

YOUR SUPPORT NETWORK GUIDE



London



A network of people and partners for
everyone affected by spinal cord injury

GET INFORMED

USING YOUR GUIDE

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YOUR LOCAL SPINAL CORD INJURY CENTRE (SCIC)

London Spinal Cord Injury Centre (LSCIC)
Royal National Orthopaedic Hospital
Brockley Hill
Stanmore
Middlesex
HA7 4LP

SCAN THE QR CODE



For more information about your SCIC just scan this QR code.

“The booklet is very informative... our go-to book.”

Family member of SCI person



INSIDE THIS BOOKLET

Your Support Network Guide summarises the services SIA offers as a charity and highlights our partnerships with key trusted organisations. We've handpicked them as partners because we know they can help meet your immediate and longer-term needs as you rebuild your life after spinal cord injury, whether you're newly injured or at any time afterwards.

SPECIALIST SPINAL CORD INJURY CENTRES (SCICs)

SIA works closely with the national Spinal Cord Injury Centres. Currently, only one spinal cord injured person in every three gets admitted for specialist care and rehabilitation at one of these centres. We're campaigning to change that. But you do have the right to be referred to your local spinal cord injury centre for an appointment with a spinal consultant, although this doesn't guarantee you'll be admitted for rehab there. Give your doctor this link to the National Spinal Database so they can find out more about your local SCIC: www.nscisb.nhs.uk/

GET INFORMED

WHAT IS SPINAL CORD INJURY?



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

Spinal cord injury is life-changing, causing paralysis and loss of sensation below the level of damage to the spinal cord. You might not be able to walk, or you might lose control of your bladder and bowel function.

If you have a higher-level injury, you may also have limited or no hand and arm function or rely on a ventilator to breathe. Some people might still be able to walk but experience other complications because of their injury.

A spinal cord injury can be hugely traumatic – for both the person directly affected and their family. The news that you may never walk again, or can no longer control your bladder or bowels, is devastating. The physical and psychological impact of sustaining a life-changing disability that affects every aspect of your own life, and the lives of those closest to you, is undeniably huge.

But you're not alone. This guide is your first step to building a network of practical, emotional and psychological support to help you lead an independent and fulfilled life.

Turn over to find out more about how SIA – and our network of trusted partners – can help you rebuild your life after spinal cord injury.



GET SUPPORT

HOW SIA CAN HELP

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

We'll help you build a network of support so you and your family can adapt to every aspect of life with spinal cord injury.

We've split your guide into three sections, to help you navigate the challenges you may face.

SIA's services are offered to you and your family completely free of charge, to help equip you with the knowledge, skills and support you'll need to lead a fulfilled life.

Body matters: practical advice from a peer on sensitive, must-know topics such as bladder and bowel management, self image, relationships and sexual function, plus expert advice from clinical specialists. Our SCI clinical specialists can work with anyone involved in your healthcare needs to make sure your care is always safe, appropriate and right for you.

Mind matters: emotional support from peers who've been there, and a unique peer-led counselling service to help you and your family adapt to life with spinal cord injury.

Life matters: an experienced team with a proven track record of success in advocating and campaigning for the rights of people with spinal cord injury. From helping you secure funding, access benefits and get back to work, we can also signpost you to help with wheelchair skills, transport, holidays or starting a family. Whatever you need to lead the life you want.

GET SUPPORT

A NETWORK OF TRUSTED PARTNERS



As well as the services SIA can offer you, at no cost to you or family, we know you'll need more than we alone can offer to achieve a fulfilled life with spinal cord injury.

So, we're working with an ever-increasing number of local and national partners, creating the best network possible, so that we can serve, support and fight for every aspect of what defines your fulfilled life.

Because we understand that a fulfilled life looks different for each of us. And we know it could be a range of hopes, dreams and aspirations that are important to you. Retaining a job, having children, going to the shops – not just the all-important basics such as good bowel management and skin care.

How we choose our trusted partners

Our trusted partners are organisations that you, our members, recognise as the best. They have the skills, knowledge and understanding to help you not just adapt to injury, but also to thrive. We don't just mean an estate agent with a wider door, but one that goes further, prioritising a portfolio of appropriate, accessible 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 with a spinal cord injury.

All our trusted partners:

- ✓ commit to SIA's values and code of conduct
- ✓ are recognised as industry leaders
- ✓ offer initial advice free of charge with no obligations
- ✓ are accredited by their relevant regulatory body
- ✓ undergo due diligence processes before joining our network
- ✓ commit to regular reviews, training and feedback meetings

Our trusted partners are organisations that you, our members, recognise as the best.

The support, advocacy and advice we provided last year

Membership of nearly
14,500



Around 400

healthcare professionals received training and education from our expanded clinical specialist team



More than
3,000 enquiries

handled by our support line



Over 1,400

support sessions delivered to meet practical and emotional needs of SCI people



Over 12,300

subscribers received our monthly e-newsletter



Over 300

connections enabled between our members and partnership organisations



GET SUPPORT

BUILDING YOUR NETWORK OF SUPPORT

Our support starts when you're newly injured and continues throughout your life. SIA's regional support coordinators, assisted by a set of dedicated volunteers, all live with spinal cord injury themselves. They're uniquely qualified to support you, and in addition they'll connect you to trusted partners and signpost all the other services that can help you.

As your first main point of contact with SIA, your support coordinator offers a positive insight into life beyond injury. As well as hope for the future, they'll impart practical advice on topics as diverse as managing continence, transferring safely, getting back to work, raising a family, driving, holidays, and being an active member of society.

We've split the country into ten regions to ensure that everyone gets the network of support they need within their local community.

YOUR SIA SUPPORT COORDINATOR

Jack Mannings

Support coordinator
London

T. 01908 208547

M. 07817 758144

E. j.mannings@spinal.co.uk



"After finding it hard on occasions to know where to turn, our daughter now feels she has someone she can trust and would be able to get good advice from again. Thank you for the great work that you do. You provide an invaluable service."

Parent of SCI person

"It's very reassuring to get help and advice from someone who has been through all of this before. It's very much appreciated, especially when you're feeling so bewildered by everything."

