pius’ brother took away his wheelchair and put him in a small room with a bed too small to turn in, and even took his mobile phone so that he could not communicate with friends or family. Such attitudes toward disabled people are not uncommon in areas where survival

depends on subsistence farming.

As the days passed, Pius became very weak and developed huge pressure ulcers. He asked his brother for help but he was too busy farming.

Thankfully, the neighbours came to Pius’ aid and helped him to get out of bed – he met with friends who gave him money for transport. The following morning Pius travelled to KCMC by bus, fearing he wouldn’t be admitted because of his extensive sores. He was, of course, admitted to the hospital where he also met with peer trainers.

Reflecting on the help he received, Pius said,

“I realised that I was not eating a balanced diet, and that I did not turn frequently enough to prevent pressure ulcers – this was why I had so many health complications. It will be good for trainers to go and visit my family so that they can see people who are in a wheelchair but are very active and happy – I want to be happy just like others”.

Pius received information on bowel and bladder management, rights issues and how to use a wheelchair – this has helped him to become strong and active – he now only wishes for his family’s support.

At a time when ‘first world aid’ is largely viewed in material terms, it is important to appreciate just how vital sharing of information can be.

**Tim Rushby-Smith T12**

# Consumers of care

I suspect it's a no-brainer and no one would accept being told by the shopkeeper what bread they can eat and when they can eat it.

And yet, time and again, I hear people complaining that the agency providing their care is telling them that they can't provide the care they want. Perhaps the agency is stipulating the times of care visits, irrespective of whether these are convenient to the service user or not. Perhaps they won't even guarantee the time of a visit. They often won't guarantee that the same person will visit more than once. Perhaps they are saying their carers can't perform certain tasks (without giving good reasons why) or insisting their carers wear 'uniforms' that are inappropriate for the home setting.

Whatever it is, it feels to me as though care agencies all too often dictate their terms of business to service users. There are very few other businesses that get away with this kind of behaviour and stay in business for any length of time.

It wasn't that long ago that home delivery services would only give the day on which they would be delivering something. Consumers made it clear

Imagine the scenario. It's 2pm. You want some wholemeal granary bread but don't have any in the house. So you go to the shop, but the shopkeeper tells you that they only sell white bread and they only sell it at 5am. Do you

- a say "Oh, all right I will pop back at 5am tomorrow" and get some white bread, or
- b go in search of a shop that sells the bread you want at the time you want?



that this wasn't acceptable and now my experience is that at the very least they will stipulate either the morning or the afternoon and, increasingly,

they are guaranteeing delivery within a one-hour time slot.

Care agencies are businesses that depend on our custom in order to survive. However, many of us behave like passive customers in a way that we would never dream of doing with other businesses.

For example, if I am going shopping in a supermarket I take a detailed shopping list with me. If that supermarket consistently fails to have all of the items on my list I will soon take my business to one that does. However, when we are looking for a care agency how often do we draw up a specific and detailed 'shopping list' and then shop around various agencies to see which one can deliver on our shopping list consistently?

If there are elements of our shopping list that the agency cannot guarantee, how often do we ask them to explain why and see if we can find a way of making it possible? Sometimes this may involve additional costs, but we may be happy to bear those if it guarantees the service we need.

One example of this is when care agencies say they cannot deliver bladder and bowel care – usually due to the lack of appropriate insurance. But perhaps they would be happy to train a specific carer to do bladder and bowel care and then put the appropriate insurance in place for a small premium?

I think it's about time we started dictating the terms of business with our care agencies. Yes, this will probably involve substantial time and effort on our part in the initial stages to make sure we have the right 'shopping list' and ask the right questions. But the quality of care that we receive is surely important enough to us to make this worthwhile?

**Brian O'Shea C4/5**  
SIA Continuing Healthcare Adviser



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# The Role of SIA's Continuing Health and Social Care Working Group

Third Sector organisations and we work closely with our Public Affairs colleagues to bring focus on care issues to the All Party Parliamentary Group on SCI.

## How SIA works to protect your interests

**SIA** has a passionate and pioneering Working Group focussed on Health and Social Care issues. Chaired by Rupert Earl, Trustee and Honorary Lead on Care Policy, the group comprises our Care Advisers (Brian O'Shea and Simon Legg) and Head of Public Affairs (Dan Burden), Trustees John Borthwick (hugely experienced on care matters) and Martin McClelland (who as a retired SCI Consultant provides key clinical input) and representatives of specialist SCI care agencies. Its remit is to influence Government and key policy makers on care matters that impinge on SCI people, and it does this by, amongst other things, meeting with and making representations to the Care Services Minister, and NHS England Leads on Continuing Healthcare.

We are represented on the NHS Continuing Healthcare Stakeholders' Group, a high-level forum between the Department of Health, NHS England and

Another important aspect of our work is an ongoing series of workshops on Continuing Healthcare. We hold these for SCI Centre Discharge teams, allowing them and us an opportunity to exchange intelligence on the often problematic and postcode lottery implementation by Care Commissioning Groups of the care package recommendations made by the SCI Centres.

It is at discharge that many SCI people, especially those with high-level tetraplegia, have the greatest need for a viable and adequate package of care, yet all too often there is a battle to secure this and to retain it at subsequent reviews. Rupert told us "We on the Working Group do our utmost to stand up for the care needs of SCI people, and especially for SIA's most vulnerable members, both strategically and, if necessary, operationally, when geography or capacity issues would otherwise mean people would go unsupported at key appeal hearings. As a charity, SIA punches above its weight on care on many levels".

# Why commissioners must take the long view in care

**Medical advances mean people with spinal cord injury are significantly better treated in acute hospitals than they were just a generation ago.**



**M**ore people are surviving SCI with little reduction in their life expectancy. The result is that more people require specialised rehabilitation – a service the UK is, as a whole, not yet delivering to a sufficient quality.

Historically, the UK has failed to provide appropriate – sometimes even acceptable – care. It's a postcode lottery for good services.

Not long ago the care provider where I am chief executive officer, PJ Care, admitted a 51-year-old man, let's call him Richard, who was left paralysed from the waist down after injuring his back in a cycling accident.

His spinal cord was damaged, he fractured two vertebrae, and doctors had told Richard he would never walk

again. Fortunately, the swelling in his spinal cord was controlled, and rehabilitation meant the paralysis was only temporary.

