

back up
transforming lives after spinal cord injury

YOUNG PEOPLE (13+) GUIDE

Life after spinal cord injury. A guide for young people



WHAT TO EXPECT AFTER LIFE WITH SPINAL CORD INJURY

"I think this guide will be really helpful for young people to gain insight into their injury and the confidence to ask questions using the prompts provided. It has a lot of really useful resources that will be beneficial for young people. I think it'll give newly injured young people direction to the support they may need and also show that they are not alone!" **Hannah, aged 20**

INTRODUCTION

In this guide, you'll find some useful advice from other young people who have lived experience of spinal cord injury. The information will hopefully help you better understand what it means for you.

When we say 'spinal cord injury' in this guide, we mean damage to the spinal cord. That could be an injury you have from a sports accident, or an illness like transverse myelitis.

This guide has mainly been put together by young people like you. Every part has been written by or influenced by young people who have shared their experiences and advice about life with spinal cord injury.

Back Up are the only charity in the UK with dedicated services for children and young people with spinal cord injury. Check the bottom of each page for how to get in touch with us or access our support.



FINDING OUT YOU HAVE A SPINAL CORD INJURY

If you've just found out you have a spinal cord injury, you probably have a lot of mixed feelings and emotions. You might feel angry or sad. Or worried and confused. There's no right or wrong way to feel – however you feel is normal and understandable.

A spinal cord injury is life-changing, and it'll feel overwhelming at times.

REMEMBER

- It's not your fault.
- You're not alone.
- You can live a happy and fun life with spinal cord injury.
- Life may be different, but it's not over.

COMMON QUESTIONS IN THE EARLY DAYS

It's totally normal to have all sorts of questions about your injury and what it means to you. You might be wondering:

- What has happened?
- What does this mean?
- Will I get better?
- Why me?
- What things can I still do?
- Who can I talk to?

It's a lot to take in. You might want to learn everything you can about your spinal cord injury, or you may want to learn a bit at a time.

BEING IN THE KNOW

All the medical professionals giving you advice might use words you've never heard of, and you might feel nervous about what you'll find out.

It's up to you how much or how little you want to know. But it can be helpful to better understand what's going on.

If there's something you don't understand, want to know more about, or if something's worrying you, it's okay to ask your doctors and nurses to explain things using words you know. Remember – it's your body, and you have the right to ask what's happening.

It's not always easy to speak up. We get it. But you're the one this is happening to. So it's okay to ask about things you don't understand or make suggestions about what you need.

It can be helpful to write down questions you have before talking to medical professionals. You might want to also write down their answers so you don't forget.

Some questions you may want to ask include:

- What happened?
- What level is my injury? Can you point to it on a picture for me?
- Could I have done something to stop this?
- Are there other people like me?
- How long will I be in hospital?
- What happens next?
- What parts of my body are affected?
- What will people think?
- What will my rehabilitation look like?
- When can I go home?
- Will it get better/easier?
- Why is it taking so long?
- Who will make decisions about my recovery?
- Who can I talk to about how I'm feeling?
- Can I talk to you without my parents or family members if I want to?
- Will I be able to go back to my school?
- Is hospital the only place I can get support?
- Why do I need to take this medication?
- Are there side effects of the medication I'm taking? If so, are there ways to reduce them?

FACTS ABOUT SPINAL CORD INJURY

There’s lots of information about spinal cord injury you can find online. But it’s important to use websites you trust to give you correct information. If you’re not sure where to look or have seen something that’s worried you, you can chat with our children and young people’s team at Back Up.

You can find out more information at www.backuptrust.org.uk

WHAT CAUSES A SPINAL CORD INJURY?

The spinal cord is a bundle of nerves and other tissue that go right from the brain’s base at the top of your neck down the length of your back. It’s protected by the bones (or vertebrae) that make up the spine, and by spinal fluid.

Your brain and spinal cord are important for controlling your bodily functions. The spinal cord sends two-way messages to and from the brain to all body parts – your muscles, organs and skin. We can feel pain and move our arms and legs because of these messages.

