



back up
transforming lives after spinal cord injury

Parent Guide

Life after spinal cord injury

What to expect after spinal cord injury

Preface

This guide has been written in collaboration between our children and young people’s team at Back Up, and parents of children affected by spinal cord injury.

Back Up are a national charity that support and inspire people affected by spinal cord injury to get the most out of life. We support children, young people, and their families to rebuild their independence and confidence after a devastating spinal cord injury.

Introduction

Let’s not beat around the bush: spinal cord injury or damage can be devastating and life-changing. But we believe it shouldn’t stop anyone from getting the most out of life. We wish no parent had to read this guide – but if you are reading it, we hope we can provide you with some helpful information and support. You’re not alone.

We hope you begin to feel that as you read about the experiences and advice from other parents and families throughout this guide.

There is no right or wrong way to feel after your child sustains a spinal cord injury. You and your family will probably think there’s a lot of information to absorb and changes to adjust to. Just remember to look after yourself too. There’s so much support out there to help you find your way through this journey.

“My overriding message would be to stay positive – that life isn’t over.”
Parent



What is spinal cord injury?

When we refer to spinal cord injury in this guide, we mean damage to the spinal cord. That could be an injury through a sports accident or an illness like transverse myelitis.

We're not medical experts and can't give you medical advice. But we can share information, advice and guidance that we have learned while supporting many families like yours.

Every spinal cord injury is unique, so not all the information you read will apply to your child. We've created this guide to give you an overview of things you may want to know more about. We don't want to scare or overwhelm you. But we want you to have access to information if and when you want it.

Some of the facts

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

If the spinal cord is damaged or injured, some messages or impulses may be 'interrupted'. This can lead to partial or total loss of feeling or movement in parts of your body – including your arms, legs and internal organs.

"It was initially very worrying because we didn't know what was happening. Through a process of elimination, doctors worked out that it was transverse myelitis, an auto-immune disease, that had severed her spinal cord at T4 level."

Parent

You may hear of the International Standards for Neurological Classification of Spinal Cord Injury (ISNCSCI) scoring. It's a neurological examination that'll help determine the sensory (feeling) and motor (movement) levels affected by the spinal cord injury. It's challenging to do this examination on a young child, and it's not always very accurate for children under eight years old. Clinicians can show you the test by performing it on themselves, on you, or a doll to make you feel less nervous about it. You'll have a chance to ask questions you or your child may have.

Hospital staff will track your child's injury level and severity. They'll either examine the nerves or use X-rays and MRI scans, giving them a better idea of the injury level.

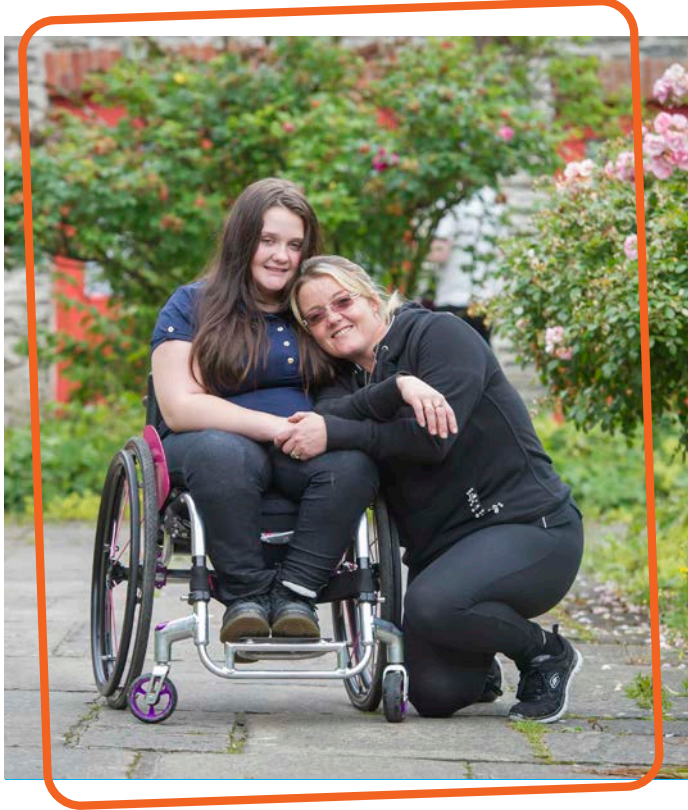
Injury levels

Most spinal cord injuries stop movement and feeling in the body parts below the level of injury.