When Richard arrived at Eagle Wood, our specialist care centre in Peterborough, he had made some progress. But even with support, Richard could only walk 50 metres.

With daily physical rehabilitation, including hydrotherapy, occupational therapy, a walking programme using a frame, and consultations with neuro-rehabilitation doctors, Richard was soon on the way to reaching his goal of walking independently with a stick. After six months he was discharged, and now lives semi-independently in the community.

Specialist rehabilitation in a properly-resourced centre is, in the short-term, more costly. But let's look at the available evidence for longer-term outcomes. For example, *The Brain Injury Journal* published peer-reviewed research in September last year which found that 'quality rehabilitation' in residential post-acute neurobehavioural centres saves between £200,000 and £1.13 million per patient in lifetime care costs such as GP contact, hospital admissions and social services support. The study was based on 274 individuals.

This is the reason why experts such as Professor Michael Barnes, chair of the UK Acquired Brain Injury Forum, are calling for more investment in rehabilitation.

Professor Barnes told the BBC, "There is good evidence that although rehabilitation costs more money clearly than someone going home, or going to a nursing home, that money is recouped over two to three years by that person requiring less support from the state, getting back to work and earning money."

Like all NHS providers we are



eagerly awaiting the commissioning landscape to settle, so we can put our case to NHS England's service area teams of specialist commissioners. Too often we feel that key personnel within Care Commissioning Groups have (for reasons we understand) little in-depth familiarity with specialist care for people with long-term spinal cord and neurological conditions.

In the meantime, we will continue to push the message that specialised longer-term care and treatment is, as

the evidence shows, the way forward, clinically and in terms of cost. There is every reason, I hope, that NHS England's five-year strategy for specialised commissioning, due to be published in July, will reflect this.

PJ Care was founded in 2000 by Jan Flawn, a registered nurse who had

seen what she described to me as appalling treatment in many of the care homes where she worked. Jan witnessed young people with spinal cord injuries, and neurological conditions like young onset dementia, inappropriately placed. No rehabilitation. No specialist care. Abandoned, really.

She said that after seeing such terrible care for young people with long term spinal and neurological conditions, two decades ago she sat down at her kitchen table and scribbled on the back of an envelope the vision and plan for a neurological care centre in Milton Keynes. As a nurse, Jan wanted to try and put things right, and deliver better life and health outcomes for people with neurological conditions. It's a vision that binds everyone at PJ Care together.

I hope commissioners will not only share this vision, but help ensure it is reflected in care pathways for people with long term spinal cord and neurological conditions.

**Johann van Zyl**

*"...quality rehabilitation in residential post-acute neurobehavioural centres saves between £200,000 and £1.13 million per patient in lifetime care costs"*



Johann is CEO at PJ Care, a provider of specialist care and neuro-rehabilitation for people with spinal injuries as well as progressive or acquired neurological conditions.  
[www.pjcare.co.uk](http://www.pjcare.co.uk)

**The Gateway in Middlesbrough is the latest state-of-the-art rehabilitation centre to be opened by leading spinal and neuro specialists, Keiro. Dubbed 'the future of neuro and spinal-rehab', the £10million facility is the first of its new designs to be introduced as part of a unified rehabilitation model set to roll out across the UK over the next five years.**

Boasting six purpose-designed floors with 40 beds as well as a specialist health and wellbeing hub with fully integrated health club for clients and visitors, the facility also offers a range of transitional and supported housing options with housing partner Erimus, part of Fabrick Housing Group.

In April, Keiro will be announcing the appointment of a consultant in spinal cord injuries, in addition to the recently announced addition of a consultant in rehabilitation medicine to the team.

With a choice of apartment, bungalows or houses, the extended service enables The Gateway to assist clients with a step forward to independent living and long-term housing options.

The wellbeing hub, hosting a hydro-pool, spa, steam room, hydro shower, gymnasium, therapy rooms and a bistro-style café is available to use for both clients and non-residents. It offers an array

of service partners from voluntary, independent, statutory and education organisations with a knowledge centre to support clients and their families to self-manage their condition.

The Gateway is based in Newcastle upon Tyne and welcomed its first clients in January this year. Keiro also operate one of the UK's leading neuro-rehabilitation facilities, Chase Park Neuro Centre in Gateshead. The advanced centre includes two specialist suites. The Rehabilitation Suite supports

people with acquired brain and spinal injuries and neurological conditions for a move to independent living. The Nursing Suite provides a specialist nursing service for people with neurological conditions and complex needs aged 18 and over. Chase Park Neuro Centre also offers a health club which includes a fully accessible café, gym, beauty and holistic therapy studio, hydrotherapy pool and spa.

# REHABILITATION



SIA Outreach Team members, Simon Pinnell and Ian Younghusband, visited The Gateway and were impressed with the facility. "It was a useful visit for The Gateway as well, says Simon. "In conjunction with staff from the Golden Jubilee SCI Centre in Middlesbrough, we were able to provide some feedback on the facilities and their accessibility from the perspective of an SCI wheelchair user."



## FOR SCI

Keiro has also organised an accessible music and arts event, Chase Park Festival, for the past four years.

SIA member and musician Tom Doughty is one of the artists who has played the festival. The event includes people of all ages and abilities, helping to break down the cultural barriers and stereotypes often faced by disabled people. It holds a silver level accreditation by national music charity Attitude is Everything and is aiming to become the third to achieve gold after Liberty and Glastonbury festivals. This year Keiro will be launching its debut Middlesbrough music festival for The Gateway in August.

More information is available at [www.keirogroup.co.uk/gateway](http://www.keirogroup.co.uk/gateway)

## What you need to know about personal health care budgets

### NHS Continuing Healthcare is now available as a Direct Payment

From April 2014 everyone who is eligible for NHS Continuing Healthcare funding in England has the right to 'ask' for a Personal Health Budget. Because it is only the right to 'ask' there is a theoretical possibility that the Clinical Commissioning Group (CCG) can refuse to give one. However, if they do, they must be able to show that they have good reason for this refusal, for example that the individual lacks the capacity to manage the Budget.

From October 2014 the right to 'ask' for a Personal Health Budget will become a right to 'have' a Personal Health Budget. This will mean that the CCG must say 'yes' unless they can show exceptional reasons why not.