SCI person

GET SUPPORT

SUPPORT FROM A PEER

SCAN TO BOOK



Jack Mannings - Support coordinator London

Hi – I'm Jack, your support coordinator. If you've recently become injured or you're already living with a spinal cord injury, or are close to someone who is, you're in the right place.

I sustained a complete C5 spinal cord injury following a road traffic collision, which means I have limited function in my arms, no hand function and paralysis from the chest down. I've been living with tetraplegia and as a wheelchair user since 2015.

Book an appointment with me here and I can refer you to the most suitable services available locally and nationally.

From counselling to rehabilitation and medical support, to legal advice and benefits expertise, the help is out there. I'm trained to offer support and advice for your circumstances. And I can offer my insight and experience into life with a spinal cord injury.

I look forward to speaking with you soon. To book a virtual appointment with me, scan the QR above.

Map of areas covered



GET SUPPORT

BODY MATTERS

However you sustained your spinal cord injury, your body has been through immense trauma. By helping you understand your body now, we can support you to lay down the building blocks for a fulfilled life with spinal cord injury, whatever that means for you personally.

“SIA’s clinical specialists put me at my ease, gave me clarification where I’ve struggled to find answers, spoke to me in language I could understand.”

SCI person

SCI clinical specialists

SIA has a team of specialist clinicians – including nurses and an occupational therapist – who all have a wealth of knowledge and experience in the clinical aspects of living with a spinal cord injury.

Learn more about dealing with your bladder, bowel, skin and other SCI body matters at www.spinal.co.uk/get-support



CLINICAL SPECIALIST IN YOUR REGION

Mark Jarratt
SCI clinical specialist
South East Region

E. SCINurseSpecialists@spinal.co.uk

ARRANGE A CALL



To arrange a call with me or one of my colleagues, scan the QR code above.

SCI emergency care plans

Your clinical specialist can complete an emergency care plan with you. This is a very useful document detailing your individual care needs should you require a future hospital admission.

Scan the QR code above to book an appointment to complete your emergency care plan.

SCAN TO BOOK



No matter where you are – hospital, home or community care facility – your clinical specialist can discuss with you how you may be able to better manage your bowel, bladder, skin, pain and all other physical aspects that you may experience following a spinal cord injury.

They can also negotiate with – and provide training for – the medics, district nurses or care teams involved in your care.

“The nurses really paid attention to my SIA emergency care plan and I received much better care than on previous hospital admissions.”

Jane, C5 tetraplegia

BODY MATTERS

EDUCATION AND TRAINING



Our SIA Academy training is available to PAs and carers as well as people working in more formal healthcare settings.

Our specialist clinicians facilitate virtual and face-to-face sessions, which give an insight into the complex and sometimes unique issues that affect people living with spinal cord injury.

If you think someone involved in your care could benefit – please get in touch. Please note we do charge for most of these sessions. See www.spinal.co.uk/healthcare-professionals/courses/ for full details.

SIA Academy programme

Good clinical practice in SCI – a face-to-face session and in-house study day covering different aspects of SCI care. Ideal for larger groups within their workplace, usually 20 people or more.

Managing SCI – the virtual version of our good clinical practice session, this can be tailored to individuals’ needs. Ideal for the district nurses, carers or PAs involved in your care.

Managing the neurogenic bowel after SCI – care providers can gain the knowledge and practical skills to support SCI people with their essential bowel care.



FIND OUT MORE



Scan the QR code to find out more or book a session.



Karen Mikalsen
Health and care quality
team coordinator

E. academy@spinal.co.uk

“This was the best study day I have attended.”

RGN working in the community

Under pressure: the neurogenic skin – virtual sessions on understanding skin care for SCI people – including the causes, impact, treatment and prevention of pressure ulcers.

To breathe or not to breathe: respiratory issues in acute SCI – a virtual session on how SCI impacts the respiratory system and appropriate care to prevent complications.

SCI management for therapists – a session for therapists on rehabilitation and maximising function for SCI people.

A fulfilled life – the final chapter – an online resource detailing appropriate care for SCI people at end of life.

BODY MATTERS

HELPING YOU FIND THE RIGHT CARE OPTIONS



Selecting good quality care that's right for you is essential to leading a fulfilled, independent life with spinal cord injury.

It's an important decision and we're here to help. Your local SIA support coordinator and our advocacy team work together to explain different care options and the funding possibilities. But here's a brief overview...

Applying for funding

There are two main sources of funding for the care you may need:

NHS Continuing Healthcare (CHC)

This is paid to your care provider through your local integrated care boards (ICB). Your ICB decides how NHS services are delivered in your local area. This funding isn't means tested, so you won't have to pay towards the cost of your care package if your application is successful.

Social services through your local authority

This funding is based on how much money you have, which means you'll have to contribute to your care if you have savings or assets of £23,250 or more.

Whether your care is funded by the NHS or your local authority, they have a legal duty to meet your needs.

Completing a care assessment

You need to carry out a care assessment to find out who is responsible for your care. This splits your care needs into either:

'health care' needs – tasks that help you manage your injury, such as bowel management

'social care' needs – like supporting you to get out to meet other people.

If most of your care needs are 'health', you'll get funding through NHS Continuing Healthcare. If they are 'social', your local authority is responsible for funding.

The assessment process is time-consuming and complex. If you want to apply for funding for your care, get in touch with our advocacy team who can support you with your application. Just scan the QR code to contact us.

To find out more, contact your local SIA support coordinator, or:

- call our support line on **0800 980 0501** to speak to our advocacy team
- visit www.spinal.co.uk/carefunding - where you can try our online learning tool and download a template case assessment

SCAN TO CALL US



ONLINE LEARNING

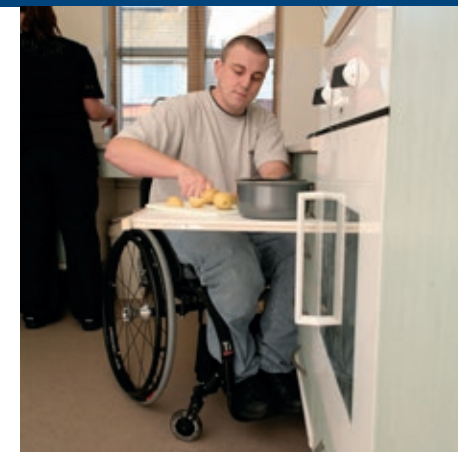


Selecting good quality care that's right for you is essential to leading a fulfilled, independent life with spinal cord injury.