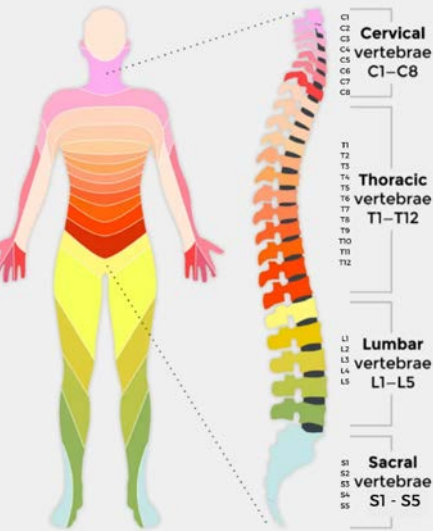
If the spinal cord is damaged or injured, some messages may be ‘interrupted’. This can lead to partially or completely losing feeling or movement in parts of your body – including your arms, legs and internal organs.

Sometimes when you injure your spinal cord, it can stop you from being able to move or feel certain parts of your body. For example, if you hurt your spinal cord near your neck, more of your body might not work than if you hurt it lower down your back.

A spinal cord injury can also affect how you feel on the inside and make you and your family feel emotional and stressed out. Back Up can help you and your loved ones adjust to life with spinal cord injury.

KEY THINGS TO KNOW:

- A spinal cord injury affects not only being able to move your body. It also affects things like being in control of your body temperature and feeling sensations like touch or pain.
- Some children and young people with spinal cord injuries can walk. Some use crutches or other mobility aids, and others use a manual wheelchair or powerchair.
- A spinal cord injury can change your bladder and bowel functions (how you go for a wee or a poo).
- Children and young people with spinal cord injuries might feel pain, tiredness and muscle spasms that can make it hard to focus and go to school.
- If someone has a higher level injury, they might also have autonomic dysreflexia, which can raise their blood pressure while making their heartbeat slower.



Cervical vertebrae

- C1–C3 Head control
- C4 Breathing and movement of shoulders
- C5 Lifting arms and extending elbows
- C6 Extending elbows and raising wrists
- C7 Extending shoulders, arms, and fingers
- C8 Finger joint movement

Thoracic vertebrae

- T1 Finger movement
- T2–T12 Deep breathing
- T6–L1 Deep exhale of breath, and stability while sitting

Lumbar vertebrae

- L1–L2 Hip joint movement
- L2–L3 Hip movement towards middle of body
- L3–L4 Moving knee into straight position
- L4–L5 Extending ankle
- L5 Extending big toe

Sacral vertebrae

- S1 Movement of foot and ankle
- S1–S2 Toe movement
- S2–S5 Function of bladder and bowel

BEING IN HOSPITAL

Being in hospital isn’t easy. It might be the first time you’ve stayed away from home overnight. Hospital can feel lonely, noisy and frightening.

“I sustained a C2 level incomplete spinal cord injury. I was in hospital for around nine months, but because of my age (eight), I was very naïve about my injury. I didn’t understand what had happened.” **Bel, aged 19**



Here are some tips from other young people about being in hospital:

- Breathe.
- It’s okay to be scared. You will leave hospital one day, even if it doesn’t feel like it now.
- Open your curtains if you’re on a ward – you may be able to talk to others in your area and make friends.
- Keep yourself entertained – play games with your family/friends, watch TV, or draw.
- Ask questions – no question is a silly question, so if you want to find out more, just ask.
- As your recovery (rehabilitation) progresses, ask to go outside for fresh air. You might be able to go as part of your therapy sessions or with a family member.
- It’s okay to not feel up to talking some days. Everyone is different and is affected differently, so take your time.
- Try to stay in contact with friends from school and home.
- Look after yourself and find ways to relax.
- If there are activities happening in your hospital/ward, give them a go.
- Ask your therapy team what you can do outside their sessions. They may give you some exercises or tasks to have a go at.
- Contact Back Up for support and guidance. They have Youth Lounges where you can meet other young people online and they’re a great way to make friends.

After going into hospital, you may then go to a spinal centre for specialist care. Or you might stay at your local children’s hospital near to home. As part of your rehabilitation (recovery), the healthcare staff will show you ways to do things like:

- Getting dressed.
- Moving from the bed into a wheelchair.
- Using equipment like a wheelchair or crutches.
- Showing others how to support you with your care.

