

Your Support Network Guide

Northern Ireland

sia spinal injuries association
FOR LIFE AFTER SPINAL CORD INJURY



A Network of
People and Partners

A Network of People and Partners

Our ambition is for a fulfilled life for everyone affected by spinal cord injury (SCI). To achieve this, we want every SCI person in the UK, with your diverse range of ambitions, needs and challenges, to reach and be reached by the best people and the best organisations. By creating the best network possible for you, we can serve, support and fight for every aspect of what each person defines as a fulfilled life. And we can be there for you for life.

In building our vision of a national support network, we are working with organisations across many different sectors. We know that having a fulfilled life is not just about bowel management, but retaining a job, having children, or going to the shops. We're working with organisations – many long-standing supporters of SIA who you, our users, recognise as the best. That's not just an estate agent with a wider door, but one that prioritises a portfolio of disabled-people-appropriate housing; not just a legal firm that can hunt down a personal injury claim but one that understands the diversity of legal needs throughout your life.

We are therefore committed to working with you personally to build a bespoke and ever-expanding network of people and partners, region by region and nationally. The network will be built around your unique needs.

This booklet is just one aspect. Our Support Network Officers and Volunteers – who all live with SCI themselves and are therefore uniquely qualified to support others paralysed by SCI – are on hand to provide personal contact and support and can connect you to all of the charity's services as well as the network. And our website spinal.co.uk has further information on how we support every aspect of an injured person's life.

Please use this booklet as the first stage in building your network and getting the information, advocacy and support you need. We're here for you – so please get in touch.



Nik Hartley OBE
Chief Executive

What is spinal cord injury?

There are around 50,000 people living with spinal cord injury (SCI) in the UK and each year around 2,500 are injured or diagnosed – one every four hours – through accident or injury, or through other health conditions such as a tumour or spinal compression.

SCI is life changing, causing paralysis and loss of sensation below the level of damage to the spinal cord. For example, it results in being unable to walk or have control over bladder or bowel function. Those with a higher-level injury may also have limited or no hand and arm function or be reliant on a ventilator to breathe. For some it might mean retaining their ability to walk but experiencing other complications.

The news that you may never walk again or have control of your bowel and bladder is devastating. SCI people and their families and friends must come to terms with the psychological impact of sustaining a life-changing disability that affects every aspect

of their own lives and those closest to them.

Like other disabilities, SCI people can find themselves further facing inequality and exclusion in their daily lives. Employment discrimination, poor care packages and an assumption of mental incapacity, are just a few of the challenges faced by SCI people day-to-day.

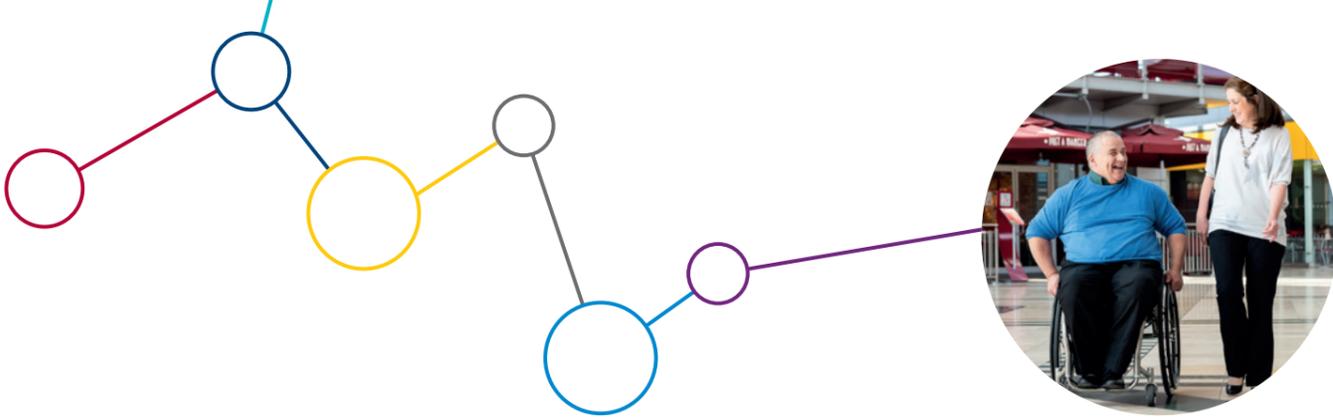
But we believe, and have long experience, that with the right support, every SCI person can achieve a fulfilled and independent life, making a valuable contribution to society and family life. Getting back into work, living independently, and raising a family are all possible.