Our trusted care partners

Over the next few pages, we've featured our trusted care partners, experts in supporting spinal cord injured people with all their care needs. They work with you to assemble a team of carers and the right healthcare products for your specific needs and wishes. They'll provide initial advice free of charge and guide you through the range of services available.

Find out more at www.spinal.co.uk/partners



BODY MATTERS

HEALTHCARE
PARTNER

SIA Healthcare



A dedicated home delivery service for spinal cord injured people

SIA Healthcare is a dedicated home delivery service that provides spinal cord injured people with all of their urology and stoma products and prescription medication efficiently and discreetly to their door.

“Your service has been impeccable. All I can say is thank you, you’ve made my life so much easier”

SIA Healthcare user

Company information

Locations

Offering support across the UK.

Contact details

T 0800 470 4576 E enquiries@siahealthcare.com W www.spinal.co.uk/get-support/sia-healthcare

Meet the team

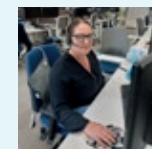
SIA Healthcare is a dedicated home delivery service that provides spinal cord injured people with all their urology and stoma products, and prescription medication efficiently and discreetly to your door or to a place that is convenient for you.

SIA Healthcare was built on a long-standing relationship between SIA and Bullen Healthcare to establish an industry-leading delivery service for spinal cord injured people, their families and the wider spinal cord injury community.

It's really easy to register for SIA Healthcare and the service is completely free! Just tell us what you need, and we'll take care of the rest - including talking to your GP about your prescription.

Call us today on **0800 470 4576**
or email enquiries@siahealthcare.com

Hear what some of the SIA Healthcare team say



Maxine – Personal advisor

I really enjoy working at SIA Healthcare. For me, it is the day-to-day contact with our customers that is the best bit. As well as taking their orders, I get to hear about what they are up to, things that are happening in their lives, and that gives me such a great feeling.



Lewis – Driver

In most delivery jobs you just turn up, hand over the parcel and off you go, not with SIA Healthcare. I deliver to the same people every month so you get to know them. Sometimes they might ask for help getting their parcel into the house, or they might take the mickey out of me for the football result at the weekend!



of SIA Healthcare users find our service 'very' or 'extremely' reliable



of people using the service would recommend it

SIA Healthcare is a service set up by Spinal Injuries Association and operated on its behalf by Bullen Healthcare Group Limited and Pharmore Plus.



BODY MATTERS

TRUSTED CARE PARTNERS



Complete Care Amegreen



Complete Care Amegreen can support and empower you to realise your health outcomes and goals, achieve your personal ambitions and to live your life your way. Their nurse-led, affordable homecare services enable spinal cord injured people to live independently at home, take part in family life, stay in work and education, and have active and fulfilling social lives.

Complete Care Amegreen specialises in complex healthcare at home including long-term ventilation, tracheostomy care, gastrostomy, management of medication and bowel and bladder care, providing up to 24-hour care as hourly packages.

Company information

Locations

Offering support across the UK, based in Telford, Shropshire

Contact details

T 0333 121 5301 W www.completecare.co.uk/what-we-do/spinal-cord-injury

“This company really understands the term ‘person-centred care’. I feel respected, listened to and treated like an equal person. I am encouraged to verbally direct my care and achieve maximum independence to achieve a great quality of life.”

C Simcock, Complete Care Amegreen client

Meet the team



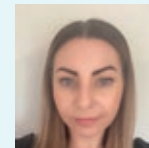
Lynsay Beckett
Head of operations

Experience: 25 years of care experience across hospital and home settings.



Christine Brookes
Chief nurse

Experience: 10 years in ICU; Eight years in complex care.



Jody Tierney
Care service manager

Experience: 12 years working in care, including recruitment, client manager and branch manager.



Complete Care Amegreen were amongst the first UK Care Providers to enable a ventilated client to live independently in their own home and have been supporting SCI clients for over 20 years

MORE INFO

To find out more information on our trusted partners scan the QR code to visit our website.

VISIT US



BODY MATTERS

TRUSTED CARE PARTNERS



Premium Care Solutions Ltd

Premium Care Solutions (PCS)



Premium Care Solutions (PCS) are recognised nationally for their expertise in planning and providing the very best complex care for spinal cord injured adults and young people. They have over 20 years' experience supporting SCI people to regain their independence and lead the best possible life after injury.

PCS recognises that every client is different, and each of their care packages is designed specifically for each person, with tailored 24-hour support seven days a week (or less as required) from their nurse-led care services.

Company information

Locations

Offering support across the UK, based in Kettering, Northants

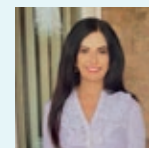
Contact details

T 01536 213680 E sia@premium-care.co.uk W www.pcs.uk.com

"We talked about being discharged from hospital and everything that would need to be in place before I could go home. PCS took all the stress away from me by sorting out my care package, which is tailored to me and delivered by carers local to where I live."

Laura, 23, C2-C6 incomplete spinal cord injury

Meet the team



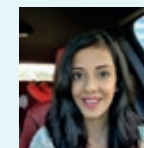
Jin Garcha
Clinical director and co-founder

Experience: 30 years' nursing: 10 in ICU, 20 setting up tailored care packages for SCI people

Areas covered: East of England, East Midlands, West Midlands, Wales

T 01536 213 681

E jgarcha@premium-care.co.uk



Neelam Kaur-Gupta
Head of business development

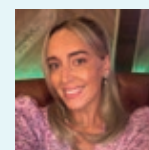
Experience: working with people with complex care needs, their care professionals and the commissioners of

care packages

Areas covered: London, South East, South West

T 07736 884 564

E nkgupta@premium-care.co.uk



Kelsey Byers
Regional manager – North

Experience: hands-on experience supporting SCI people, including ventilated clients; working with

commissioning services and case managers on hospital discharges and establishing complex care packages

Areas covered: North East, North West

T 07809 207 113

E kbuyers@premium-care.co.uk



Tailored 24-hour support seven days a week (or less as required) from PCS' nurse-led care services

MORE INFO

To find out more information on our trusted partners scan the QR code to visit our website.

