

YOUR NATIONAL SUPPORT NETWORK 2024



National Support Guide

Your network of people and partners for
a fulfilled life with spinal cord injury.

WHAT IS SPINAL CORD INJURY?

Spinal cord injury is life changing. Not just for the person injured, but for family too.

Causing paralysis and loss of sensation below the level of damage, spinal cord injury can mean you might:

- not be able to walk
- lose control of your bladder and bowel function

- be unable to regulate your body temperature
- have altered sexual function
- be at risk of developing pressure ulcers
- have limited arm and hand function
- need a ventilator to breathe

The physical and psychological impact of spinal cord injury is huge.

But you're not alone...



Around 50,000 people are living with spinal cord injury in the UK



Every four hours, someone sustains a spinal cord injury

HOW CAN SIA HELP?

With and for our members



As the expert guiding voice for life after spinal cord injury, we're here to help you and your loved ones lead a fulfilled life, whatever that looks like for you, at any point after your injury.

1

Providing critical health and care support for people with spinal cord injury

2

Coordinating a network of support services nationwide

3

Building vital specialist expertise across the health and care sector

4

Campaigning for change

Whether you're recently injured or not, whether you're in a healthcare setting or at home, we're here to help.

We can help

Perhaps you're ready to take on your next challenge – new job, starting a family, going travelling – and you're not sure where to start. We can help.

You might have urgent questions and critical healthcare needs. We can help.

Maybe you're getting by OK. But you want to do more and feel better. We can help.

We know a fulfilled life looks different for every person. And for each person, their fulfilled life is likely to evolve and develop as they do. So, wherever you are and whatever you need – talk to us to see if we can help.

Become a member today – for a lifetime of support – whenever you need it.

INSIDE THIS GUIDE

Welcome to YOUR Support Network – built by you, powered by SIA and partners.

- Connecting you to the best people and services to meet your immediate and longer-term needs.
- Empowering you as you rebuild your life after spinal cord injury, whether you're newly injured or at any time afterwards.

Use this national guide – alongside spinal.co.uk, your regional guide and SIA's **Network Directory** – to build your own personalised network of support for a fulfilled life with spinal cord injury.

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Connecting and empowering YOU

You can meet your local team in your regional guide, or at spinal.co.uk/local. As well as SIA's own experts – many with lived experience of spinal cord injury – you'll see there are other specialists who can support you too.

TAKE A LOOK



Meet your trusted partners and business members.

Selected for being among the best in their sector AND for their understanding of spinal cord injury, we're confident these organisations

can offer solutions to the challenges you may face at any point after sustaining a spinal cord injury.

Join us today get support for life – whenever you need it

Join as a member for free at spinal.co.uk/joinus – opt into emails when you sign up to stay in touch with your monthly copy of The Voice.



NETWORK DIRECTORY

We work closely with more than 70 organisations that understand spinal cord injury. Find out how they might be able to help you in our Network Directory.

To view the directory visit spinal.co.uk/directory

TAKE A LOOK



PRACTICALITIES

Based on what our members say to us, we've listed some frequently asked questions, along with answers and ideas for more information and support.

To help you find the most relevant questions, we've colour-coded them:

purple = most relevant if you're recently injured **orange = relevant for anyone at any point post-injury**

How do I go to the toilet?

Spinal cord injury can affect bladder and bowel control because the nerve pathway from the brain to the muscles in the bladder, rectum and anus has been interrupted. So, you're likely to have lost sensation and control of when your bladder or bowels will empty.

Feeling worried or embarrassed about this is natural. Many members tell us it's their biggest area of concern. But there are lots of ways to manage your bladder and bowels. SIA's clinical specialists can help you find the routine that works best for you. It's important for your self-esteem and it can help you avoid infections and other health complications too.

- Read more about bladder and bowel management under 'body matters' at spinal.co.uk/knowledge-hub
- Scan the QR code or visit spinal.co.uk/clinical-specialists to book an appointment with SIA's clinical specialists to take control of your bladder and bowel management.

