

YOUR SUPPORT NETWORK GUIDE



**GET INFORMED** 

## **USING** YOUR GUIDE

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### **CENTRE (SCIC)**

Spinal Outpatient Department / Longford Ward

Salisbury

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 quarantee 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

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.



## YOUR LOCAL SPINAL CORD INJURY

Spinal Treatment Centre - Salisbury Salisbury District Hospital

Odstock Rd SP2 8BJ

**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

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.

#### The support, advocacy and advice we provided last year



### **Over 1,400** support sessions delivered to

meet practical and emotional needs of SCI people



### **Around 400**

healthcare professionals received training and expanded clinical specialist team





### Over up by

subscribers our monthly e-newsletter



#### **Over 300** connections enabled between our members and partnership organisations



**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

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

#### 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
- undergo due diligence processes before ioinina our network
- commit to regular reviews, training and feedback meetings

**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**

**Gareth Jones** Support coordinator South West

T. 01908 732161

E. g.jones@spinal.co.uk



"Gareth was a shining light. It was such a relief to hear him say "I've got an injury very much like your dad's". And everything I mentioned catheter, pressure sores, wheelchair, mental health - he said yes, SIA can help with that."

**Daughter of SCI person** 

"Gareth was without question a hero on the call and has continued to be so. He was thoroughly professional but with a friendly manner. I can't thank him enough for giving me back my life."

SCI person

"Gareth really helped me to change my outlook for the better."

SCI person

**GET SUPPORT** 

## **SUPPORT** FROM A PEER



Gareth Jones - Support coordinator South West

Hi – I'm Gareth, 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

I sustained my injury in September 2014 while cycling home from work. I don't remember the collision apart from being in A&E and then in intensive care, where I was told I had dislocated my spine at T3, leaving me paralysed from the chest down.

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**

"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

Learn more about dealing with your bladder, bowel, skin and other SCI body matters at

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.

However you sustained your spinal cord injury.

aspects of living with a spinal cord injury.

www.spinal.co.uk/get-support



### **CLINICAL SPECIALIST** IN YOUR REGION

**Damian Smith** SCI clinical specialist South West 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 TO BOOK** 

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

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.



**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

#### **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.

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





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







#### **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.



#### **BODY MATTERS**

# TRUSTED CARE PARTNERS



**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.



#### **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.



**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.

"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."

#### **Company information**

#### Locations

Hemel Hempstead, Gatwick, Bristol

#### **Contact details**

T 0300 77 77 188 E info@neurokinex.org W www.neurokinex.org



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.







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

SUPPORT LINE **0800 980 0501** 

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

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.



### 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)

#### lan 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

#### 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 hest

#### LIFE MATTERS

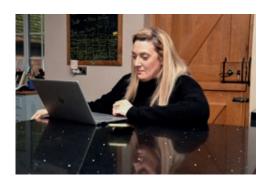
# FIGHTING FOR YOUR RIGHTS

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.

#### 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.



LIFF MATTERS

## GETTING LEGAL SUPPORT



Getting expert legal and financial advice is something we strongly recommended 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



#### 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.

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.

#### 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.



#### LIFF MATTERS

# TRUSTED LEGAL PARTNER



#### **JMW Solicitors**



JMW Solicitors' catastrophic injury team has a specialist spinal cord injury team lead by Cathy Leech, SIA award-winning solicitor and fundraiser. The personal injury team specialises in spinal injuries, however caused, including:

- road traffic accidents, pedestrian, cycling or motor vehicle
- · accidents at work

- foreign accidents or overseas claimants injured in the UK
- sporting injuries
- military claims including AFCS

The clinical negligence team is renowned for its long-standing expertise in SCI claims including cauda equina. They have handled hundreds of SCI medical negligence claims such as delayed or misdiagnosed treatment, inappropriate advice, and surgical errors.

#### **Company information**

#### Locations

Offices based in Manchester, Liverpool and London – supporting clients nationally. One of SIA's trusted legal partners in the North West and the South West.

#### **Contact details**

T 03456 461 744



#### Meet the team



Cathy Leech Head of catastrophic injury, partner

E cathy.leech@jmw.co.uk Specialist SCI solicitor for over 20 years. Winner of two SIA

Rebuilding Lives awards – excellence in legal care and fundraising. Legal 500 2022 'Catherine Leech is probably the best spinal injury solicitor in the country.'



Paul Breen personal injury, partner

E paul.breen@jmw.co.uk
Paul has over 35 years'
experience of dealing with
a wide range of serious and

catastrophic injury claims, including those arising from road traffic accidents, accidents at work, pedestrian accidents and assaults resulting in claims to the criminal injuries compensation authority.