Personal Health Budgets are not available in Wales and NHS Continuing Healthcare operates differently in Scotland and Northern Ireland.

In England, Personal Health Budgets are designed to give people the freedom to design their own NHS care. It is an amount of money given to the individual which means they will have more choice and control over the nature of the care and support they receive.

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

- A notional budget held by the Health Authority Commissioner (eg a number of hours of care that the service user can draw down at their discretion).

- A budget managed on the individual's behalf by a third party (eg an Independent User Trust).
- As a cash payment to the individual (the same as the Direct Payment/Individual Budget method used by social services).

These developments are of particular interest to people who are currently receiving social services funded care packages as a Direct Payment/ Individual Budget and managing their own care but are facing the prospect of moving over to NHS Continuing Healthcare. It means that they should be able to continue organising their

care in exactly the same way they currently do under the Direct Payment/ Individual Budget.

**Simon Legg**  
SIA Social Care Caseworker



# Personal Health Budgets The Contrarian Perspective



**Ejaz M Nabi, Chief Executive  
– Active Assistance**



I was privileged enough to be in the audience in January when the Minister of Health, Norman Lamb MP, announced that from October 2014 all individuals in receipt of Continuing Healthcare will be given the “right to have” a Personal Health Budget (PHB).

As someone who for over 25 years has advocated greater individual choice and freedom on allocation of healthcare resources, you would be forgiven for thinking that this was a cause for unbridled joy. Yet I have some concerns, serious concerns around the application

and roll out of PHBs.

There are some great commissioning authorities around; equally there are others whose track record for spinal clients has not exactly inspired confidence. There is a danger that PHBs may be set at such a level (to save money), that they inhibit rather than increase choice. If funding levels are such that the client has no choice but to become an employer, or deploy non-specialist domiciliary care provision then the cause of SCI community will be put back. This presents serious risks for the client.

Firstly, does the client really want to become an employer with all the associated responsibilities of training, supervision, discipline, absence management and other aspects of employment law? This fundamentally changes the relationship between the client and PA. Ensuring all PAs are competent and that there is continuity in terms of sickness absence and holidays is also crucial.

Then there are the risks both to the client as employer and PA as employee.



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Suppose the employer (a client) makes a remark which the employee (PA) considers hurtful, racist or sexist. In an Employment Tribunal it will not be the Clinical Commissioning Group (CCG) that is answerable but the client (employer). As an employer of PAs, I can tell readers of *forward* that in any given month we receive numerous complaints from PAs alleging verbal abuse, threatening behaviour and even threats of violence from the client or their family. We manage this and diffuse much of this as intermediaries between PA and client. Often abuse from the family arises when the PA spots something which is a risk to the client. If fear of dismissal inhibits the PA from reporting this, then a potentially abusive situation could persist.

There is also a risk of clients being put under emotional pressure to employ members of the extended family or acquaintances. There is nothing wrong with that as long as the client now realises that he has three relationships: employer, relative and client. Sadly we have come across several instances of

financial abuse and neglect by members of extended families.

On the other hand many clients become 'too dependent' upon PAs and there is a risk of the PA abusing the client's trust. A third party external employer can quickly remedy this situation. In the absence of external review the client has little protection in these circumstances.

In summary, there is little quality review. The Care Quality Commission will neither inspect the commissioning authority, nor view the client's individual circumstance nor is there a central register of care staff. This is in stark contrast to the external scrutiny that provider companies like Active Assistance face.

In conclusion the roll out of PHBs is to be greatly welcomed. However, I would urge the Department of Health to look carefully at governance arrangements. Do we really need a Panorama exposé or another 'Mid Staffs' in a few years time to highlight any potential abuse?

## Preparing for a care assessment to meet your support needs

When your local council's social services or your local NHS are carrying out an assessment or a review of the support you need, the most important thing to remember is that you almost certainly understand more about your needs than they do. You live with your needs every day, and only you are in a position to understand how to have your needs met in a way which enables you to live your life as you want to. Besides, most social workers and care managers have had very little experience of spinal cord injury (SCI). For these reasons, it is important to try to be in control of the assessment process as far as possible. Only good preparation can help you to achieve this.

When thinking about the care and support you need there are two areas to consider:

- Specific care needs
- Life outcomes of support plans

When identifying specific care needs, for example your morning routine, toileting, washing, dressing, positioning in wheelchair, detail is everything. It's easy to forget the detail of the care needed to manage an SCI on a day-to-day basis.

To get the best outcomes from your assessment, SIA recommends that you prepare, in advance, a Daily Care Plan. It is also a good idea to produce a Personal Support Plan based on questions like:

- What is important to you?
- What do you want to change or achieve?
- How will you be supported?
- How will you use your individual budget?
- How will your support be managed?
- How will you stay in control of your life?
- What are you going to do to make this plan happen?

Examples of a Daily Care Plan and Personal Support Plan can be obtained from the SIA Advice Line.

# 12

## hints and tips

**1** It is vital that you prepare for your assessment in advance to ensure that you qualify for support under your Council's or the NHS eligibility criteria and that all your eligible needs are met in full.

**2** Do not expect that the worker sent to assess you is familiar with your condition or knows what is required on a day-to-day basis to manage an SCI.

**3** Make sure you know what you're going to say. You may find it useful to have a written list of the points you need to make. It is easy to come out of the meeting realising that there are things you have forgotten to say.

**4** Most Councils have a self-assessment form of some kind, which you can download from their website or you can ask for a paper copy to be sent to you. Go through it before the assessment to understand the type of questions you will be asked.

**5** Eligibility for Social Care (provided by a local council) and Continuing Healthcare (provided by the NHS) is measured by different criteria and understanding the criteria before the assessment process begins can help with accessing funding.

**6** It is useful to prepare a 'care diary' prior to the assessment listing exactly what support you needed for each activity and how long it took. This will help you prepare your Daily Care Plan and Personal Support Plan.

**7** It is important not to under-report your care needs. It is always going to be easier to reduce the amount of care you receive than to increase it, so go for the maximum amount. >

## Simplifying the law on social care

**8** You will be 'marked up' for identified need, so it's important that you fully identify ALL your needs.

**9** You will be 'marked down' for any informal care arrangements you may have that are provided by family and friends. If you do talk to an assessor about informal care arrangements, make sure they understand if the unpaid carer is under a lot of stress, or if their caring role is affecting their health, their quality of life or their ability to work or to maintain other aspects of their lives that are important to them.