VISIT US



BODY MATTERS

TRUSTED CARE PARTNERS



Eximius Live-in Support



Eximius' aim is to provide exceptional live-in care and companionship for people who need help and support while living life to the full with a spinal cord injury.

With access to a private GP and a professional team of clinical lead nurses, the care they offer is of the highest standard, and helps their SCI clients continue to stay in their own homes leading lead fulfilling, active and independent lives.

Company information

Locations

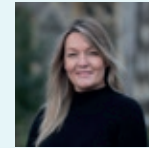
Offering support across the south of the UK, based in Beaconsfield, Buckinghamshire

Contact details

T 0203 7949933 E sia@eximiussupport.uk W www.eximiussupport.uk

"I have complex care that requires three live-in carers which is a challenge. All the staff at Eximius are passionate about providing the right staff to make my team suitable for all my needs."

Meet the team



Maria Climie
Managing director

Experience: 25 years in care, including domiciliary care, recruitment and live-in care for people with neurological conditions

T 07486 467 530

E maria@eximiussupport.uk



Dawn Jackson
Care manager

Experience: 25 years in care, including dementia and end-of-life care

E dawn@eximiussupport.uk



Lisa Witts
Field care supervisor

Experience: 23 years in hospital and home settings, including complex care for conditions such as MS, MND, brain injury, palliative care and dementia

T 07765 975 813

E lisa@eximiussupport.uk



Dawn Gaul
Field care supervisor

Experience: Six years in care, initially in mental health, then in complex care including spinal cord injury

T 07496 637 993

E dawn@eximiussupport.uk



Eximius Live-in Support are one of only 5% of care providers in the UK to have been rated as outstanding by the Care Quality Commission

MORE INFO

To find out more information on our trusted partners scan the QR code to visit our website.

VISIT US



BODY MATTERS

WORKING TOGETHER

neuro
kinex

Neurokinex



The Neurokinex programme for spinal cord injury is one of the leading activity-based rehabilitation programmes in the UK, helping you become fitter, stronger and more independent.

Whether you're looking to continue with your rehabilitation, maximise your fitness or improve your overall wellbeing, Neurokinex can create a programme unique to your needs.

Company information

Locations

Hemel Hempstead, Gatwick, Bristol

Contact details

T 0300 77 77 188

E info@neurokinex.org

W www.neurokinex.org

“The Neurokinex programme can help you adjust from the highly structured hospital routine to life back at home. The momentum you gain from having those initial six free sessions is vital to ensure ongoing rehabilitation gains.”

Damian Riley

250

The Neurokinex team carries out around 250 hours of therapy each week

GET SUPPORT

MIND MATTERS

Having a spinal cord injury is a sudden and devastating change. You may find it hard to take in what has happened and to understand what you're being told by health professionals.

Adjusting to your new life can feel daunting and overwhelming. There's no set rule about how you should respond. If you're feeling depressed, you're not alone. There is support available.

Look after your mental health

Try to follow the advice from health professionals about how to manage your injury. This will make things easier and help you feel more positive about the future. For example, establishing a bowel and bladder routine will make you feel more confident to go out.

A balanced lifestyle is also important. A spinal cord injury doesn't have to stop you from being active. Getting plenty of exercise and eating well will support your mental health.

Talk about your feelings

Coming to terms with your spinal cord injury can take time. There's a lot to get your head around, from managing your bowel routine to losing your sense of purpose. You may find yourself feeling depressed. It's when you feel persistently sad for weeks or months, rather than just a few days.

This is a natural and understandable response, and part of the grieving you'll go through as you process the loss of your ability to do many of the things you used to.

If you feel depressed for a long time or start to feel worse, do seek help. Talk to your GP about treatment options which include medication, lifestyle changes and talking therapy.

On the next page, find out how to book a call with our counselling and wellbeing manager, Ian Younghusband, who has a spinal cord injury.



2-3
in 10

Between two and three in 10 spinal cord injured people show significant signs of depression, according to the World Health Organisation

GET SUPPORT

MIND MATTERS

SIA has a unique in-house counselling service offered by trained counsellors who live with a spinal cord injury. Talking to someone who has experienced a similar journey and challenges can help provide an extra level of insight and support. Free-of-charge to anyone affected by spinal cord injury – those injured as well as their family members – the service offers support with issues



IN-HOUSE COUNSELLING

ARRANGE A CALL



To access this service and book a call with one of our counsellors:

- Scan the QR code
- Call SIA's support line on 0800 980 0501 (Monday to Friday, 9am to 5pm)

Ian Younghusband

Ian Younghusband is our in-house counselling and wellbeing manager. Ian has a C5 complete injury following an accident 21 years ago. He is a registered member of the British Association for Counsellors and Psychotherapists (BACP) and operates within their ethical framework to ensure a safe and professional service.

“You’re not alone in how you’re feeling. Speaking to somebody who has gone through the same thing and can share similar experiences can help.”

Ian Younghusband, our counselling and wellbeing manager

SUPPORT LINE
0800 980 0501

affecting mental health and wellbeing. These can include aspects such as relationships, work, socialising and the psychological impact of living with a spinal cord injury.

We offer six, 50-minute sessions of telephone counselling, with the potential to offer ten sessions altogether.

MIND MATTERS

WORKING TOGETHER



Breathe and Recover

“Yoga sessions during my time on the ward were an essential part of my rehabilitation as the breathing techniques were beneficial for dealing with pain, stress, anxiety and confusion. Being taught to breathe properly is still useful today after returning home and coming to terms with home life.”