BOOK HERE



Can I go back to my own home?

With planning and support, you'll find the right home for you and your family. It might be your existing home, adapted. Or it might be a new home that is better suited to your needs.

Adapting your current home is not always affordable or practical. So, that might mean moving to a home that has already been modified. The options can depend on your financial situation, but there may be financial help available.

- Talk to your support network coordinator or scan the QR code to find out more.
- Contact our friends at Aspire, a charity specialising in housing advice for people affected by spinal cord injury.

E housingadvice@aspire.org.uk T 020 8420 6709

MORE INFO



How will I get about if I can't walk?

Depending on the level of your spinal cord injury, you may need a wheelchair to get about. Talk to your support network coordinator about this – they'll have plenty of personal insights to share, and they can explain the practicalities too.

There are various options available: fully funded NHS wheelchairs, personal wheelchair budgets (an NHS grant towards your own wheelchair), as well as grants from charities or the government's Access to Work scheme.

- Scan the QR code to book a call with your support network coordinator
- Read more about wheelchair options at wheelchair-alliance.co.uk

MORE INFO



What equipment will I need and how do I get it?

You're likely to need healthcare products that help you manage your bladder and bowels, irrespective of your injury level. Other equipment you might need will depend on the level of your injury and your personal circumstances. For example, if you have a high-level injury, you might need a ventilator. Or, mindful of ageing well with spinal cord injury, you might prefer a powered wheelchair over a manual one. If you're ready to take up a new hobby or play a specific sport, you might need specialist or adapted equipment. You might want to adapt your home by fitting a lift. Your support network coordinator is the perfect first port of call to discuss what you might need, whenever you might need it.

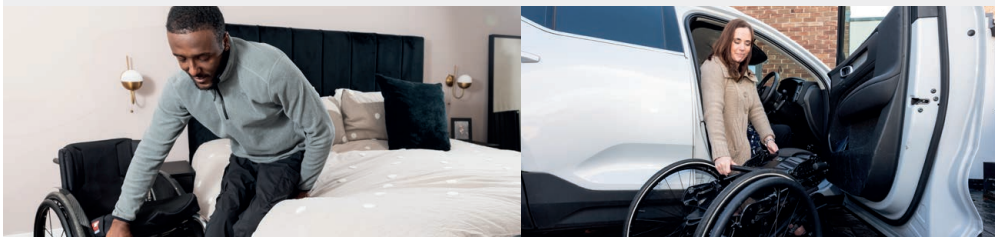
- Scan the QR code to book a call with your support network coordinator
- SIA Healthcare is a dedicated home delivery service for people living with spinal cord injury. We've teamed up with the largest independent supplier in the UK so we can source and deliver any specialist products and prescription medication or equipment you might need. Find out more at spinal.co.uk/sia-healthcare

BOOK HERE



DON'T FORGET

Reviewing your wheelchair cushion regularly can help reduce the risk of pressure ulcers.



"My son can now see some light at the end of the very dark tunnel. We wish we'd been told about you sooner. 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

NETWORK DIRECTORY

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To view the directory visit spinal.co.uk/directory

TAKE A LOOK



Should I change what I eat or drink?

You might not need to make big changes to what you eat or drink. Most nutritional advice for people living with spinal cord injury is the same as for the general population. Eating well – with a good balance of protein and fibre in your diet – can help regulate bladder and bowel function, and support bone and skin health. And drinking plenty of fluids (at least 2 litres of water a day) can help avoid health problems such as dehydration, constipation, urinary tract infections and pressure ulcers.

The main things to remember are:

1. Problems associated with poor diet and nutrition can have greater impact when you have a spinal cord injury, and
2. People with spinal cord injury don't need as many calories, because of reduced activity levels.

Find out more about nutrition and spinal cord injury at spinal.co.uk/nutrition

Who can I talk to about how I feel?