**10** It is vital that you explain the complexity of your needs, how one thing affects another, and what the consequences and knock-on effects are if your needs are not properly met. For example, the way that proper diet and regular, appropriate mealtimes may be necessary for good bowel management. How a well-managed bowel routine may prevent autonomic dysreflexia, whereas a poorly managed one may cause skin problems.

**11** Download the factsheets on NHS Continuing Healthcare and Social Care available on the SIA website or obtain a hard copy or other format by calling the SIA Advice Line. Better still, sign up for the SIA training course on Funding and managing your care needs.

**12** REMEMBER – You will only get the best outcomes from an assessment if you properly prepare for it.

After all this, when your assessment or review has been completed, if you do not feel that the support you are offered is adequate to meet your needs, SIA may be able to advise you or help you challenge the decision. Please



contact Brian O'Shea, SIA's Continuing Healthcare Adviser. Mick Hutchins C4/5 Public Affairs Campaigns Officer

**The Care Bill is designed to simplify the law about social care (social services provided through your local council). It combines a whole confusing mishmash of Acts of Parliament, rules and regulations, Government guidance and plans for the future into a single piece of legislation. It is going through Parliament now, and is expected to get Royal Assent this year and will begin to be put into effect next year.**

It has a new guiding principle, well-being, which applies to carers as well as disabled people. This includes having choice and control over your life, but it falls short of the Independent Living principle which SIA and others have campaigned for.

The Care Bill includes some of the recommendations of the Dilnott Report. If you move from one local authority to another, your new council must fund the support that your old council was giving you, until they have carried out their own assessment. If they reduce your care after doing their own assessment, they must give you a written justification as to why they have reduced it. This is called 'portability of care'. From 2016, the Government plans to start applying the 'cap on care charges' which puts a limit on the total amount you can be charged for local authority care over your lifetime. It has been set at £72,000 for people over pension age, and lower for younger people who receive care. Care may be

free for the youngest users, but this is still to be decided in regulations. For older people at least, this is a higher cut-off point than Dilnott recommended. To benefit from the cap, you will need to be assessed by the council while you are paying your own care costs. The amount you are deemed to have paid towards the cap will be the amount they assess you as being entitled to, rather than the amount you actually pay.

### Additions and omissions

For the first time, personal budgets, safeguarding procedures and actions to be taken in the event of a large-scale provider failure are to be given the legal force which comes from an Act of Parliament. Care standards and inspection are addressed, and two new bodies are created, Health Education England and the Health Research Authority. There are concerns that the Bill does not give a strong enough right to advocacy (although this may be further addressed through guidance).

## Help and Advice

You can contact Brian O'Shea, SIA'S Continuing Healthcare Adviser, on 0845 678 6633 or email [b.oshea@spinal.co.uk](mailto:b.oshea@spinal.co.uk) or contact Simon Legg, SIA's Social Care Caseworker on 07535 774135 or email [s.legg@spinal.co.uk](mailto:s.legg@spinal.co.uk). Simon and Brian are available on Tuesdays, Wednesdays and Thursdays. The SIA Freephone Advice Line is open Monday to Friday 9.30am – 4.30pm on 0800 980 0501

# Charging for social care

There is no mention of the United Nations Convention on the Rights of Persons with Disabilities, even though the Government has officially ratified it, and the Bill does not enshrine all of the rights given by the Convention – for example there is no right to a choice of place of residence.

Despite the original Appeal Court ruling that the decision to close the Independent Living Fund (ILF) was unlawful, because the decision was made without due regard to the impact on its users, the opportunity has not been taken to build into the future care system some of the aspects of the ILF which have made it so popular and successful (which are the reasons the Government consultation found that none of its users wished to see it closed).

The Bill provides for later national guidance to determine what eligibility level councils should be obliged to meet. Councils assess your needs as being either critical, substantial, moderate or low, and at present they can choose which to meet. Most councils today only meet critical or substantial needs. In June 2013, the Government proposed all councils should have to meet substantial and critical needs, but the joint Commons/Lords Committee on the Care Bill recommended the inclusion of moderate needs too. The Care and Support Alliance has undertaken a study which shows that meeting moderate needs will save more money than it costs.

Nothing in the Bill addresses the inadequate and worsening funding of social care (which may be exacerbated by the additional duty for councils to assess self-funders to monitor their progress towards the cost cap) and, as we know, underfunding can undermine all of the positive duties contained in the Bill.

**Simon Legg**

**SIA Social Care Caseworker**

**If you rely on a Non Residential Social Care Service provided by your local council it is likely that you will have to undertake a financial assessment (or means test) to establish if you have to make a contribution towards the cost and how much that contribution will be. These services can either be provided directly by the council, commissioned by the council, or provided via a Direct Payment.**

Although local councils do not have to charge for social care, the reality in today's world of diminishing budgets is that almost every council will exercise their right to do so.

However, a council is required to follow Government guidelines if it chooses to charge for a care service it provides. These guidelines set out what income a council can take into account and what income and expenditure it must disregard to establish the amount of expendable income a person has and is required to pay towards the service(s) they receive.

**Under the guidelines a council can take the following income into account:**

- Income Support
- Incapacity Benefit or Employment Support Allowance
- State Retirement Pension
- Attendance Allowance
- The care component of DLA
- The severe disability premium paid with your income support
- Constant Attendance Allowance/Exceptional Severe Disablement Allowance paid with Industrial Injuries Benefit & War pensions
- Any savings or investments you have or share with a partner

*NB – If you have any savings over £23,250 a council can charge you the full cost of any care service they provide*

**Councils must ignore the following as income:**

- The mobility component of DLA
- Any contribution paid towards Independent Living Fund support
- The War Pensioners mobility supplement
- £10 of any War Disablement or War Widows Pension
- Any earnings you or your partner get if you are working
- Child Tax and Working Tax credit
- Savings part of Pension Credit

**And these must be offset against income:**

- Rent (less any housing benefit you get)
  - Council Tax (less any council tax benefit you get)
  - Water Rates & Insurance (at the councils discretion)
  - Your Disability Related Expenditure (the extra costs associated with managing your disability not covered by disability benefits – this is often overlooked or under-estimated)
- NB – A council should have a policy on Disability Related Expenditure, which should be transparent, fair to all and drawn up in consultation with local care service users*