Breathe and Recover is based on the Living Yoga Method™. They use the power of breathwork and yoga to get the most out of the respiratory and nervous systems which govern so much of our physical and mental health. Breathing is one of the most overlooked tools after a spinal cord injury has happened that we can use to create energy and health in our systems.

Meet the team

The Breathe and Recover team is made up of Living Yoga Method trained teachers with first-hand long-term experience of working with people who have experienced trauma and specifically spinal cord injury, including a paramedic, charge nurse at a spinal rehabilitation centre and a clinical project officer and trauma-informed breathwork and yoga teacher.

Company information

Locations

Based in Southampton, delivering online group classes

Contact details

T 07743 396 551

E contact@breatheandrecover.com

W www.breatheandrecover.com



breathwork and yoga works for everyone, whatever your age

GET SUPPORT

LIFE MATTERS



In this section of your guide, we're looking at services that can support you with every aspect of leading a fulfilled life with spinal cord injury, whatever that means to you personally.

Adjusting to life with spinal cord injury – understanding and looking after your body and your mind – is the all-important foundation to leading your fulfilled life. Now you can focus on what you like to do, and how you'll go about doing it.

This section covers everything from addressing your legal needs to managing your finances, so that you can have accessible accommodation, get back to work, play sport, start a family, socialise with friends or go on holiday.

First, we'll tell you a bit more about how SIA fights for your rights to a fulfilled life. Then we'll introduce you to our trusted partners in law, finance and accessible housing. Then we'll signpost you to services in your local area that can help you get where you want to be, doing what you like to do best.

SIA advocacy team – fighting inequality and exclusion

As with other disabilities, SCI people can find themselves 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 every day.

Our advocacy team has an enviable track record of success. If you need information, support or advice, or are experiencing injustice, discrimination or exclusion, then please contact us on the freephone SIA support line number from 9am to 5pm, Monday to Friday.

SUPPORT LINE
0800 980 0501

LIFE MATTERS

FIGHTING FOR YOUR RIGHTS

As the national patient representative body, we are committed to fighting for everyone touched by spinal cord injury to receive the treatment, support and care that best meets their needs.

Just one person in every three who sustains an SCI will get care and rehabilitation at one of the UK's specialist NHS spinal cord injury centres.

We know many SCI people struggle to get the long-term care and support they need after being discharged from hospital, with funding for care often difficult to secure, even for those who need it most.

With years of advocacy and campaigning experience across an array of policy and societal challenges, our team will work hard on your behalf, challenging barriers to support and services that you have a right to access.



FIND OUT MORE



Find out more and get involved at www.spinal.co.uk/all-party-parliamentary-group/

Additionally, the daily support we offer you informs how we campaign to influence public policy, engage with politicians and decision makers and secure positive changes in health and care provision. For example, we're campaigning hard in the following areas.

Ensuring access to specialist health services for all spinal cord injured people.

Increasing capacity in the system, coupled with improved access for spinal cord injured ventilated patients.

Ending unacceptable admission delays to specialist SCI services.

Keeping 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.

Improving local health services, so SCI people have access to ongoing treatment and support closer to home.

LIFE MATTERS

GETTING LEGAL SUPPORT



Getting expert legal and financial advice is something we strongly recommend to anyone who has sustained a spinal cord injury. Over the next few pages, we'll introduce you to your local trusted legal partners as well as SIA's trusted financial partners.

Your local trusted legal partners

We're confident our trusted legal partners are among the most qualified and experienced legal professionals out there. Crucially they've also assisted many SCI people on the road to recovery after injury, and they know from that experience – and through their work with SIA – the unique nature of the support and advice you'll need, whether it be supporting you with a potential compensation claim or answering your general legal queries relating to life after injury.

Find out more and meet the team on pages 28 – 31.

We're confident our trusted legal partners are among the most qualified and experienced legal professionals out there.

LIFE MATTERS

MANAGING YOUR FINANCIAL SECURITY



They can help plan your finances to support any immediate financial needs such as adapting a house, buying a car or fitting specialist equipment in your home, alongside providing assistance with funding to support you long term.

Find out more about our financial partners on pages 32 – 34 and get in touch for your free, no-obligation consultation.

Aspire welfare benefits advice

We can also refer you to Aspire for welfare benefits advice.

Aspire's benefits advice team can help with benefit checks, completing forms and online applications and preparing evidence, as well as advocacy should you need to appeal. Tailored to provide appropriate advice and support for SCI people, the service can help you ensure you're getting all the help you're entitled to. Read more on page 35.

Our trusted financial partners

We've handpicked three specialist financial advisers and investment managers who all have experience of supporting SCI people with financial matters after injury.

The support they can offer you ranges from advice on managing compensation from a legal claim or settlement, to private wealth and investment management tips, accessing disability and care benefits and assistance with setting up trusts and pensions.

Need further financial advice? Contact our advocacy team

Alongside the expert advice offered by our trusted financial partners, SIA's advocacy team offers information to support you in managing your finances after injury, including advice on Disabled Facilities Grants, Access to Work and other schemes to help you get the financial support you need.

For further information, visit www.spinal.co.uk/finance/ or call 0800 980 0501.

SUPPORT LINE
0800 980 0501

LIFE MATTERS

TRUSTED LEGAL PARTNER

Leigh Day

Leigh Day



Leigh Day are specialists in their field and ranked top by the two foremost legal directories, Chambers & Partners and The Legal 500.

Their personal injury team act in all kinds of cases, including:

- road traffic accidents • accidents at work
- accidents at home • extreme sports
- train crashes • terrorist attacks

Their clinical negligence team helps people injured because of substandard care by a medical professional, including misdiagnosis, delayed diagnosis, incorrect treatment and surgical mistakes.

They can also help you get the welfare benefits you need, their employment team can help with issues around returning to work, and their highly regarded human rights team can help you access health and social care.

Company information

Locations

Based in central London, supporting clients across London and surrounding areas; SIA's trusted legal partner in London.

Contact details

T 020 7650 1200

WEBSITE



"Leigh Day's support was like an envelope of reassurance."