For example, if you damage or break your spinal cord close to your neck, a larger area of the body will be paralysed than if you damaged your spinal cord lower down your back.

As well as the physical impact of a spinal cord injury, there are emotional and psychological effects on the person concerned – and their family.

The diagram below shows the parts of the body that are affected depending on the level of injury. This will vary depending on the degree of damage to the spinal cord.



The early days in hospital

The first few days in hospital can be daunting and exhausting.

If you're spending time at the hospital with your child, you may find yourself juggling lots of things. That could be a job, caring for other children, and coping on little sleep while you stay close to your child's bedside. It might all feel physically and emotionally draining.

Navigating the early days

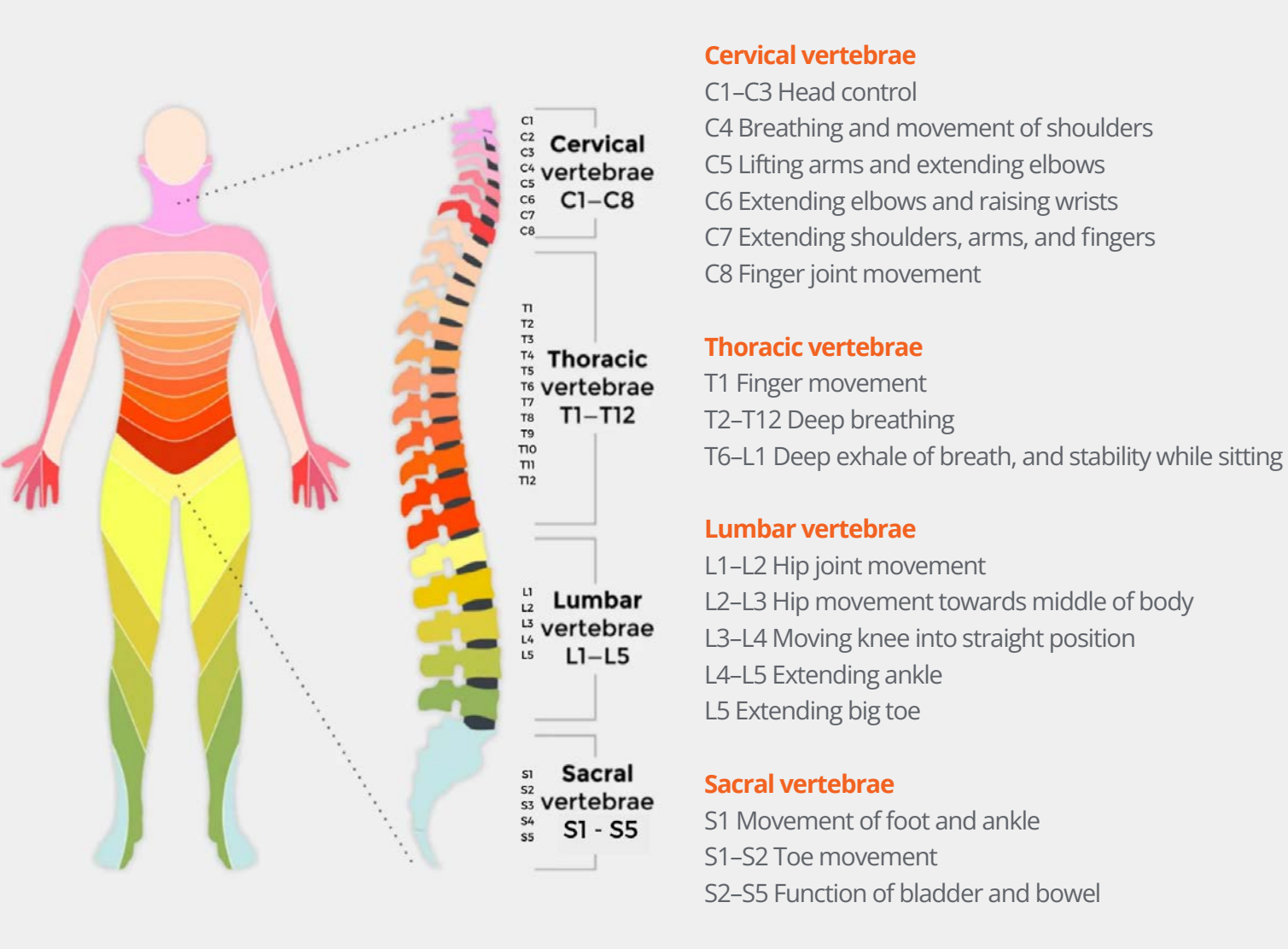
There's an awful lot of information to take in during the early days in hospital. You may also be in shock about what has happened. This is completely normal. Other family members, including you or your child's other parent/guardian, may have also been injured at the same time as your child. Later in this guide, we have a section that covers some of these things you may want to know more about. But at the beginning, you might feel you're in survival mode.