That support is at the heart of the network we will help you build, unique to your needs, with information, advocacy and support that will help you rebuild your life after injury, whether you are newly injured or at any time afterwards.

Inside this booklet

The aim of this booklet is to summarise the services SIA offers as a charity, but also the partnerships we have with key trusted businesses to meet some of the early fundamental needs for so many newly injured people – such as healthcare support once out of NHS-hosted rehabilitation, legal services and financial services.

The booklet does list some important services in your area on p18 '**Building a support network for life**', but we will soon be launching a much more detailed online and offline guide for you.





We offer lifelong support built around your needs. Whenever you need us, we are here to help.



Building your network of support

Your Support Network Officer

Our support starts when you are newly injured and continues throughout your life.

Coordinating that in each region of the country is a Support Network Officer, supported by a set of dedicated volunteers. They all live with spinal cord injury (SCI) themselves and are therefore uniquely qualified to support other SCI people. In the initial stages after injury, most SCI people find they are the main point of contact they need. They provide a positive insight into life beyond injury – particularly in the early stages of recovery and rehabilitation post-injury - giving those they support both hope for the future, as well as practical advice on topics as diverse as managing continence, working, raising a family, driving, holidays, or being an active member of society.

You can talk candidly about sensitive “must know” topics such as bladder and bowel management, self-image, relationships,

and sexual function, all with someone who understands the difficulties you are facing. Practical solutions to the new challenges of everyday life can be found through the team’s personal knowledge and experiences, or by utilising the support of other SIA services or signposting to external support.

We have split the country into 10 regions to ensure that everyone gets the network of support they need within their community.



Get in touch

To contact your local Support Network Officer please call **0800 980 0501** or visit www.spinal.co.uk/support-network-officers/ On the website you’ll also find a breakdown of our regions and the services available to you in your area.

By your side with all your health needs

SIA has a team of expert SCI Nurse Specialists, with decades of experience in all aspects of care for spinal cord injured people. They are available during office hours, Monday to Friday to offer information, advice and guidance on all aspects of care.

Wherever you are – in a district general hospital, rehabilitation setting or at home – our SCI Nurse Specialists will work with your care team to raise awareness of the issues relating to your SCI and provide guidance on appropriate care.

We know that it can be daunting when going into a non-specialist hospital for treatment where the healthcare professionals are not experts in SCI care. Our SCI Nurse Specialist service will provide you with a care plan that can be completed prior to admission, so that you can be confident that your SCI needs will be met during any visit to hospital or a medical facility.

We can also help you prepare an Emergency Care Plan, which will cover your essential care needs if you are admitted to hospital unexpectedly.



SCI Nurse Specialists

To access the service, please complete our [referral form](#), call **0800 980 0501** or email SCINurseSpecialists@spinal.co.uk

A unique Counselling Service for spinal cord injured people

SIA has an in-house counselling service that is offered by a trained counsellor who also lives with a spinal cord injury. The service is unique and provides an extra level of insight through talking to someone who has experienced a similar journey and challenges.

This service is free-of-charge to anyone affected by SCI – injured people as well as their family members – to support with issues affecting their mental health and wellbeing. These can include aspects such as relationships, work, social and the psychological impact of living with an SCI.

Six sessions of telephone counselling are available with the potential to offer ten sessions altogether. Each session lasts 50 minutes.