Leigh Day client

Meet the team



Daniel Easton

T 020 7650 1226

E deaston@leighday.co.uk

Daniel has worked alongside SIA for many years, specialising in complex personal injury claims, such as spinal cord injury, amputation and fatal accidents.

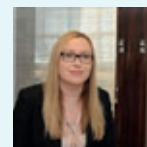


Olive Lewin

T 020 7650 1251

E olewin@leighday.co.uk

Olive is an experienced healthcare lawyer who has specialised in the field for more than 25 years, having previously trained as a nurse.



Bethany Sanders

T 020 7650 1149

E bsanders@leighday.co.uk

Bethany specialises in serious injury claims, including spinal injury, brain injury, amputee claims and fatal accidents.



Kirsten Wall

T 020 7650 1200

E kwall@leighday.co.uk

With over 15 years' experience in clinical negligence cases, Kirsten specialises in claims involving spinal cord injuries, including delayed diagnosis of cauda equina syndrome and surgical procedures.



For over 30 years Leigh Day have been helping spinal cord injured people achieve financial security and rebuild their lives

FIND OUT MORE



Scan the QR code to read more about Leigh Day and watch Rod's story.

LIFE MATTERS

TRUSTED LEGAL PARTNER



Spinal Cord Injury Solicitors

Aspire Law



Aspire Law is the leading law firm for spinal cord injury claims with many of their lawyers ranked as leaders in the field of spinal cord injury.

Aspire Law is the only law firm in the UK with dedicated spinal cord injury lawyers, dealing exclusively with spinal cord injury claims. They donate 50% of their profits to Aspire, a spinal cord injury charity.

The financial results Aspire Law get for their clients are first rate with cases settling frequently for seven and eight figure sums, several of which are regarded as some of the highest settlements for spinal cord injury.

Company information

Locations

National law firm based in central London, supporting clients across London and regionally. One of SIA's trusted legal partners in London.

Contact details

T 0208 176 4716

WEBSITE



"Your hard work has allowed me to hopefully get some closure and please God maybe start to rebuild my life."

Aspire Law SCI client

Meet the team



Damian Horan

T 0208 176 4716
E damian.horan@aspirelaw.co.uk

Damian is widely regarded as one of the most experienced spinal cord injury solicitors in the UK with an incredibly successful track record in achieving fantastic outcomes for the clients he represents.



Raquel Sigantoria

T 07551 055103
E raquel.sigantoria@aspirelaw.co.uk

Raquel represents adults and children who sustain spinal cord injuries due to medical negligence or personal injury. Raquel has personal experience of spinal cord injury having become injured in 1993 as a child.



Anna West

T 07384 467656
E anna.west@aspirelaw.co.uk

Anna understands the life-changing impact that spinal cord injuries have, not only on clients, but on their loved ones too. Anna is a staunch advocate for early intervention and support for clients.



Matthew Claxson

T 07715 700901
E matthew.claxson@aspirelaw.co.uk

Matthew will always meet with his clients to understand their situation and objectives. Matthew enjoys working as part of a team to establish liability having garnered extensive experience in acting for clients where liability is initially denied.



In the last three years, Aspire Law has secured more than £140m in compensation for clients

FIND OUT MORE



Scan the QR code to read more about Aspire Law.

LIFE MATTERS

TRUSTED FINANCIAL PARTNER



Evelyn Partners



Evelyn Partners' team of specialist financial planners, investment managers and technical specialists are all dedicated to working with clients affected by serious injury or clinical negligence. They want you to benefit from the best possible advice, so you feel informed and in control of your financial future.

Services include:

- Lifetime financial planning
- Trusted investment services
- Periodical payment checks
- State benefit assessments

“Evelyn Partners helped me and my family move on from the accident itself and concentrate on getting on with our lives knowing that the money was being looked after the way it needed to be.”

Andrew Russell, Evelyn Partners serious injury client

Company information

Locations

UK-wide support, based in central London

Contact details

Nick Geere - managing partner

Region: London & East Anglia

T 07725 497 639 **E** nick.geere@tilney.co.uk **W** www.evelyn.com



Evelyn Partners has over 180 years of experience helping clients to achieve their goals

LIFE MATTERS

TRUSTED FINANCIAL PARTNER



Irwin Mitchell



“They’ve given me great financial advice... Irwin Mitchell were like a breath of fresh air, looking at the entire picture. I feel much better informed and in control of my finances.”
IM client Nathalie McGloin

Irwin Mitchell have been providing financial advice to people who have sustained a spinal cord injury for over 20 years, and they've developed their services so they can give you and your family all-round financial planning advice. Their goal is to ensure that your money looks after you now, and in the future, so you can focus on what really matters.

Their financial planners understand how much of an impact a serious injury or illness can have on you or your loved one's finances. Whether you're recently injured or have had your injury for some time, they

can guide you through adapting your finances to your situation and keeping them on track, so you get stability and peace of mind.

Services include:

- Making new budgets and cutting down costs
- Benefits and tax reliefs
- Reviewing your existing investments and financial products
- Managing debt
- Releasing money from pensions
- Tax-efficient investments

Company information

Locations

UK-wide support, based in Sheffield

Contact details

Bronwen Lancaster - financial planner

London, South East, Wales and the Borders

T 07703 473 759 **E** bronwen.lancaster@irwinmitchell.com **W** www.irwinmitchell.com/wealth-management



Irwin Mitchell builds long-term relationships with their clients – 99% of their clients stay with them

LIFE MATTERS

TRUSTED FINANCIAL PARTNER



Adroit Financial Planning



Adroit's financial consultants are recognised throughout the legal industry as experts in advising injured clients. They've also advised Government on the structuring of personal injury awards and several members of the Adroit team form part of an expert panel that regularly advise and serve the personal injury legal community.

80
125

The Adroit team has around 80 years' experience in personal injury and over 125 years' experience in financial planning and wealth management

Company information

Locations

UK-wide support, based in Manchester

Contact details

T 0800 884 0006 E enquiries@adroitfp.co.uk

W www.adroitfp.co.uk/financial-planning-services

"Adroit gave us great ideas and investment opportunities and we're now planning for, and looking forward to, the rest of our lives ahead."