You can usually stay overnight with your child in hospital. If staff haven't already offered, ask them to give you an extra bed or mattress. We understand, though, that not all parents can stay at hospital with their child. You may have other children to care for or need to be at work – and being apart can be tough for both you and your child.

Caring for other children and/or dealing with the financial stress of being out of work can be really challenging. Some places offer emergency grants for things like travel to the hospital or accommodation. Let us know if you'd like help with applying for these.

Tell us if your employer's putting pressure on you to go back to work or if there are any disputes with them about being out of work to support your child. We may be able to help with writing a letter of support or direct you to letter templates from legal support organisations.

Don't forget to look after yourself. Perhaps think about taking some time away from the commotion of monitors and machinery or leaving the hospital grounds for a short while altogether. It can give you time to gather your thoughts and take a breather. **You're better positioned to help and support your child if you also look after your own needs.**



Asking questions

Note down questions you have. You may have limited time with your child’s consultant or have difficulty remembering everything you want to ask. So writing questions down as they pop up can be helpful.

“Don’t just take everything at face value – ask questions, and if something doesn’t feel right, then trust yourself. You are with your child a lot of the time, so you will notice the little things that can get overlooked sometimes. Don’t be afraid to ask what’s happening and what medication is being given to your child. I’d encourage any parent to ask ‘why?’ if you don’t understand something.” **Parent**

Whether you prefer to write your questions in an email or a list on your phone, do whatever feels easiest for you. You can also ask that professionals send you a summary of appointments (if there are things you want to remember or need to do) afterwards. You can then request that every department and/or consultant you’re working with copies in all other relevant people in emails and letters (give them a list of your key contacts). That way, everyone always knows what’s going on, and you have it in writing to refer to later.

The following departments might support your child:

- Physiotherapy
- Occupational therapy
- Psychological therapy
- Neurology
- Urology
- Orthotics
- Nursing
- Speech and language therapy
- Dietician
- Play therapy
- Teacher

“Ask questions, even if they seem obvious. Sometimes the answers are not what you expect, and if you don’t understand the answer, don’t be afraid to say you don’t understand and ask if it can be explained a different way. A good consultant will do this.” **Parent.**

What equipment should my child be using?

You’ll probably come across equipment you’ve never heard of, from monitors to specialised mattresses. The hospital equipment is usually being used to make sure the spine is stable. It will also manage any medical or surgical condition, so your child is as healthy as possible before looking at rehabilitation.