Not everyone has the same way of doing things. Listen to the advice from your occupational therapist (OT) and physiotherapist but find a way that works best for you. Make the most out of your rehabilitation. Give it 100%. That way, you will better adjust to your spinal cord injury and how to manage it. When you learn new ways of doing things and know how to look after your health and body, you’ll be able to better picture what life will look like when you leave hospital.

Remember, although the days in hospital can feel long, lonely and exhausting, you will go home again. You’ll learn new things. You’ll visit new places. You’ll get there.

YOUR MEDICAL TEAM

In hospital, you'll meet lots of people who are there to help you. They all have different jobs, and they're all important in supporting you. It can be hard to remember all their names and what they do, so we've made a chart to help you keep track of who's who and what they do.

What's their role?	What's their name?	What do they do?
Clinical nurse specialist		
Consultant		
Physiotherapist		
Occupational therapist		
Orthotist		The orthotist checks and measures your body to see if you need special devices like splints and back braces. These devices can help you move better or keep your joints and spine in the right position.
Dietician		
Case manager		
Clinical psychologist		
Social worker		
Back Up contact		Provide information, advice and guidance on a range of topics that may be useful to you as a young person with spinal cord injury. They can also tell you more about the different services that they offer to help build your independence, increase your confidence, and meet other young people affected by spinal cord injury
Surgeon		
Need to add anyone else? We've added some more space below.		



WORDS YOU MAY HEAR



When you're in hospital, you might hear doctors and nurses using words and phrases you've never heard before. One young person said it sounded like ! "inaudible doctor muttering!" We'll explain some of the important words and phrases that you might hear, but if there's anything you don't understand, don't be afraid to ask your medical team or our team at Back Up.

Autonomic dysreflexia: This can happen to people who have a spinal cord injury near the top of their back (at or above the T6 level). It means that the parts of their body below the injury can't communicate properly with the brain, which can cause their blood pressure to go up.

Complete injury: When someone has a 'complete' spinal cord injury, they can't move or feel anything below the spot where their injury is.

Incomplete injury: If someone has an 'incomplete' injury, they might still be able to feel or move some parts of their body below the injury.

Tetraplegia/quadriplegia: This means all four limbs (arms and legs) are paralysed, and many of the organs inside the body might not work properly either.

Paraplegia: A condition where someone can't move their legs (either completely or partially), and sometimes their organs don't work well either. But they can still move their arms.



Traumatic/non-traumatic: When doctors talk about a spinal cord injury being 'traumatic' or 'non-traumatic,' they're trying to describe whether it was caused by an accident (like a car crash) or an illness (like a disease).

Rehabilitation/rehab: Rehabilitation (or 'rehab' for short) is when doctors and therapists help someone learn how to take care of their body and be as independent as possible after a spinal cord injury. They also help the person adjust to their new way of life and stay active and healthy. Rehab can last for days, weeks or even months.

Catheters: Sometimes, if you have a spinal cord injury, you might need help to go to the toilet. A catheter is a tube that goes into your bladder to help you wee.

Suppositories: A suppository is a medication that helps you empty your bowels (do a poo). You insert a small, jelly-like capsule into your bottom using a lubricant (special gel) to make it go in easily.

Manual evacuation: This is when someone uses a glove and some lubrication to gently remove poo from your bowels.

Temperature regulation (poikilothermia): If you have a high level spinal cord injury, you may have trouble regulating your body temperature. Body temperature will drop in the cold and rise in the warm.



Pressure ulcers (sores) and pressure relief: When you have a spinal cord injury, you might be more likely to get pressure marks on your skin from sitting or lying in the same position for too long. These marks are called pressure sores or bed sores. It's really important to catch them early and take pressure off the area to help it heal. You can do this by changing your position regularly, using special seating cushions, and checking your skin often (perhaps by using a mirror). Chat to your nurse to learn more about how to prevent pressure sores.

Spasms: When your muscles move on their own and you can't control it, like when your leg shakes or your foot moves without you wanting it to.

Physiotherapy: A way to help your joints and muscles stay flexible and healthy. It uses things like massage, heat treatment, stretching and exercise to strengthen your body.

Occupational therapy: A way to help you learn how to do everyday things like getting dressed, brushing your teeth or cooking.

Computerised tomography (CT or CAT) scan: This uses a machine to take pictures of the inside of your body using x-rays and computers. You lie on a bed that moves through the middle of a big, round machine. The scan can take anywhere from five minutes to 20 minutes, depending on what the doctors are looking for.