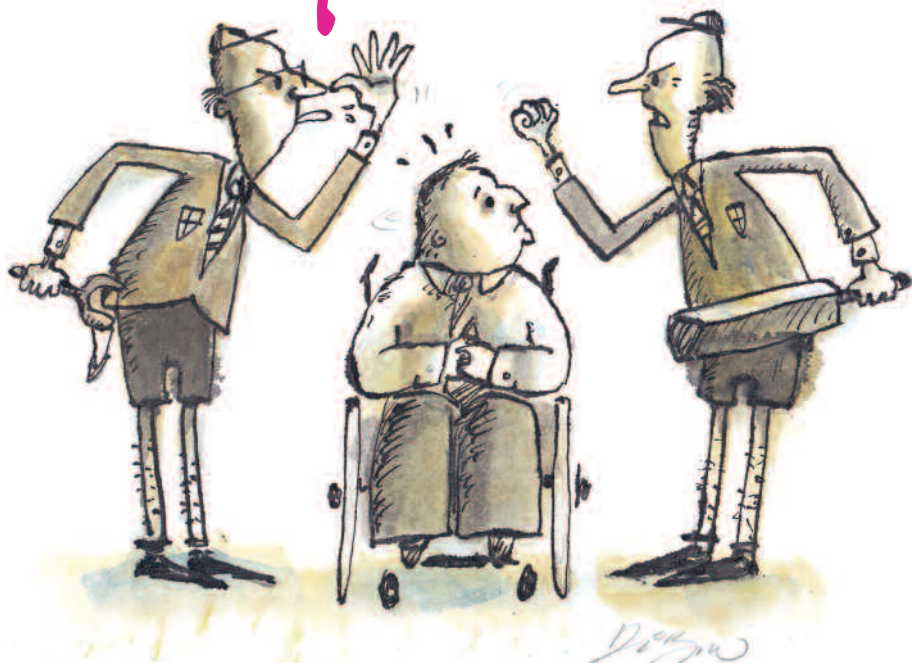
**The guidance also states that:**

- The charges you pay should not reduce your weekly income below a certain minimum level. You must be left with enough money to live on.
- If your income is below this minimum level then you should not pay any charges at all.
- If your income is above the minimum level, only the excess can be treated as available to pay charges.
- A person must not be charged for services if their overall income does not exceed the basic level of income support or income-based jobseeker's allowance together with a 25 per cent buffer.

**Mick Hutchins**

**SIA Public Affairs Campaigns Officer**

# First impressions



## A day in the life of a PA in the workplace...

Since I started work with SIA in 2005 I have relied on a Personal Assistant (PA) to assist me with my personal needs (the clue is in the job title) when I need to travel to attend various meetings, seminars, consultation events etc, in connection with my work.

Most external events I am required to attend are in London which is great because I can let the train take the strain.

In relation to supporting me in this work, my PA's work is much and varied. They can be required to do anything from help me in/out of my coat to galloping off to find someone in a high-vis First Great Western vest or an un-locked ramp to get me off a train when I've been left abandoned on the far reaches of platform 14 at Paddington – which is somewhere on the outskirts of Southall.

When escorting me on a London trip my PA's day goes something like this: attend to my morning care needs; drive to/from our local station in Newbury; help me during the journey; ensure we get off/on at Paddington (see above); help me in/out of taxis; hold my chair down for dear life as we hurtle on two

wheels around the streets paved with gold; assist me with going to the loo; assist with any support required during the meeting; get me a pint from the bar back at Paddington (when work duties are completed of course!); and finally, on return home, cook my dinner!

All of which has to be carried out while listening to my constant inane drive! A day's work that is not for the faint hearted! Sometimes though such a trip has its perks, a decent free lunch or a look around an institution not everyone gets to see.

### Visiting the seat of power

About half a dozen or so times a year I am required to attend a meeting at the Houses of Parliament and after nearly nine years I'm now rather blasé about it. However, every time I go there with a new PA riding shotgun, their sense of anticipation reminds me of how awestruck I was during my first visits.

Some first impressions though are not all good, especially when the natives are on edge because the tuck shop is shut.

My PA Dee, for example, after only a couple of weeks in my employment and

on her first trip was soon under no illusion about those who govern over us. We were being escorted, by a parliamentary escort, through the Palace of Westminster corridors and passages to a lift, for a meeting on the first floor.

On our way, a man in a rush overtakes us in a corridor and utters an apology for taking our racing line. Upon reaching the lift lobby containing two lifts, one regular one and a wide one reserved for wheelchair users and MPs (are MPs extra wide?), we catch up with the man who is clearly wired and anxious. The wide lift opens first and the man jumps in. I then enter and manoeuvre myself to one side to make room for the others (what a prince!). My PA and our escort cram in followed by another man who seemingly appears from nowhere. The lift door shuts and the fun starts.

Man number two turns to man number one, "That was very rude of you pushing in, in front of this disabled gentleman!" (Gentleman? He obviously doesn't know me).

Man number one replies, voice raised, "Don't you start on me over something like this!"

"Don't threaten me!" shouts the second man.

"I'm not threatening you!" shouts the first man now completely enraged.

"Yes you are!" bellows the second man, as they square up in the crowded lift. "Your finger is pointing right in my face!"

"Don't have a go at me then! I've got to get to a Select Committee and I'm late!"

Before the two elected members actually come to blows, the lift reaches the first floor. "Ping!" The bell rings, doors open, end of round one! The aggressors leave the lift and go their separate ways along the corridor, leaving us all in stunned silence.

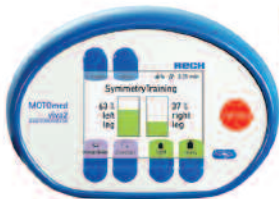
When the escort left us outside the meeting room I felt the need to offer an explanation to my PA. The whole place, I explained, was run like a public school and was in the main filled with ex-public school boys, who even in adulthood, yearn for the days when they were still in short trousers. Luckily, Dee wasn't at all fazed, she has four sons and said she was used to such juvenile behaviour.