A few questions you may have, and could write down to ask the medical team, include the following:

- Will my child need a wheelchair?
- What will it look like?
- How much is the wheelchair likely to weigh?
- Will my child need a pressure-relieving cushion for their wheelchair?
- My child is really young – are there specialised pushchairs that are available?
- Is my child using a specialised mattress so they don’t get pressure sores?
- What equipment do they need for sleep positioning?
- Do I need equipment/training to move my child from their bed to a chair (e.g. hoist/slide board)?
- Will my child need an adapted toilet/shower chair?
- What equipment/training do we need for bowel and bladder management?

If you want to ask us questions, Please get in touch by scanning the QR code here



How do I tell my child about their spinal cord injury?

There’s no easy way to have this conversation. You may want to be with your child when a medical professional tells them about their spinal cord injury. Or be the one to tell them. This will depend on many things, from your child’s age, your circumstances, and what feels most appropriate for your family.

Talk to your child in language they understand. It’s important to respond gently but truthfully, especially when something doesn’t move or they can’t feel a part of their body. Talk about what has happened – little and often. This will help them digest everything and the impact of their injury. Help your child focus on their abilities and how to work with this going forward.

Children cope with trauma in different ways. Acknowledge your child’s emotions and listen to what they’re feeling. As a parent, your comfort, support and reassurance can be really important in making your child feel safe and able to express their feelings.

It’s normal for both you and your child to have a lot of questions. The whole family will have a lot to learn, and it’s okay not to have the answers to everything. We’ve created a similar guide to this one for young people, so ask us if you haven’t got a copy. Seeing their parent upset can be distressing for your child, so you may feel pressure to keep your feelings bottled up. But you must get support too. Make sure you have a place to process your own emotions – see section 2: Psychological support and support networks.



Vocabulary you may hear

Some terms healthcare staff use may feel overwhelming or confusing. We're explaining these terms to make sure you understand what they mean and know how to help minimise some effects of spinal cord injury. Talk to your child's medical team if you want to know more or have questions. **You can also get support from us.**



Autonomic dysreflexia (AD) and temperature regulation (poikilothermia)

The charity, Spinal Injuries Association, summarises this condition: "Autonomic dysreflexia is the name given to a condition where there is a sudden and potentially lethal rise in blood pressure (BP). It is your body's way of responding to a problem. It is often triggered by acute pain or some other harmful stimulus within the body. It is unique to spinal cord injury and most commonly affects spinal cord injured people with injuries at or above T6."

You can often manage AD episodes by locating and solving the root of the problem, for example, needing to empty the bladder or bowel, or relieving a pressure point. Depending on your child's injury level, they may be prescribed emergency medication if the problem can't be easily solved.

Children with cervical (C1–C8) and high thoracic (T1–T12) spinal cord injuries may have trouble regulating their body temperature. Your child's body temperature may change depending on the room temperature. Body temperature will drop in the cold and rise in the warm.

- With this in mind, there are things you can do to stop their body temperature from varying too much:**
- Make sure they're wearing appropriate clothes for the temperature.
 - Use a fan or cooling blankets in warmer weather.
 - Have regular breaks to warm up after being outside in the winter.

Autonomic system

In contrast to the sensory system, the autonomic nervous system is made up of motor neurons that control our automatic functions. Examples are:

- Our heart rate.
- Breathing.
- Digestion.
- Other bodily processes that we don't have to think about.

It has two systems that work together to maintain balance – sympathetic and parasympathetic. Spinal cord injury disrupts both systems to varying degrees.

Bladder management

Spinal cord injury affects the messages and impulses that go to and from the brain to all areas of the body (or 'interrupts' them). This may mean your child struggles to know when their bladder is full and needs a catheter to empty it. A catheter is a tube put into the bladder to drain urine. Your child may need to establish a routine to manage their bladder, such as how frequently to empty it with a catheter.

Bone health and bone density

Bones can weaken straight after spinal cord injury and continue to weaken for several years after the injury. Osteoporosis is the medical term for weakened bones. Some measures can be taken to protect against bone density loss, e.g. using standing frames and a vitamin D supplement.