To access this service please call our Support Line on **0800 980 0501**. The line is open Monday to Friday, 9am – 5pm. If you call outside these hours, please leave a message and someone will get back to you as soon as possible.

Please note that there is a high and increasing demand for this service. Our intention is to expand the service in the next 12 months.

Ian Younghusband

Ian Younghusband is SIA's in-house Counsellor & Wellbeing Officer. Ian has a C5 complete injury following an accident 21 years ago. He is a registered Member of the BACP (British Association for Counsellors and Psychotherapists) and operates within the BACP's ethical framework to ensure a safe and professional service.



Fighting for your rights – taking action



SIA believes all spinal cord injured people can live long, healthy and fulfilling lives. We are committed to fighting for everyone touched by spinal cord injury (SCI) to receive the treatment, support and care that best meet their needs.

Sadly, there's a huge need to campaign for better care for every SCI person. Just one in every three people who sustains a SCI will get care and rehabilitation at one of the UK's 11 specialist NHS Spinal Cord Injury Centres. Many more struggle to get the long-term care and support they need after they have been discharged from hospital; funding for care can be difficult to secure even for those who need it the most.

With many years' experience across an array of policy and societal challenges, our Advocacy Team will work hard on your behalf to challenge barriers to support and services you have a right to access.

The Advocacy Team has an enviable track record of success. If you need information, support or advice, or find you are experiencing injustice, discrimination, or exclusion, then please contact us via the Support Line – we are here to help. The Support Line is available from 9am-5pm on weekdays and the Freephone number is: 0800 980 0501.

In addition we use our daily support to you, our users, to then **Campaign** to influence public policy, engage with politicians and decision makers, and secure positive changes in health and care provision to enable SCI people to lead fulfilled lives.

For example, we are campaigning hard for improved specialist health services provision, seeking to influence the Government, NHS England and other stakeholders to:

- Ensure access to specialist health services for all spinal cord injured people.
- Increase capacity in the system, coupled with improved access for spinal cord injured ventilated patients.
- End unacceptable delays to admission to specialist SCI services.
- Improve local health services, so SCI people have access to ongoing treatment and support closer to their homes.

We also keep the needs of SCI people high on the agenda in Parliament, by administering and working closely with the cross-party and influential All Party Parliamentary Group (APPG) on Spinal Cord Injury.

Building a support network for life

As well as the business partners featured in this brochure, the most important service we think we can offer is to build the bespoke network of appropriate services for your needs. See page 5 introducing you to our **Support Network Team**.

We know that your needs will evolve and change over many years, and we want to make sure we are there to find you the appropriate people and partners to access – whether fighting to keep a job, re-training, looking for peer groups, starting a family, moving home, or tackling emerging health challenges. We will continue to develop these networks which you can find at www.spinal.co.uk/support-network-officers/ and by contacting your regional Support Network Officer. In the meantime, here are a few tips and links that may be relevant to you right away:

Other support near you

Reaching out to speak to others in similar situations (particularly others near you) can be a lifeline after injury or diagnosis. Learning to drive after injury, getting back into sports, or finding out how to go on a well-earned holiday all contribute to a fulfilled life after injury – and our team can help with all of that, and much more.

Finding community groups in your area

Finding a local community group in your area is a great way to connect to other SCI people and their friends and families to socialise with people on a regular basis. To find a local group near you, contact your local Support Network Officer.

Digital support (the SCI Owners Club)

The SCI Owners Club is a private Facebook group with approximately 2,000 members. You must have an SCI to join and it's an

excellent source of information, support and friendship with other people living with SCI. Contact: www.facebook.com/groups/sciownersclub

Sporting sessions, getting active

Many injured people go on to play sport both recreationally and competitively as well as supporting their favourite teams. Speak to your Support Network Officer to find out what sports you can get involved in locally and further afield.

Driving post-injury

Getting back behind the wheel is a fantastic way to regain your independence to help rebuild your life – and makes life so much easier. We have a wealth of knowledge whether it be the practicalities of adaptive vehicles, registering your disability, or finding the right car for you.