**Mick Hutchins C4/5**  
SIA Public Affairs Campaigns Officer

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# Considering a nursing home?

Living in a Nursing Home has been a 'no go' topic of conversation for most spinal cord injured people. The very idea of 'ending up' in such a place was firmly brushed under the carpet. But, as people's circumstances change, the idea is gradually becoming more acceptable and more of a reality. With the lifespan of SCI people increasing, care in later life is an issue that must be faced. It doesn't necessarily have to be feared.

The main anxiety is probably around personal care issues. Will nursing home staff be able to manage the needs of an SCI person, in particular, bladder, bowel and skin care routines to the required standard?

## Planning ahead

It is important to have a plan for the future and, most importantly, tell those closest to you what that plan is, very much in the same way that you will have a Will written out and kept in a predetermined place in your home.

When considering long term care discussions with a partner, children, other family members and friends is a vital part of the decision making process. GPs may be able to offer some good advice.

Start to plan in advance by thinking ahead in blocks of time. Ask yourself, 'What care and equipment might I need in two years time, in three years time and in five years time?' For ageing tetraplegics, planning ahead in two- to three-year periods is realistic and for ageing paraplegics perhaps consider a three- to five-year period.

A carefully planned transition to living in a nursing home is preferable to having to make the change due to an unforeseen crisis, such as the illness of your main carer or partner. Let's consider the WHY, WHEN and HOW?

## WHY might you consider the Nursing Home option?

- deterioration in your health
- ageing partner can no longer cope with your personal care needs
- death of partner
- funding issues
- deterioration in mental health

Moving to a nursing home may have positive benefits:



- your quality of life may well improve
- you are less likely to suffer depression
- you may be better nourished and suffer less fatigue
- you may gain a new level of independence and prevent social isolation.

## WHEN is the time right?

- you may wish to move close to your children and grandchildren  
This may be prompted by the loss of a partner
- financial issues – you may wish to sell your property to release money or because it is too big for your needs

- if you are paraplegic, you may well have managed without any outside care but may find that you need assistance later in life and moving into a nursing home will give you care and security
- if you receive a care package from your local authority, it is likely that you are contributing ever larger sums of money for your care
- if you live alone, living in a nursing home will help prevent you becoming isolated, lonely and depressed
- and importantly, when you feel you can and are ready to adapt to your changing needs.

# Vocational

**Regardless of disability, work is important. It gives us productivity and focus in our lives, a reason to get out of bed in the morning. It gives us the opportunity to make new friends and meet new people, to seek new challenges both physically and mentally.**

**SIA** knows how significant work is to SCI people and believes that everyone who sustains damage to their spinal cord, regardless of the level of injury, should have the opportunity to find, or retain, a fulfilling, sustainable vocation, whether in paid employment, voluntary work or education.

But we also know that it isn't easy. Finding the motivation to seek a return to work can be difficult, having the confidence to apply for a job, college course or voluntary position doesn't always come naturally. Finding a new direction and knowing what you're capable of can require support and advice.

To help you along this path SIA, working alongside Occupational Therapy departments and in partnership with the National Careers Service, runs Vocational Clinics at the majority of spinal cord injury centres in England and Wales. Whether you've been injured six months or six years, an appointment in one of these clinics will enable you to:

- discuss your vocational aspirations with a member of SIA's Outreach Team, who is also spinal cord injured and has personal experience of returning to work following SCI
- meet with a specialist National Careers Adviser who will provide you with comprehensive advice and information to help you achieve your career goals
- talk to a member of the OT department who can advise on what sort of adaptations and support might enable you to return to work or study. You will be provided with a written



As every individual case is different, you may wish to obtain specialist advice on funding from SIA's Continuing Healthcare Adviser or SIA Social Care Adviser via the Advice Line Tel: 0800 980 0501.

Age UK has produced a very comprehensive series of fact sheets, including a full check list of all the factors to take into consideration and what to look for when choosing the right home for you. You can download these fact sheets from the Age UK website [www.ageuk.org.uk/publications](http://www.ageuk.org.uk/publications) or ring their Advice Line on 0800 169 6565.

## > HOW will you do this?

Moving to a nursing home should ideally be a decision made in a timely fashion and not as a result of a domestic or health crisis

- deciding where you want to live may be the first question. Will you take this opportunity to move away or stay in familiar surroundings?
- drawing up a list of suitable nursing homes – you can look on the Care Quality Commission website for information about nursing homes [www.cqc.org.uk/about-us/services-we-regulate/care-homes](http://www.cqc.org.uk/about-us/services-we-regulate/care-homes)
- your local authority should hold an up-to-date list of nursing homes in your area
- make a list of the homes you wish to visit
- draw up a list of essential requirements prior to visiting
- always take someone with you – four eyes are better than two
- take with you a copy of the Age UK fact sheet *Care home check list*. It is an invaluable aid.

## Funding your care

There are essentially four ways your care could be funded:

- 1 You may qualify for NHS Continuing Healthcare
- 2 Local Authority funding
- 3 Joint funding – Local Authority and Clinical Commissioning Group (CCG – formerly Primary Care Trust)
- 4 Funded Nursing Care – this is the funding provided by the NHS to care homes providing nursing for those assessed as eligible. If the individual has such a need determined, then this would consequently lead to eligibility for NHS-funded nursing care. Once the need for such care is agreed, the CCG has a responsibility to pay a flat rate contribution to the care home towards registered nursing care costs.

**Joy H Sinclair**  
Ageing Well Adviser



# support



By **Jamie Rhind**  
**Outreach Services**  
**Manager**

Action Plan detailing your long-term goals, with short- and medium-term achievable steps along the way.

You'll also receive information about the disability-specific support available, whether that's help through the Access to Work scheme, course funding, or your rights as a disabled employee.

## John attended a recent clinic at Southport...

"I heard about the clinic from a member of SIA's Peer Support Team, they suggested booking an appointment as I wasn't really doing anything with my life post-injury. To be honest I hadn't thought about what I was going to do in terms of work after I left hospital, I knew I couldn't go back to what I was doing before, and when I did leave I ended up just drifting along and before you know it the weeks turned into months and I found it difficult to motivate myself.