Coming to terms with your spinal cord injury can take time – for you and your family. Feeling some depression is a part of the grieving you're likely to go through as you process what's happened. Talking to your support network coordinator about your feelings can help. SIA also offers counselling for injured people and their family members. Our specialist counsellors have lived experience of spinal cord injury.

- Ask your support network coordinator to refer you to SIA's counselling team at spinal.co.uk/counselling
- Scan the QR code to read more about mental health and spinal cord injury or visit 'mind matters' at spinal.co.uk/knowledge-hub

MORE INFO



Am I more likely to get ill?

Having a spinal cord injury can mean you're at more risk of some illnesses or health complications. For example, urinary tract infections (UTIs) can be more common. That's one of the reasons a good bladder management routine is important; you can help mitigate the risk by emptying your bladder fully at regular intervals.

In addition, reduced mobility, sensation, circulation and body temperature regulation below the level of injury can put you at risk of skin problems such as pressure ulcers. And if your injury is at T6 or above, you need to know about 'autonomic dysreflexia', a medical emergency unique to people with spinal cord injury. It's the body's way of responding to a problem (such as an overfull bladder) and it can cause a sudden, potentially dangerous, rise in blood pressure.

- Scan the QR code or visit spinal.co.uk/clinical-specialists to book an appointment with SIA's clinical specialists. They can help you avoid serious health complications by supporting you with good bladder, bowel and skin management, as well as making a personal care plan (to help with working out the care you might need day to day) and an emergency care plan (a lifesaver should you ever need to go to hospital).

BOOK HERE



Will my condition change with age?

Ageing affects us all, and good planning can help us continue to live as independently as possible. We can help with care planning, and our clinical specialists can help you write an emergency care plan. This will help hospital staff understand your unique needs should you ever need to be admitted as an in-patient.

If you use a wheelchair, regular stretching can help maintain good posture and relieve pressure. Reviewing your equipment regularly (e.g. your wheelchair cushion) can help keep you healthy too. It's also worth considering how you push and transfer, to minimise shoulder wear and tear. And don't forget that your metabolism can change with age, which might mean you need to review your bowel management.

- Scan the QR code or visit spinal.co.uk/clinical-specialists to book a call with our clinical specialists to talk through any of these issues and more.

BOOK HERE



DON'T FORGET

You and your family can access our counselling service at any point after your injury. And our clinicians can support you at any point post-injury to improve your bowel, bladder and skin management routines, or make your personal or emergency care plans.



“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.”

SIA member with spinal cord injury

NETWORK DIRECTORY

We work closely with more than 70 organisations that understand spinal cord injury. Find out how they might be able to help you in our Network Directory.

To view the directory visit spinal.co.uk/directory

TAKE A LOOK



How will my family cope?

Life with a spinal cord injury can mean big changes for you and your family. And it can mean uncertainty for you all, which might feel scary and frustrating. Roles and responsibilities within the family may shift, and with that comes a change in the dynamics of your relationships. On top of this, family members may struggle to understand how you feel, which can cause frustration and tension. Keep talking and sharing, as much as you can. And don't forget, your support network coordinator will have been here. Talk to them about how you're feeling, and encourage family members to do the same. They can refer you or your family to SIA's specialist counselling team too.

- Scan the QR code to book a call with your support network coordinator or find your local team at spinal.co.uk/local

BOOK HERE



What about sex?

Sex may not be the first thing on your mind when you sustain a spinal cord injury. But when you do consider it, it's likely you'll have questions and concerns. You're not alone. You can hear from our support network coordinators talking candidly about their sexual experiences after spinal cord injury at spinal.co.uk. Many people living with spinal cord injury say their sex life continues, but in a different way to before. Changes in sensation and mobility led them to experiment with new things in the bedroom.

- Sex and spinal cord injury – your questions answered – spinal.co.uk/sex

MORE INFO



How do I explain my condition to others, particularly children?