Disability friendly venues

There is a wealth of information online available to help with planning trips out for SCI people – if you know where to find it! Sites like [accessibleGo](http://www.accessiblego.co.uk) and [Access Able](http://www.accessible.co.uk) do the hard work for you.

Holidays

Going on holiday after an injury can be daunting, but it's well worth making the effort. You may have lots of questions such as, how do I get through the airport? How do I get on and off a plane? What happens with my chair?

For all these queries and more, please contact us: **0800 980 0501**.

Stay connected

Follow SIA on [Facebook](https://www.facebook.com/sia), [Twitter](https://twitter.com/sia), [YouTube](https://www.youtube.com/sia) and [Instagram](https://www.instagram.com/sia) to stay up to date with news and what other SIA members are up to.



GET YOUR SIA FORWARD MAGAZINE SUBSCRIPTION TODAY

Regular features include:

News • Health • Daily Living • Volunteering • Interviews



For more information about **FORWARD** subscriptions visit our online shop or email our Supporter Care and Data Coordinator, Catherine Stribling **01908 604191 Ext: 206** c.stribling@spinal.co.uk

Registered Charity No. 1054097

“Zoe... made my rehab work and found the people to suit me best. Thank you, Zoe for everything. I will keep working and hopefully improving thanks to you.”

SIA Case Management client



Our legal partners

Every spinal cord injured (SCI) person should get the best possible legal advice after sustaining or acquiring an injury. That process can be lengthy and complicated, but by introducing you to our legal partners, we can make that process easier for you and your family.

Our legal partners across the UK offer their expertise and advice to get the best possible outcome for SCI people who may have a legal claim as a result of their SCI.

They have all met strict criteria set by SIA, and we feel confident that they are amongst the most qualified and experienced professionals out there to help SCI people through the legal process. Based on SIA's experience of working with our trusted legal partners in your region, we would recommend that you call their experts and see if they can support you through this process. Most importantly, they are all experts, experienced in handling catastrophic injury claims and clinical negligence cases, and we trust that they are some of the best possible sources of information to help you through what is a very tough time.

All our partners provide free initial advice to talk through your case and whether you may have a claim for compensation.

All solicitors have to abide by strict codes of conduct – both an SIA Code of Conduct, and that of the Solicitors Regulatory Authority.

We have produced a handy FAQ list about the most common questions asked of solicitors, to give you an idea of where to start that process.

Not sure who to talk to? Call our Partners for quick, free advice, no matter what the question is.

As well as supporting you with a catastrophic injury or clinical negligence claim, many of our partners can also support you with other legal issues (such as changing a will, or granting power of attorney), and practical support on life after injury.

In the following pages the partner we work with in your region has set out how they can support SCI people. To contact our Trusted Legal Partners in your region, speak to your local Support Network team, or visit www.spinal.co.uk/support-network-officers/, where you can learn more about them and all our legal partners and further advice on thinking about how to select legal services that are appropriate for you.

SIA Case Management

In addition to the legal partners, the charity itself provides a case management service: SIA Case Management. It is now the UK's largest case management service working solely with adults and children following a spinal cord injury (SCI). Our expert team works closely with clients and their solicitors to identify, plan and meet specific needs to help rebuild lives following an SCI. To access our online case manager search tool, make an enquiry and to find out more visit www.siacasemanagement.co.uk



Delivering medical needs to your home

SIA Healthcare

Over many years SCI people have fed back on the need to have easy access to a high-quality delivery service to meet their urology, stoma, pharmaceutical and lifestyle needs.

Seven years ago, SIA, in partnership with Bullen Healthcare, developed a social business to achieve just that, with profits for

the business shared with the Charity. Now with over 3,000 registered users, this service has been especially valuable to members during the pandemic. The following feedback from the 2019 annual customer satisfaction survey highlights its value.

“I had terrible problems getting appliances from my local pharmacy. It was unreliable and the last straw was when they couldn't source catheters from their wholesalers. SIA Healthcare changed all that. It's a five-star service, reliable 100% of the time, with warm and friendly advisors who are always ultra-helpful. They deliver on time, every time. I'd recommend this service to anyone.”