Mr and Mrs B, Adroit Clients, Manchester

LIFE MATTERS

WORKING TOGETHER



Aspire



Many people who've sustained a spinal cord injury find themselves discharged somewhere totally unsuitable, such as an un-adapted house or a care home. This robs people of their independence at a time when they should be ready to rebuild their lives.

The Aspire accessible housing programme offers an alternative. It provides homes located around the UK for use on a short-term basis while a permanent housing solution is found. It might be that your own property is being adapted, or you're waiting for your local authority to find you something suitable. Meanwhile, in an Aspire house you can be back

among friends and family, getting on with your life. Get in touch direct at housing@aspire.org.uk.

For information and advice about accommodation and adaptations to your home following a spinal cord injury, you can also contact Aspire's free-of-charge housing advice service at housingadvice@aspire.org.uk

Aspire welfare benefits advice

Aspire also has a free-of-charge, dedicated welfare benefits advice service. Find out more on page 27 of this guide, or get in touch at welfarebenefits@aspire.org.uk

Company information

Locations

UK-wide support, based in Stanmore, North London

Contact details

T 020 8954 5759

W www.aspire.org.uk

Aspire's benefits advice team supported almost 300 clients last year, helping them claim a total of £560,000.

LIFE MATTERS

SUPPORT
FOR LIFE

Whether you're fighting to keep a job, starting a family or tackling new health challenges, your needs will evolve and change over the years. We'll be there to find you the right people and partners to support you, whatever stage you're at.

Your local SIA support coordinator is here for you at any point. See pages 6 – 7 of this guide for their contact details. Or visit our website to get in touch at www.spinal.co.uk/find-support-now/

Employment and careers

Being treated unequally because of your spinal injury at work can feel degrading, unjust and humiliating. Most importantly, it should not happen. The Equality Act 2020 for disability protects you from any discrimination because of your injury. Find advice and support at www.spinal.co.uk/employment.

4.1m

Over 4.1 million disabled people in the UK are employed – so there's no reason why you can't be part of the workforce too



SIGN UP NOW

**STAY CONNECTED**

Follow SIA on Facebook, Twitter, YouTube and Instagram to stay up to date with news from us, our trusted partners and other SIA members.

When you join us as a member free of charge, you can choose to receive our monthly news update The Voice. It features news, stories, reports and special offers especially relevant to the SCI community. Scan the QR to sign up now.

Finding community groups in your area

Local community groups are a great way of connecting to other SCI people, their friends and families and they offer regular opportunities to socialise. To find a group near you, contact your local support coordinator.

Social networks

There are also SCI-related private Facebook groups you can join. Find ours at www.facebook.com/groups/supportnetworkteam and also check out the SCI Owners Club Facebook group. It has around 2,000 members and is open to every SCI person. These groups are an excellent way of connecting and a great source of information and support.

FACEBOOK



Scan the QR code to find our Facebook group.

LIFE MATTERS

SUPPORT
FOR LIFE**Driving after injury**

Getting back behind the wheel helps with regaining independence and makes daily living much easier. We have a wealth of knowledge on driving with a spinal cord injury – from the practicalities of adaptive vehicles to registering your disability. You can also find out more about driving and getting out and about at www.motability.co.uk/

Public transport

By law, it's a requirement for all public transport to be fully accessible to wheelchair users. For example, a ramp and priority spaces on buses. On trains, someone to assist you on and off, typically with a ramp. Find out more at www.spinal.co.uk/transport/

Sporting sessions and getting active

Many spinal cord injured people play sport recreationally and competitively. Speak to your support coordinator to discover what sports you can get involved in locally and further afield. We also refer members to Back Up for wheelchair skills and other activity courses.

Disability-friendly venues

Check out websites like www.accessibleGO.com and www.AccessAble.co.uk for help with planning trips out. And read more on our website at www.spinal.co.uk/accessibility/ or contact our advocacy team for advice and support with access issues on 0800 980 0501

Holidays

Going on holiday after an injury can be daunting, but it's worth making the effort. You're bound to have questions about travelling and we can help. We also feature travel inspiration from SIA members in our quarterly magazine FORWARD. See page 38 for details of how to subscribe.

SCAN TO BOOK



Scan the QR to see our holiday guide to help you plan your travels.

GET IN TOUCH TODAY

If you have questions about any of the topics we've listed on these pages – or any other aspect of life with a spinal cord injury – please don't hesitate to get in touch. Your local SIA support coordinator will always be happy to help. And our support line can inform, advise and signpost you to services that could help you lead your fulfilled life.

Call us on the freephone number 0800 980 0501, Monday to Friday, 9am – 5pm.

SUBSCRIBE TO OUR FORWARD MAGAZINE TODAY

Regular features include:

news • health • daily living • research • interviews



**SUBSCRIBE
ONLINE TODAY**



For more information, email Klaudia Ochman, our member engagement officer, at k.ochman@spinal.co.uk or call 01908 604191 (ext:166)



www.spinal.co.uk/subscribe-forward

Registered Charity No 1054097

GET INFORMED IN YOUR WORDS

“I just wanted to say thank you SIA, for helping me find – not just the words – but the courage to ask for help and to not just accept that things are what they are.”

SCI person

“The patient met with the support coordinator from SIA on his own and didn’t give me very much information about the content of the meeting. However, there appeared to be a marked difference to his approach to and engagement with his rehab sessions afterwards.”

Healthcare professional

“My son can now see some light at the end of the very dark tunnel. We wish we’d been told about you sooner. The open and honest conversations we’ve had have been so helpful. We know our boy will be in a better place soon and with the help on offer he will do well.”