Helping a child cope with their reactions to a parent's spinal cord injury may not always be easy, especially if you feel stressed, which is a common and completely natural reaction.

Remember that younger children may not realise how the injury could affect family life in the long term. But it's likely they'll feel confused, sad or worried because you're not at home and can't take them to school or do everything you used to do with them. Frequent visits to see you at the hospital or spinal cord injury centre can be helpful and reassuring for you all. Try to answer questions as honestly as you can. Your support network coordinator can help you with this. And you will be able to do things with them again; you'll find new ways of doing the things that are important to you, like school runs, hobbies, bathtimes, etc.

- Scan the QR code or visit spinal.co.uk/local to book a visit from your support network coordinator to help you explain things to your children.

BOOK HERE



Can I still have children?

A spinal cord injury doesn't mean you can't become a parent. There's no evidence that a spinal cord injury has a negative impact on female fertility. Often women report that their periods stop for several months – but some have become pregnant even before their periods start again. And for fathers-to-be, there are more options than ever available to you. As with the general population, some couples can fall pregnant conventionally. Others may need the help of fertility specialists. It all depends on the level and type of injury and the resulting changes in your body. There are plenty of people you can talk to about starting a family after spinal cord injury. Ask your SIA support network coordinator for more information.

- Scan the QR code or visit 'body matters' at spinal.co.uk/knowledge-hub to read our factsheet on fertility and fatherhood after spinal cord injury.

MORE INFO



“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

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TAKE A LOOK



How will I pay the mortgage?

Many people worry about their finances and how they will afford to live after sustaining a spinal cord injury. Depending on your age and your circumstances, your mortgage might be your largest monthly outgoing and your first concern finance-wise. Some lenders offer 'payment holidays' for up to six months, which don't affect your credit rating. But before you make any decisions, talk to people who've been through it or who understand it. Our support network coordinators can signpost you to organisations that specialise in exactly this sort of concern.

- Find your trusted finance partners and your local trusted legal partner to discuss any concerns about affording your mortgage after spinal cord injury. Select your region at spinal.co.uk/local then scroll down to your local 'life matters' partners.

MORE INFO



How will I pay for care if I need it?

Getting the care that's right for you and your family can feel like a minefield. It's an important decision but can be complicated. So, we're here to help.

You may be able to apply for NHS Continuing Healthcare (CHC) to help with any health needs relating directly to your injury. For example, managing your bowel care routine. CHC isn't means tested, so you won't have to contribute if your application is successful.

Find out more about CHC:

MORE INFO



- Read more about care funding on our website spinal.co.uk/carefunding

ONLINE TOOL



- Try our online learning tool for info on eligibility, applications and appeals
- Contact our advocacy team on **0800 980 0501** - for help with applying

As well as questions about the cost of care, you might have questions about what that care looks like and who can provide it. Chat to your support network coordinator to get a feel for this. With lived experience of spinal cord injury, they can advise you and your family. In addition, they can introduce you to SIA's trusted care partners and business members should you need their services.

- Find your support network coordinator at spinal.co.uk/local

Can I claim any benefits?

The short answer could be yes. You might qualify for a reduction on your council tax bill, and you could be eligible for the Personal Independence Payment (PIP – previously Disability Living Allowance). And, depending on your income, you might be entitled to the housing costs part of universal credit.

Accessing the benefits you're entitled to can feel daunting and confusing at first. Your support network coordinator can help. Or you could contact spinal cord injury specialists Aspire, who can advise you on welfare benefits as well as any housing or accommodation challenges or concerns.

- Find out more about spinal cord injury and benefits at aspire.org.uk/welfare-benefits-faqs

MORE INFO



Will I be able to work again?

Worrying about how a spinal cord injury will affect your career is normal. But the reality is that it shouldn't affect it very much at all.

Your rights are protected, employers cannot discriminate against you, and you have access to a wide range of support to propel your career forward.

By law, your employer must make reasonable adjustments to help you continue working as you did before. These include improving access to work premises, being flexible about working hours and providing modified equipment. Everything should be about making your transition back to work as smooth as possible.