"The clinic was brilliant! Being able to discuss things with someone who understands really helped. The advice I got from the Careers Adviser about the transferable skills I already had definitely boosted my confidence and I wasn't aware of how much support I could get through Access to Work. It has really opened my eyes as to what's possible, and achievable, as a wheelchair user. I've enrolled myself onto a course at my local college and am looking into getting some voluntary work organised ASAP. I'm a lot more motivated now and positive about the future."

SIA wishes to acknowledge with thanks JMW Solicitors and the DPULO Facilitation Fund for their sponsorship of the Vocational Support Service.

## Dates for Vocational Clinics in 2014

If you're inspired by John's story and would like to book an appointment at a clinic near you, please call our Advice Line on 0800 980 0501 or email [sia@spinal.co.uk](mailto:sia@spinal.co.uk) or speak to the OT department at your SCI Centre.

### PINDERFIELDS

21 May  
20 August  
26 November

### SOUTHPORT

21 May  
20 August  
19 November

### SHEFFIELD

TBC May  
TBC July  
TBC September  
TBC November

### OSWESTRY

9 June TBC  
1 September TBC  
24 November TBC

### STOKE

**MANDEVILLE**  
29 April  
27 May  
24 June  
29 July  
19 August  
30 September  
28 October  
25 November

### STANMORE

5 May TBC  
16 June TBC  
28 July TBC  
8 September TBC  
20 October TBC  
1 December TBC

### SALISBURY

13 May  
24 June  
5 August TBC  
16 September TBC  
28 October TBC  
9 December TBC

### ROOKWOOD

Dates to be confirmed



# Best foot forward

## Physician, heal thyself...

**Just after I filed my previous contribution, Linda and I decided to put some money aside and fund some serious physiotherapy, with the dual aims of helping me to recover my former leg-strength and taking a different approach to managing the pain. Out of three local providers I chose Stuart and, at the end of my first session, he made two observations.**

We had agreed that my most debilitating pain was more likely a form of sciatica, distorted and amplified by the L1 spinal injury rather than referred directly from it. I'm an old man. With that in mind, he noted that my left leg (apparently the femur) was as much as a centimetre shorter than the right-hand one. Maybe the femur had become impacted into the pelvis, thus trapping the sciatic nerve that somehow wiggles its way through there. Secondly, he wondered whether that same nerve was being agitated by the piriformis muscle, one of scores of tissues jostling for position at the back of my arse (your arse too, come to think of it).

It's quite common, apparently, to have legs of varying lengths. I always walked with something of a sailor's gait; many years ago, at naval college, an entire squad of fellow cadets broke into the Laurel & Hardy theme as they passed me on the hill. "Doo di-doo, doo di-doo, doo-bee-di-doo, doo-bee-di-doo." Much later, while recovering from my flying accident, I showed a Stoke Mandeville physio a tape of some TV work I had done (the Sooty

Show, if you must know) and she blurted out, "Blimey Andy, you walk better now than you did then!"

So it came as no real surprise and ever since, as I sit on the bed or floor with my legs out straight, it seems so blindingly obvious that I wonder how I ever missed it. And the piriformis? The problem is well documented, it's even got a syndrome named after it. Piriformis Syndrome. Stuart says he comes across it regularly – in fact, he reckons it's the most common cause of sciatica he sees.

I mentioned this to a doctor at Stoke Mandeville. He latched onto it immediately and, before I knew it, I had a letter inviting me for a shot of Botox to be injected into said muscle. This will temporarily paralyse the piriformis, thus reducing the irritation and giving me a break for an undetermined period.

I'm happy to go along with that, especially since the physiotherapy appears, so far, to have had little effect on the pain. But I am forming the impression that

doctors, as a breed, are terribly keen on sticking stuff into one. In fact, it appears invasion is the default setting. My 'pain pathway', set up by my Consultant three or four years ago, involved injections to block nerves and the operation that I had last summer. That was it. It would have been more productive to take a more holistic approach. There was no thought of sitting down somewhere quiet with a physio for 30 minutes one-on-one. Maybe such a session could have saved the NHS a few bob.

Even now, however, it might provide an answer. As I walk, my left foot tends to swing outwards while kicking forward. Guess which muscle contributes to keeping it pointing fore-and-aft? The piriformis. Between now and my appointment in April, as well as getting

my hip x-rayed for signs of impaction, I shall do all I can to exercise and strengthen that pesky lever. It may not work as it's mighty close to the original level of paralysis. But you never know. It may just have fallen into disuse over many years of walking with even more of a sailor's roll.

And frankly, I'm not entirely enthusiastic at the prospect of having a toxin stuck into me bum.

**Andrew Healey L1**



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Exclusive  
price for  
SIA members

# Carers & children

## Emily Clacy C6 looks forward to a break in her routine

Getting the right carers is such a hard job; there are so many things to consider. When you spend so much time with one person, especially in sometimes quite intimate situations, you need to feel one-hundred-percent comfortable in the relationship. It's one thing when it's just you and your own personal care and daily tasks that you need assistance with, it is something entirely different when you throw young children into the mix. It adds a whole heap of other emotions and frustrations into the working relationship and I've found getting the personal qualities of a carer who's right for the job can be challenging.

You'd think that after more than ten years of employing personal care I'd have a set method for getting rid of the dead wood. However, as my life evolves, so do my care needs. Whereas I used to have live-in care and I could send my PAs off on errands that earned us some time apart, I now spend up to twelve intense hours a day with my carers, mostly without any respite. It is a very different way of managing care than before I had children.

### Getting along comfortably

I have always found striking the right balance between companionship and professionalism most difficult. When I interviewed candidates for the help I have currently, I was judging character more than taking an interest in skill sets. I knew that I needed someone I could get along with on a personal level, someone whom I felt comfortable leaving my children with, as well as someone who was competent and hard working. Being a carer is just as much about common sense as anything. It is hard to sum up what a person will be like in a couple of hours and, unfortunately, it doesn't always work out how I hoped it might.

I'm struggling with one of my PAs currently. I already had a PA who worked two days a week with Freya and I, and



*"I have always found striking the right balance between companionship and professionalism most difficult. When I interviewed candidates for help, I was judging character more than taking an interest in skill sets"*

when I had Lydia I needed someone else to do the other three days a week. I employed a younger and more inexperienced PA than my existing one in the hopes that I could (for want of a better word), 'mould' her to my needs. She doesn't have any childcare experience and has come from a care assistant background. As time has gone on this has proven to be to the detriment of our working relationship and I have been feeling less and less comfortable leaving her to manage Lydia alone. I don't think it's her fault; she does her best with no real training and is very caring. What she lacks in childcare experience she makes up for in other

ways. But, if I'm not relaxed about someone's competency in managing certain situations with regards to Lydia's care, then there is no point in employing a PA who compounds my frustrations rather than eases them.