SIA Healthcare member

Want to find out more?

SIA Healthcare Freephone:
0800 023 8841

Email: enquiries@siahealthcare.com

Or fill in our [Enquiry Form](#).



Planning your financial future

Having financial security for yourself and your family can be one of the toughest parts of life after a spinal cord injury (SCI). Our Support Network Team, trusted partners and members who specialise in offering financial advice can all help you plan for your future. Their support can cover: a legal claim and settlement, private wealth, and advice on disability and care benefits such as Continuing Healthcare.

We work with a range of specialist financial advisers and investment managers who all have experience of supporting SCI people with financial matters after injury. They can help with your immediate financial needs such as adapting a house, buying a car or fitting specialist equipment in your home, as well as more long-term funding to support you if you're unable to return to work after an injury.

Our partners are fully accredited by the financial conduct authority (FCA) and have been vetted by SIA to make sure they adhere to our own values and a strict code of conduct. They offer a free initial consultation to help you find out more about the processes, whether seeking advice from a financial adviser, or appointing someone to manage your financial assets.

For support managing your financial matters post-injury, contact your local Support Network Officer on 0800 980 0501.



Getting back to work

Your local Support Network Team will be very happy to discuss any questions you may have about returning to work, whether it be about returning to an existing role (and helping your employers adapt your role), or finding a new role.



Choosing a care agency

After you leave hospital, you may need ongoing support to live independently at home or within a residential care setting. No two cases are the same, but every SCI person has the right to a fulfilled and independent life and organising good quality care is an essential part of a fulfilled life.

We can help you and your family understand the different ways to fund your care. We can also help if your funding is under review or if you need to challenge a decision made about funding your care needs – **see p8 about the Advocacy Team** you can access through our Support Line.

Find out more about [NHS Continuing Healthcare](#) and [Social Care](#), how we can help you and how your support will ensure these services continue in the future via our website: www.spinal.co.uk/how-we-help/funding-your-care/

We can help you find the people to provide your care, whether that is an agency to help you hire your own carers or move to a residential home after discharge. Our Support Network Team works closely with many specialist care providers, care agencies and residential care companies across the UK – all of whom can provide excellent options for people to live a fulfilled life post-injury. Many offer free consultations with SIA members to talk through your care planning and help you make the right decisions. For more information, contact your Support Network Team on **0800 980 0501**.



Working together

We work closely with other third parties including another SCI charity – Aspire – to offer our members expert advice on housing benefits, and other practical support in terms of managing your finances after injury. Visit www.aspire.org.uk

We also refer members to Back Up for wheelchair skills and other activity courses. Visit www.backuptrust.org.uk

“The expert help you gave me when I needed it most made all the difference to my rehabilitation.”

SIA member



About SIA

The Spinal Injuries Association (SIA) is the UK’s leading organisation for the 50,000 people paralysed by a spinal cord injury (SCI) – as well as the hundreds of thousands of people who are their families, friends, carers and healthcare providers.

An SCI can be devastating – for the person directly affected and their family. But with the right care and support, a fulfilled life is possible. That’s where SIA comes in.

Whether it’s peer support from other SCI people who can give advice and positive insight, advocating on behalf of someone with an SCI to defend their rights or improving patient care through our SCI Nurse Specialist service – the charity can change lives.

Sign up today

Join SIA today and get a lifetime of support – whenever you need it.

Membership is free – whether you have an SCI, know someone who has been injured or diagnosed, or are a carer.

Join here: www.spinal.co.uk/how-we-help/join_sia/



Spinal Injuries Association

SIA House, 2 Trueman Place, Milton Keynes, MK6 2HH

Tel: 01908 604 191

Freephone Advice Line: 0800 980 0501

sia@spinal.co.uk

www.spinal.co.uk

Registered Charity No. 1054097

Charitable Company No. 3175203