Parent of newly injured person



GET INFORMED

IN YOUR WORDS



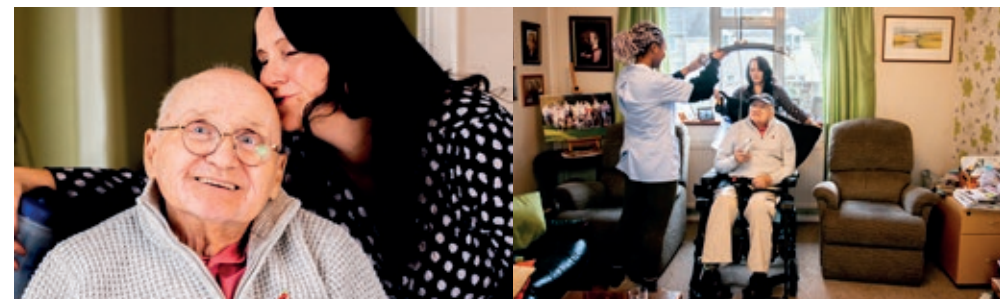
My name's Tina. My lovely dad, David, was a fit, active 83-year-old. Laying decking, directing traffic at Scouts' fundraisers, president of the local classic car club. Until blood cancer began attacking his kidneys and his bones.

Having walked into hospital for a few tests – he was discharged in a wheelchair, paralysed from the chest down, with a T4 spinal fracture.

When someone you love comes home with a spinal cord injury, it can feel a bit like being handed a new-born baby. That same huge sense of responsibility. The same overwhelming fear you'll do something wrong. Except, as a parent, you've got family, friends, books you can refer to. You know where to go for help. We were lost – had no idea where to turn to help our dad. Until we found SIA.

"Teresa was, quite literally, a lifesaver. She referred us to our local SIA support coordinator. It was such a relief to hear him say 'I've got an injury very much like your dad's'".

Tina



We were lost – had no idea where to turn to help our dad. Until we found SIA.

Compassionate, personalised support – from experts and peers

Teresa – on the charity's support line – was my first port of call. She was, quite literally, a lifesaver. She referred us to our local support coordinator. It was such a relief to hear him say "I've got an injury very much like your dad's". And to see that he was living his life. And everything I mentioned – catheter, pressure ulcers, wheelchair, mental health – he said yes, SIA can help with that. Can you imagine the relief as I reeled off my long list of worries and fears – and he checked off each one?

Emergency care plans put together by SCI specialists

For example, Dad had to go back into hospital with suspected septicaemia. With help from SIA's clinical specialists, we'd made an emergency care plan. It's just a paper form, downloaded from SIA's website, but it contains all the information about Dad's injury, his medication, the risks of autonomic dysreflexia (AD) and skin damage. And I can't tell you the peace of mind I got from handing it to the paramedics who picked him up that night. The feedback from A&E was – "this is brilliant."

As well as creating an emergency care plan with our clinical specialists (see page 8), Tina and David used several SIA services, including:

- training for carers (page 9)
- CHC funding advice and advocacy (page 10)
- counselling (page 22)

Get in touch with your local support coordinator (pages 6 - 7) or call us on 0800 980 0501 to access any or all of these services.

VISIT US



GET INVOLVED

CAN YOU HELP OTHERS AFFECTED BY SPINAL CORD INJURY?

GET INVOLVED



With your support we can help more people rebuild their lives after spinal cord injury. There are loads of ways to get involved – all of them can change lives.

- Make a one-off or regular donation.
- Support SIA as you celebrate special occasions such as birthdays, weddings and anniversaries.
- Fundraise for us by taking part in an event or hosting your own.
- Encourage your club or workplace to select SIA as their charity of the year.
- Make a gift in memory of a loved one so that their lifetime achievements can live on.
- Remember SIA in your will and help spinal cord injured people for generations to come.



How your support helps

£10 could help towards the cost of a telephone consultation with one of our clinical specialists on topics such as bowel and bladder care. Just one 30-minute conversation could save a life.

£20 could help towards the cost of a support network session. Families tell us they wouldn't have coped without this positive insight into life after injury.



“SIA members say raising funds has helped with their rehab. Setting goals, getting active, meeting people and feeling good.”

Jo Neale, head of investments & partnerships

Help us change more lives

To make a donation call 01908 604191 (option 3), visit www.spinal.co.uk/donate or email fundraising@spinal.co.uk

GET INFORMED

CHANGE LIVES

Remember us in your will

Gifts in wills have helped us become the national charity we are today, providing life-saving clinical, practical and emotional support to thousands of spinal cord injured people every year.

Your gift will help us keep growing, reaching more people with vital information, advocacy, support, confidence and hope to adapt to life after injury.

To find out more about leaving a gift in your will, contact supportercare@spinal.co.uk or visit www.spinal.co.uk/wills

Take part in an event

We have a wide range of accessible events on our website and can offer support with training as well as advice and inspiration to help make most challenges accessible. And if you can't find something that takes your fancy, we can help you create and organise your own event instead!

Volunteer for SIA

We're actively recruiting for support network volunteers – people with lived experience of spinal cord injury who can support others, providing practical advice and a positive insight into life after injury.

Complete our volunteering form if you'd like to be considered for this role – or if there's another way you'd like to volunteer that isn't currently listed.



How to fundraise for us

1. Visit www.spinal.co.uk/get-involved for information about events, fundraising ideas and to download a fundraising pack.
2. Choose what you're going to do for your fundraising event.
3. Contact SIA's fundraising team or talk to your local support coordinator for advice.
4. Set up an online giving page – you can find top tips on how to do this in the fundraising pack.

Then you're all set to start sharing your fundraising story.

Want more info?

Scan the QR to complete our volunteering form.

GET INVOLVED



Get in touch

Our fundraising team is always happy to talk about any fundraising ideas. They'd love to hear from you at fundraising@spinal.co.uk or 01908 604 191

SIGN UP TODAY

SCAN TO JOIN



Sign up today – join as a member for free and get a lifetime of support – whenever you need it.

www.spinal.co.uk/joinus



“I would highly recommend ANY SCI person to join SIA. The advice and support my wife and I received was most helpful and informative. THANK YOU, SIA, for being so supportive, professional and empowering.”

SIA member

spinal.co.uk

Spinal Injuries Association

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

Tel: 01908 604 191

Freephone support line: 0800 980 0501

sia@spinal.co.uk

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