Bowel management

Similarly to bladder management, your child may need to establish a bowel routine to help empty their bowel. You can do this through medication, such as suppositories (put into the bowel where they dissolve or melt to soften and lubricate the stools). With support from your child's medical team, your child or an appropriate caregiver can then manually remove stools (using a gloved, lubricated finger to gently remove the stools to be passed).



Physiotherapy

Physiotherapy helps people restore and maintain joint movement and muscle flexibility. It uses exercises, massages, heat treatments and stretching. The degree to which this can help will depend on the severity and type of your child's spinal cord damage.

This treatment uses knowledge of how the body moves to identify what isn't working. It can help to keep your body in good shape after a spinal cord injury.

Physiotherapy also allows you to return to or relearn ways to move and avoid any stiffness or pain.

Pressure ulcers (or sores)

Spinal cord injury can mean your child is more likely to get pressure sores. This is because they can't move much, have low levels of sensation and reduced blood flow. Skin ulcers can form when there's pressure on the skin over long periods.

You can prevent pressure sores by:

- Reduce pressure regularly by changing positions, or taking off weight from the pressure point.
- Using an appropriate pressure-relief cushion.
- Periodically checking the skin.
- Knowing the early signs.

Chat with your nurse to find out more.

Rehabilitation

Rehabilitation involves helping your child:

- Learn to take care of their body.
- Make the most of their independence.
- Cope and adjust to their disability.
- Have a healthy, active lifestyle.

Rehabilitation can last for days, weeks or even months.

Scoliosis

Scoliosis is where the spine curves to the side. It can happen because of a change in how the muscles around the spine and trunk (main part of the body that holds all of the internal organs) work. Examples of things that try to prevent or minimise scoliosis are corsets/body braces and moulded wheelchair backs. You can learn more on the NHS website.

Sensory system

The sensory nervous system is made up of motor neurons that make the skeletal muscles move. They are voluntary, meaning you control how and when they work.

Spinal shock

Spinal shock is a temporary condition that can happen immediately after a spinal cord injury. The spinal cord stops working normally, causing a loss of reflexes and tension of the muscles in the rectum below a particular level.

Standing frames

A standing frame is a piece of equipment that supports someone to stand in an upright position. You can use them in the home.

Standing frames are especially helpful for children to:

- Keep their bones strong.
- Encourage hip development.
- Increase their metabolism.
- Help with bowel management.
- Grow.

Standing frames also have psychological benefits.

Bracing

A brace worn over clothing controls the spine's position by holding the parts of the body in place. It also corrects posture. Your child may be at risk of scoliosis after spinal cord injury, so they might wear a brace to hold their torso and prevent their spine from curving.

Functional electrical stimulation (FES)

This treatment applies tiny electrical impulses to nerves or muscles to help the muscles and improve strength.

Hip dysplasia

Developmental dysplasia of the hip (DDH) is a condition where the 'ball and socket' joint of the hip doesn't properly form in babies and young children (NHS, 2022). It can develop in children who sustain an injury at a young age. Splints can prevent it, or physiotherapy can help reduce the risk of developing DDH.

Hypercalcemia

In children with spinal cord injury, high calcium levels can sometimes occur. This happens as the calcium comes out of the bones and into the blood. It leads to a fever, but can be treated with medication.

Motor system

The motor system is the complex system that controls our body movement. It's responsible for controlling voluntary movements, as well as unconscious processes such as breathing.

Muscle spasms and spasticity

This is the uncontrolled tightening or contracting of the muscles, often called 'spasms' – and they're common in people with spinal cord injuries. An example is an involuntary movement, like leg juddering or uncontrollable foot movement. Some things can help reduce it, such as physiotherapy and/or medication.