In some cases, you may find yourself physically unable to continue working in the job you did before injury. But a career you're passionate about is still possible. All that's needed is to find a position suited to your physical abilities, skills, qualities and experiences. And we can help you with that.

- Speak to your support network coordinator and find out more at spinal.co.uk/employment

MORE INFO



“Thank you for giving me hope and making me aware of help out there. I've struggled alone for a long time. After today I know that with help my future is worth living and I can still achieve life goals.”

SIA member with spinal cord injury

NETWORK DIRECTORY

We work closely with more than 70 organisations that understand spinal cord injury. Find out how they might be able to help you in our Network Directory.

To view the directory visit spinal.co.uk/directory

TAKE A LOOK



Are there specialist solicitors who understand spinal cord injury?

In short, yes. We've teamed up with the legal firms in your area that we know have an excellent understanding of, and a strong track record in supporting people affected by, spinal cord injury. These are your trusted legal partners – selected because we're confident they'll support you to find solutions that work for you. However, we believe full freedom of choice is crucial too, so do speak with different organisations until you find the right one for you.

PARTNERS



- Find your trusted legal partners under 'life matters' at spinal.co.uk/partners

DIRECTORY



- See our Network Directory for details of 70+ organisations, including specialist solicitors at spinal.co.uk/directory

Can I make a legal claim?

Every case is different, but it's always worth discussing this. You could talk to your support network coordinator initially, or seek advice from your local trusted legal partner or any of our trusted legal partners.

- Find your local trusted legal partners – select your region at spinal.co.uk/local then scroll down to your local 'life matters' partners
- See all our trusted legal partners under 'life matters' at spinal.co.uk/partners
- See our Network Directory for details of 70+ organisations, including specialist solicitors at spinal.co.uk/directory

TAKE A LOOK



How do I make sure my wishes are carried out?

You can create a lasting power of attorney (LPA) to make sure the people you trust can help you carry out your wishes. The LPA is a legal document that lets you (known as the 'donor' in this case) appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf.

There is an LPA for health and wellbeing and another for property and finance. Having an LPA in place can give you more control over what happens to you if you're not able to make decisions for a period of time. The Court of Protection is the UK government arm dealing with LPAs. You can contact them directly, or ask your support network coordinator or trusted legal partner for more information.

LPAs last for as long as you're alive. To make sure your final wishes are carried out after your death, you'll need to make a will. It won't be the first thing on your mind when you sustain a spinal cord injury, but life-changing events like this can be an important time to make or update a will.

- You can help other people affected by spinal cord injury when you make or update your will for free – find out how.

MORE INFO



How can I protect my loved ones now and in the future?

It's common to worry about your loved ones when you have a life-changing injury. Talk to us about all the different ways to keep the people you care about safe, both now and in the future. It might be about getting the right care routine in place now and planning ahead for the care you might need later. Your clinical specialists can help you with care planning, emergency care plans and more.

Your support network coordinator can talk you through equipment and adaptations so you can move around your home safely and look after the people (and any pets) who depend on you. Your trusted financial partners can help you with budgeting and planning for future needs. And your trusted legal partners can help you create LPAs (see above) and write or update your will.

Whether you're recently injured or sustained your spinal cord injury some time ago – we can connect you with experts in care, finance and legal matters so you can plan with confidence.

CLINICAL TEAM



- Talk to your clinical specialists at spinal.co.uk/clinical-specialists

OUR PARTNERS



- Meet your trusted care partners
- Meet your trusted finance partners
- Find your trusted legal partners at spinal.co.uk/partners

DID YOU KNOW

At any point after your injury, you can get in touch with our trusted legal and financial partners. They can assist and advise you with a whole range of things that might be on your mind, from investments, to budgeting, to future planning.



NETWORK DIRECTORY

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TAKE A LOOK



GETTING OUT AND ABOUT

Can I still drive?