Magnetic resonance imaging (MRI) scan: This scan uses an MRI machine to take pictures of the inside your body way using a strong magnet, radio waves and a computer. It doesn't use X-rays.

X-rays: A type of radiation that can pass through your body that you can't see or feel. They help doctors see your bones.

Blood tests: Sometimes, doctors need to take a small sample of your blood to check for different things. If you're having a blood test, don't be afraid to ask what they're testing for.

Neuropathic pain: If your nerves that carry information from your brain and spinal cord to other parts of your body get damaged, it can cause a strange feeling in your body. It might feel really sensitive, or like a burning sensation. Learn more about it from the Brain and Spine Foundation.

Spinal fluid: The full name for this is cerebrospinal fluid (CSF). It's a liquid that protects your spinal cord (and brain) from damage. If your doctor thinks you have an illness that affects your nerves, they might take a sample of your spinal fluid to check it.

Ward round: This is when your medical team visits you regularly to check how you're doing and plan your care in the future. Having a group of people come to your bed and talk about you can feel a bit intimidating, but it's okay to ask them questions or listen to what they say. You're the most important person in this and have a right to know what decisions are being made for your medical care.

EMOTIONAL IMPACT OF A SPINAL CORD INJURY

After a spinal cord injury, you might feel a bunch of different emotions like anger or frustration. It can change from one day to the next – or even from one minute to the next! That’s totally normal. Everyone who has a spinal cord injury goes through a time when they try to understand what’s happened and what it means for their future. Feeling angry is your body’s way of dealing with what’s happened to it. But learning how to deal with and manage your anger is important. It’s good to talk to someone about how you’re feeling, but it’s not always easy to do. There are different ways to manage your feelings, like listening to music.

“Early on during hospital I listened to music a lot. I listened to the band Green Day for a whole year. If the album American Idiot didn’t exist, neither would I. You kind of find things to latch on to, to occupy your head. I got into different kinds of music.” **Laura, young person**

Other ways to cope may include:

- Exercising.
- Writing your feelings in a journal.
- Taking deep breaths.
- Doing an activity you enjoy.
- Getting support from family and friends.
- Making friends on the ward.

If you’re struggling, don’t be afraid to ask for help. Most people, at some point in their lives, will feel overwhelmed by something or find it difficult to cope. You may have a friend or someone in your family you feel comfortable talking to. Or maybe you’d prefer to talk to someone who doesn’t know you. There are people out there who can help you cope with your feelings. You don’t have to go through it alone.

“Talking about how you feel probably sounds cringey, but it [spinal cord injury] is such a major life event that you deserve support with.” **Youth Advisor at Back Up**

Back Up has a mentoring service where we can team you up with someone your own age or with a similar level of injury. You can talk to them about your spinal cord injury and they can give you advice based on their own experiences. It can be really helpful chatting to someone who just gets it.

There are also other places you can get help and advice for your emotional well-being:

- Young Minds is a charity that offers information about mental health and emotional well-being.
- Mind gives information about where you can get mental health support.
- Childline can provide help and advice on many issues. You can talk to a counsellor online, send them an email or post on the message boards.
- Children and young people’s mental health services (CYPMHS) are NHS mental health services that focus on children’s and young people’s needs.
- The Mix is a free, confidential helpline service for young people under 25 who need help, but don’t know where to turn. They also have a free app that you can download.
- Samaritans are there for you to talk to anytime you like, in your own way, and off the record.
- Alumina (previously selfharmUK) is a project that helps young people affected by self-harm.
- Kooth offers free, safe and anonymous online support for young people.



FAMILY AND FRIENDS



When you’re feeling low or struggling with your emotions, you may feel like nobody understands what you’re going through. But even if people haven’t been through the exact same thing, they might have felt similar emotions before.

When your family and friends learn you have a spinal cord injury, they might also feel shocked, worried, helpless or stressed out. They might just not seem like themselves. We all have different ways of coping.

It can be tough when you’re used to doing things on your own, and suddenly need help from your parents or family members with everyday things like eating or getting dressed. It might make you feel you’ve gone backwards to a younger version of yourself.

But letting your family help you when you need it is okay. It’s still important to be involved in decisions that are made about you, that you feel listened to, and that you get time alone when you need it.