Occupational therapy

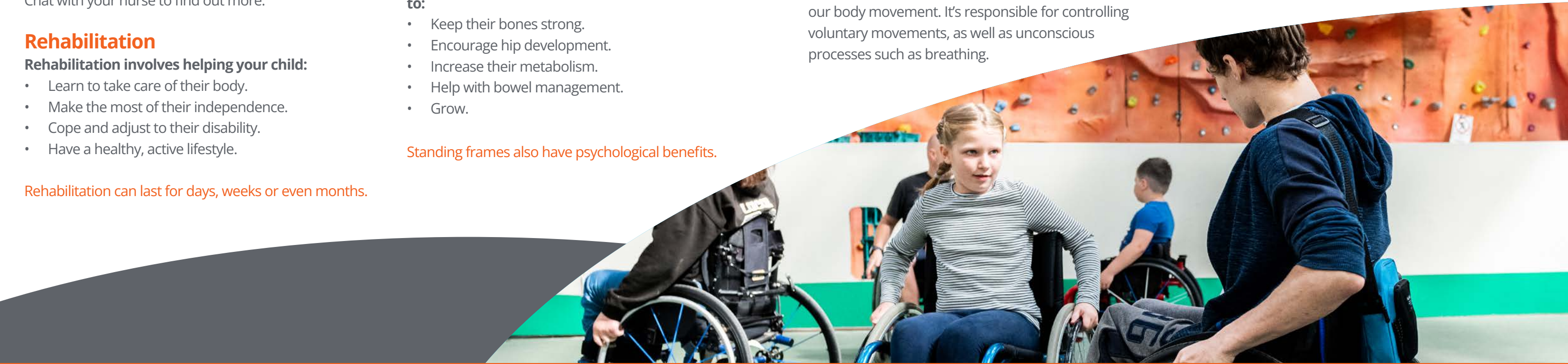
An occupational therapist can help your child with everyday tasks they struggle with because of their spinal cord injury.

Pain management

Your child may experience pain after spinal cord injury. They might feel pain in parts of the body that still have some sensation or feeling, but also in areas with little or no feeling. There is no one-size-fits-all. You can speak with your child's medical team to learn how to manage their pain.

This could be through a combination of:

- Physical treatment (like stretching and motion exercises).
- Medication.
- Psychological therapy.



Top tips from other parents

- Don't be too hard on yourself.
- If you're having a bad day, it doesn't mean the next day will be bad too.
- Accept as much help as you're offered in all areas.
- Have a holistic approach to healing – considering all aspects of the body, mind and spirit.
- Rest, eat and drink plenty of water.
- Find people to talk to that understand and have experience of the stage of your journey (The Back Up Lounge, Back Up mentoring, Facebook groups).
- Don't try to solve every problem all at once. Focus on one or two things and set achievable goals.
- Involve your child in (age-appropriate) problem-solving.
- Try not to say, 'we can't do this,' but ask, 'how can we do this?'. If it still seems impossible, ask the people who have been there before you – there's always someone who has a solution of one sort or another.
- It may feel like doors have been shut, and it's normal to grieve this. That grief will come and go even years down the line. But it's also true that many other doors will open to new experiences, friends and opportunities. Focus more on the open doors ahead of you than the closed ones behind you (not always easy!)
- Don't overthink – try to stay in the here and now.
- Talk and reach out.
- Speak to people already on the journey.
- Don't look too far ahead to problems you don't need to solve yet. And take time once in a while to reflect on how far you've come. You will surprise yourself.
- Don't give up! You are your own best advocate – you know your child and their needs.
- It will be okay.



Final word

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

Do 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. Please get in touch by scanning the QR code here



If you would like to access our free, online toolkit with lots more practical information on topics including housing support, returning home, adaptive support, emergency funding, and many more please visit our website or reach out to us for guided support. This diagram shows the range of topics we can support with:






The Spinal Cord Injury Journey





Back Up
4 Knightley Walk
London
SW18 1GZ

Tel: 020 8875 1805
Email: admin@backuptrust.org.uk

 [backuptrust](https://www.facebook.com/backuptrust)
 [@backuptrust](https://twitter.com/backuptrust)
 [@backuptrust](https://www.instagram.com/backuptrust)

Contact our children and young people's services

020 8875 1805 or
childrenandyoungpeople@backuptrust.org.uk

Please get in touch by scanning the QR code here



Registered with
**FUNDRAISING
REGULATOR**