Many people living with spinal cord injury can get back behind the wheel. You might need adaptations to a vehicle to do so. For example, hand controls instead of pedals for braking and accelerating. Or you might choose to have a transfer plate fitted to make it easier to get in and out.

The Motability Scheme lets you exchange your qualifying mobility allowance (part of your Personal Independence Payment) for a car or wheelchair-accessible vehicle. And they'll talk you through the sorts of adaptations that could work best for you and your family.

If driving isn't for you, you can exchange your mobility allowance for a scooter or powered wheelchair through the same scheme. Talk to your SIA support network coordinator about Motability – it's likely they've used the scheme themselves.

- Find out more at [motability.co.uk](https://www.motability.co.uk)

MORE INFO



Will I be able to go on holiday?

Definitely. It takes time and planning – but it's worth it. Talk to other people with spinal cord injury about their holiday experiences to get ideas and inspiration. You can read about SIA members' travel tips in our FORWARD magazine. And your support network coordinator will have lots of advice too. They can support you with, and signpost you to, information about all sorts of accessible holidays.

So, whether it's the ski slopes, the swimming pool or the safari that floats your boat – you'll find a way to revisit your favourite holiday haunts.

- Subscribe to FORWARD magazine to get travel inspiration from our members, accessible accommodation ideas, and lots more on health, employment, relationships and leading a fulfilled life with spinal cord injury. Find out more at spinal.co.uk/forward

SUBSCRIBE



How can I stay active?

Staying active is important for your mental health and physical wellbeing. Your rehab team will be supporting you to transfer safely (if you use a wheelchair) and to use other mobility aids safely (if you're a walker). But talk to your support network coordinator about how you can keep active once you get home. From daily stretching (to relieve pressure, keep muscles long and posture strong), to getting out into the countryside (with specialist mobility equipment), or taking up a new sport (or getting back to an old one). There might also be further rehab options available to you, to maximise your mobility and help you stay active and independent for longer. Ask your support network coordinator for details.

- [wheelpower.org.uk](https://www.wheelpower.org.uk) for more on wheelchair sport
- [ableize.com](https://www.ableize.com) for disability products and services for sport, socials, hobbies, travel and more
- [breathandrecover.com](https://www.breathandrecover.com) for live, online sessions based on the living yoga method
- See our Network Directory for details of 70+ organisations who can help you lead a fulfilled life with spinal cord injury at spinal.co.uk/directory

TAKE A LOOK



Where can I meet other people living with spinal cord injury?

Local community groups are a great way of connecting with other spinal cord injured people and their families. We've got groups active in most regions, but we'd love to have more. It's something we're working hard on growing (and maybe it's something you can help with if there's not a group currently active in your area?) Find your local community group meetings under the 'get support' tab at spinal.co.uk.

Social media groups create supportive, sociable communities too. They can be a brilliant source of information and advice. SIA has its own Facebook group, and there's also the SCI Owners Club Facebook group, with a 2,000-strong membership.

FACEBOOK



- Find our Facebook group

OUR GROUPS



- Scan to see all upcoming community group meetings, or find your local support network under the 'get support' tab at spinal.co.uk

“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.”

SIA member with spinal cord injury

NETWORK DIRECTORY

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TAKE A LOOK



SIGN UP TODAY

SIGN UP



Become a member today – for a lifetime of support

Join us as a member for free and get a lifetime of support – whenever you need it. We'll help you build **YOUR** network of support to lead a fulfilled life with spinal cord injury – whatever that means for you and the people you care about.

Join us today at spinal.co.uk/joinus – opt into emails when you sign up to stay in touch with your monthly copy of The Voice.



As the expert guiding voice for life after spinal cord injury, we work closely with more than 70 organisations that can help you lead **YOUR** fulfilled life.

TAKE A LOOK



See our **Network Directory** for details at spinal.co.uk/directory.

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



Registered Charity No. 1054097
Charitable Company No. 3175203