Your family cares about you and they can be a good place to get support. They can offer emotional support, like talking with you and going to the doctor with you. They can help you in a practical way, like sharing their own ways of coping with tough emotions or going with you to social events.

“It’s easy for me to say, looking back on it, that you shouldn’t push [away] your family and friends, as much as you want to, as much as it’s hard to let them in. Obviously, when you’re in a dark and depressive place you can’t see any other way out. But pushing your friends and family away is a big mistake because you need them there.” **Ben, aged 17**

When you’re in hospital, being away from your friends can be hard. They can make you feel better when you’re going through a tough time. But you may also feel distant because you can’t see them or talk to them online. You may have some friends who have gone quiet, perhaps because they don’t know what to say or are afraid of saying the wrong thing. If this happens, you can explain to them how they can help or answer questions they have about your spinal cord injury.

When something big happens in our life, it can sometimes change our relationships with people. But talking about it can help us understand each other better.

You can stay in touch with your family and friends by sending messages, letters, video calling or having visits.

Maybe your friends can tell you what’s going on at school, or you can share shock emojis when watching your favourite TV show.

If you’re struggling to use your phone or laptop on your own because of your injury, there are people that can help you with that. Just let us know if you’re interested in finding out more about it.

If you feel like you don’t have any family you want to talk to, don’t worry. You’re not alone. You can talk to a doctor, another medical professional you trust, or contact Back Up they’re here to support you!



GOING BACK TO SCHOOL, COLLEGE OR UNIVERSITY

You might be feeling unsure about going back to school or education. You probably have lots of questions. You might be worried about being treated differently by teachers and friends, wonder how you will get to the toilet and classrooms, and if you can go on trips.

It can be scary settling back into school or college life after your spinal cord injury, but there's support available for you.

You might get asked lots of questions by different people. It's okay to say if you're not comfortable talking about something. If you do, that's great because you can help others understand your situation. Sometimes it can be quite scary or overwhelming if you haven't been in school, college or university for a while. So talk to your friends, teachers and family about how you're feeling so they can support you.

Speak up if you're unsure about how to access areas or services. It's important you ask for support if you need it. This doesn't make you weak; it's a strength because you're brave enough to speak up and get the help you need to achieve your best.

You have a right to be included in everything during your education. Your voice matters, and your thoughts and feelings should be taken into consideration when figuring out how best to support your needs. You also have the right to access mainstream education, just like anyone else.

"I would say to someone who's just starting out at school after an injury, don't be afraid to say what you want. If you don't like something, say it. If you want something changed, say it."
Laura, young person

Some classmates may not know how to react when you return to school. It may feel strange and uncomfortable if they treat you differently.

Often, other students are happy to have you back and want to make you feel welcomed, but don't know what to say or how to react.

At Back Up, we can go to your school and talk to your teachers and classmates about spinal cord injuries. We can do this before you go back or whenever you feel ready. We'll only include information that you want us to. So if you want us to talk about asking people not to push your wheelchair, we'll focus on that during our presentation. We'll always be led by you.

"Try to just be yourself. You are still the same person, but with a spinal cord injury. Be honest – if you're upset or overwhelmed, speak to someone who can help you overcome the situation." **Hannah, aged 20**

- Back Up has worked with many children and young people with spinal cord injuries who have gone back to school, college or university. They've shared their experiences with us – how it felt, what worked well and what could have gone better. We can:**
- Help your teachers and classmates understand more about spinal cord injury.
 - Keep in touch with your hospital and education provider to prepare for your return.
 - Visit your school, college or university and support you in meetings, deliver assemblies, and make sure you have the right support to meet your needs.
 - Make sure your voice and experiences are heard.
 - Provide advice and support with our free, online Education Inclusion toolkit.

LEAVING HOSPITAL

If you've been in hospital for a while, it's common for doctors to suggest that you have a few visits home before fully leaving hospital. These visits could be a few days or a weekend and can help ease you into returning home, so it doesn't feel abrupt.

Leaving the hospital can be an unsettling time. It's okay to feel unsure about what happens next. You may feel excited and relieved to get back to your own bedroom and be around your family more, but you may also worry about not having the same support that you currently do in hospital. It can be a strange feeling when you first come home because hospital can feel like a safety net as there's lots of support there.