Eddie Jones Head of clinical negligence, partner

**E** eddie.jones@jmw.co.uk Eddie specialises in brain and spinal injury cases, has over 30

years' experience, and is widely regarded as a leading practitioner in the field, having secured many multi-million-pound compensation settlements for children and adults. He has particular expertise in cauda equina cases.



Angharad Hughes
Clinical negligence, partner

E angharad.hughes@jmw.co.uk With over 15 years' experience, Angharad undertakes highvalue clinical negligence work

and has a particular interest and expertise in complex brain and spinal injury cases.

"Cathy did everything possible for me and went above and beyond to help me win my case and also invested a lot of time in helping me understand what was going on, which made a massive difference and put me at ease with every situation that arose"

Dan Colley, SCI client



Scan the QR code to read more about JMW Solicitors.

#### LIFF MATTERS

# TRUSTED LEGAL PARTNER





CFG Law are specialist spinal cord injury solicitors, providing legal advice together with financial, physical and emotional support from day one. Their aim is to help your whole family and secure the best outcomes for your recovery. They provide their services on a no-win, no-fee basis, so there's no financial risk when making a claim.

#### CFG Law can:

- offer an emergency fund to help plug any gaps in your support right away
- help with benefits applications and support with appeal processes
- signpost to charities and other emergency funds

The CFG Law team can give well-informed guidance about treatment and support, liaise you're your treatment team about discharge options, and arrange and facilitate care packages and source aids and equipment.

#### **Company information**

#### Locations

Head office in Cheadle, with offices in Birmingham, Bury St. Edmunds, Cambridge, Manchester City Centre, Nottingham, Oxford, and Sunderland. One of SIA's trusted legal partners in the North East & Yorkshire and the South West.

#### **Contact details**

T 0800 988 7053



#### Meet the team



#### Caroline Trinder

Caroline, a highly experienced senior nurse, joined the team in 2021. She coordinates support for clients who have sustained life-changing injuries, liaising

with NHS staff, social services, housing departments and local authorities.



#### **David Hilton**

David has a wealth of experience helping people with all aspects of court of protection, lasting powers of attorney and personal injury

trusts. He has helped hundreds of people and their families to manage their property and financial affairs as a professional deputy.



#### Katie Pendower

Katie joined the team in 2021 and specialises in supporting people after life-changing injuries. She has extensive experience of dealing with

accidents involving motorbikes including complex liability arguments.



#### Rachael Lomas

Rachael has over 20 years' experience supporting people with life-changing injuries caused through injury or medical negligence.

"I feel so lucky to have chosen CFG to handle my case as when you have an accident you don't know who to trust. From day one they made me feel secure, reassured and they also kept me fully informed throughout the whole process. I know that I received first class legal advice, and they used top experts to support my case. I can't fault their service and am thankful for everything that they did for me."

CFG Law SCI client



Scan the QR code to read more about CFG Law.

LIFE MATTERS

# TRUSTED FINANCIAL PARTNER





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**

James Brown - Financial planner - partner Region: South West

T 07769 880 451 E james.brown@tilney.co.uk W www.evelyn.com

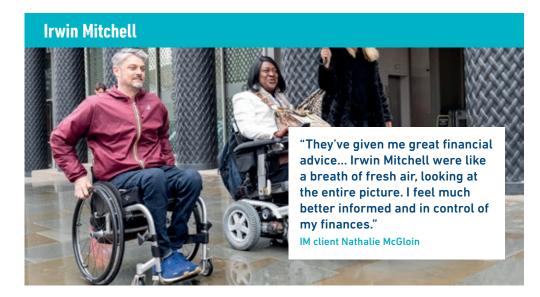
180

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

#### LIFE MATTERS

# TRUSTED FINANCIAL PARTNER





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

#### Steve Balmer - Financial planner

West Midlands and the South West

T 07802 869 976 E steven.balmer@irwinmitchell.com W www.irwinmitchell.com/wealth-management

99%

Irwin Mitchell builds longterm relationships with their clients – 99% of their clients stay with them

LIFE MATTERS

## TRUSTED FINANCIAL **PARTNER**







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.



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

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.

#### 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.



Scan the QR code to find our Facebook group.



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 enews update The Voice. It features news, stories, reports and special offers especially relevant to the SCI community. Scan the QR to sign up now.

#### 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 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



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 persor

"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



GFT 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.



#### GFT INVOLVED

# CAN YOU HELP OTHERS AFFECTED BY SPINAL CORD INJURY?



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.



"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



#### 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.



#### 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

- 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 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



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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