We've sat down and chatted about how things could change and how, as our family needs will change, so will the role. It is hard to be the 'employer' in this situation and to be diplomatic in your approach to telling a PA that things aren't working out as you had hoped. I don't want my PAs to feel I'm attacking their personality, am ungrateful for the help they give, or patronise them in anyway. To ease the stress I've recently changed my two PAs' shifts around so that my original PA is doing more days and the newer one is doing less. Luckily my newer PA is happy with me reducing her days and she is now looking into going to university in the autumn; there is no point in advertising and recruiting new help as Lydia will be starting nursery later on in the summer, so the timing should be right for both of us.

### The pressure is on!

For the last ten months I've had someone with me pretty much 24/7. When Lydia starts nursery and I can reduce my care needs, I'm looking forward to some time on my own, without having to think what comes next in childcare routines or that I have to keep someone else occupied. Currently, I feel as if I'm living by the clock and as you'll know, managing your own personal care needs can be tricky for an SCI person; our bodies don't always behave how we'd like them to! It's exhausting feeling so rushed all the time and sometimes I feel the pressure of being a mum with a disability.

It sounds like I'm wishing away my baby's first year and I promise I'm not. I'm all too aware how fast it's going and that they don't stay little for long. No matter how exhausted I am, I'm cherishing every moment.

**It's easy to advertise here!** Simply email your request to:

**lynnepunchard@btconnect.com. The closing date for contributions for the June issue should reach the editor by 1 May 2014**

## Vehicles and Accessories

### SILVER ENTERVAN – GRAND VOYAGER LIMITED CRD

Top of range 2005, automatic diesel 2.8 L, 46,959 miles in very good condition with 5 seats plus wheelchair, automatic opening door and ramp. A luxury vehicle with a variety of settings where wheelchairs can be docked.

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**STANDING CHAIR** with chin control. Fitted with chest harness and Roho cushion. In good condition and good working order. Free to SIA member in exchange for donation to Kent Air Ambulance. Contact Susan on 01797 270521  
Email: [james.care203@gmail.com](mailto:james.care203@gmail.com)

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Email: [james.care203@gmail.com](mailto:james.care203@gmail.com)

### RGK GRAND SLAM

Tennis/Badminton wheelchair. Colour blue, frame chrome, Molly sideguards, 25" wheels and anti-tip wheel. 15.5" wide. Excellent condition, not a scratch on it. £500 ono. Buyer collects. Suffolk. Tel: 07899 872734

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Email: [suebrotherwood@aol.com](mailto:suebrotherwood@aol.com) for photos. £2,000 for quick sale. Chippenham, Wiltshire.  
Tel: 01249 322300

## Equipment

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Tel: 01423 323123

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## Holiday accommodation

## FRANCE

**MAYENNE**, 18th century stone property with 4 bedrooms and a 3-acre private lake for fishing. Wheelchair accessible, with ground-floor bedroom and en-suite wet room.  
[www.francefishingholiday.co.uk](http://www.francefishingholiday.co.uk) or telephone Darren C6/7 on 01405 816 750

### COLLIOURE, SOUTH OF FRANCE

Ground-floor, 2-bedroomed apartment, sleeps 4-6. Level access throughout. Designed specifically for people with spinal cord injury. En-suite bathrooms, air-conditioning, full heating. Height-adjustable beds, pressure-relieving mattresses. Separate upstairs apartment available for family or friends.  
[www.originicare.co.uk](http://www.originicare.co.uk) click on L'Origine or call Nathalie on 00 33 632 56 61 75

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Detached single-storey villa adapted for wheelchair user. Owner T3 paraplegic. Private gardens, pool and secure parking. Sleeps 4 in two bedrooms. One with wheel-in wet room, shower and shower chair, the other with bath and shower. 10 minutes walk from the shops at LORGUES and a 45-minute drive from the coast.

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Contact Geoffrey Croasdale  
Tel: 01753 850564 E:mail [g.croasdale@btopenworld.com](mailto:g.croasdale@btopenworld.com)

## SPAIN

### JAVEA, COSTA BLANCA, SPAIN

Luxury family Villa purposely built for wheelchair owner. The villa comprises 3 bedrooms and 2 bathrooms. Master bedroom has en-suite with wheel-in shower (shower chair provided). Private pool with hoist. Restaurants, shops and wheelchair accessible beach are all within close proximity. Alicante and Valencia are the nearest airports. Contact owners Gavin or Lynda.  
Tel: 01786 811546  
Email: [lynda.hutton@talktalk.net](mailto:lynda.hutton@talktalk.net)  
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Website: [www.laspiedras.co.uk](http://www.laspiedras.co.uk)

## SPAIN, COSTA BLANCA, JAVEA

Lovely wheelchair friendly villa set in large colourful gardens on level, gated plot. Well equipped, 3 beds, 2 baths, master bed with large ensuite bathroom and wheel-in shower (chair provided), cable TV with Sky and English channels, DVD player plus DVD library, free broadband internet access, wheelchair-friendly gardens, 10 x 5m pool with easy-to-use water-powered pool lift and full-size outdoor table tennis table. T1 paraplegic owner. Contact Norman or Sue. Tel: 01900 67280  
Mobile: 07818 406861  
Email: [info@accessvillaspain.com](mailto:info@accessvillaspain.com)  
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**MARONI, CYPRUS** – Villa Carpe Diem. Large modern, wheelchair-friendly villa. 5 bedrooms and 4 bathrooms. Double bedroom with hoist, wetroom with wheel-in shower (shower chair provided). Private pool. Contact: [villacarpediemcyprus@gmail.com](mailto:villacarpediemcyprus@gmail.com)  
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Email: [lucy@ayersfloridavillas.com](mailto:lucy@ayersfloridavillas.com)

## ENGLAND

### Self Catering Accommodation

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Email [darrenpj@rocketmail.com](mailto:darrenpj@rocketmail.com)  
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