It's normal to feel a range of emotions and thoughts about leaving hospital. You'll continue to have lots of support, and we can help make sure that the right support is there for you when you get home.

- Some questions you may have include:**
- What happens now?
 - Is it safe for me to return home? Has my home been adapted if needed?
 - What happens with my therapy?
 - Will I still see a physiotherapist/occupational therapist?
 - Will I still have the support I need at home?
 - Will people see me differently?
 - Will I be asked lots of questions by my friends/family? How do I answer them?
 - What activities/sports can I do?

It's a good idea to write down any questions you have about leaving the hospital. Your medical team will help you plan for leaving hospital and keep you informed every step of the way.



Remember that Back Up is here to support you throughout your journey with a spinal cord injury, and there are lots of other organisations that can help. If you have any questions or would like to speak to another young person who's been through a similar experience, just let us know.

"Obviously because you're in hospital, it doesn't feel real. Going home was a big thing for me because I'd been relying on nurses for so long. Being home meant that I now had to do things for myself, which was a bit scary."

When you first get home, remember to take things slowly. Start with small steps like going to the supermarket and work up to bigger trips out. You may face new challenges that weren't there in hospital, like uneven pavements or needing to know where accessible toilets are. Adjusting to this new environment will take time, but you'll get there. After all you've been through and learned in hospital, you already have many of the skills and tools for overcoming these new obstacles.

It's okay to have bad days. Try to focus on the positives and remind yourself how far you've already come. Tomorrow is a new day and you can try again.



WHAT SUPPORT IS AVAILABLE TO ME?

There’s a lot of information out there about spinal cord injury and services. **It can be a lot to process, and hard to know what’s helpful and what isn’t!**

BACK UP SUPPORT

At Back Up, we have lots of different services to help you after your spinal cord injury (and for your parents and family members too).

We’re a charity. You may not have heard much about charities before or are unsure how they work. Essentially, we’re a network of people who understand what it’s like to have a spinal cord injury. When you feel ready, we are here to make things a little bit easier and even have some fun!

We have a lot of ways to help you. Here are some things we can offer:

- **Youth Break Out Lounge:**
You can talk to us online and get help from home.
- **Courses:**
You can try out fun activities and feel more confident.
- **Wheelchair skills training:**
You can learn how to do important things in your wheelchair so you can be more independent.
- **Wheelchair skills app:**
The app offers a series of short videos, so you can practice using a wheelchair wherever you are.
- **Education Inclusion support:**
We can help you get back into education and make sure you get the support you need.
- **Mentoring:**
You can talk to another young person who understands what you’re going through.
- **Volunteering:**
You can help and support other young people.

If you want to know more about any of these services, you can go to backuptrust.org.uk or ask us for our young people’s services brochure.



OTHER SUPPORT

When you leave the hospital, you’ll still have help from doctors and follow-up tests to make sure you’re doing well. If you have questions about your spinal cord injury and your health, you can ask your medical team or the centre you were treated at.

Once you’re back at school or college, your teachers and staff can also help you. They might have a SEND (special education needs and disabilities) team at your school, or a disability inclusion team at university. There may also be a well-being or mental health team that can support you.

Many young people say that getting involved in sports really helped them adjust after their spinal cord injury.

It may not be the same as before, but there may be other sports you find you enjoy now. From basketball to rugby, there are a whole range of sports you can get involved in when you have a spinal cord injury. You could join a sports club and meet new people too!

If you want to learn more about something specific, even if it’s not something we provide at Back Up, we can tell you where to look.

Here are some things you might want to find out more about:

- Local activities or sports.
- Jobs or work experience.
- Mental health support.
- Relationships and puberty.
- Books and TV shows that include spinal cord injury.
- Learning to drive.
- Moving from children’s to adult services.
- Living independently.

REMEMBER, YOU’RE NOT ALONE.

There are many people who have gone through similar experiences and can help you adjust to life with spinal cord injury.

We’re here to support you as you grow up and live the life you want. Talk to us about how we can help – we’re a friendly team with lived experience and we’ll make sure the support we offer is unique and specific to you.




You can call us on **020 8875 1805**, email childrenandyoungpeople@backuptrust.org.uk, and apply to access our support. **We’re excited to hear from you!**





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