



back up
transforming lives after spinal cord injury

Family Support Services

Helping the whole family adjust to life with a spinal cord injury

An introduction from Richard



Richard and his wife, Zoe

A spinal cord injury in the family can be devastating, but you are not alone. In this leaflet, you can read other families' stories and find out more about how Back Up's services can help you all adjust to this new stage in your lives.

Richard, age 40, talks about how his family's life changed forever when his wife sustained a spinal cord injury in 2011.

“ Zoe sustained her spinal injury when she was in hospital recovering from routine spine surgery. There was a miscommunication between the staff on the shift change and Zoe was moved when she needed to be kept still. Her unstable vertebra severed the spinal cord at the T10 level.

I accessed Back Up's mentoring service when I was having some anger issues. Speaking to another partner and finding out we are not the only people in this situation really helped. It is such a vital service. ”

Do family members need support?

Sometimes it can be hard to acknowledge that we need help when we feel the focus should be on the family member with the injury.

Richard shares his thoughts on why family members can benefit from support.

“ When spinal cord injury first entered our lives, I didn't want to speak to anyone. I imagine that's how a lot of people feel. But soon I had to accept that this was affecting me, whether I wanted to admit it or not.

It is so easy for family members to be overlooked. It is easy to slip into loneliness and isolation. But that isn't how it has to be. Family and friends do need to talk to someone and not be neglected. You can shoot the breeze with someone who knows all about the practical stuff and how it feels. That's essential. ”

To find out more about how Back Up can help, including matching you with a family mentor to speak regularly on the phone and/or attend a Family Support Morning at various spinal units, please get in touch with our family support team at familysupport@backuptrust.org.uk or call 020 8875 6721

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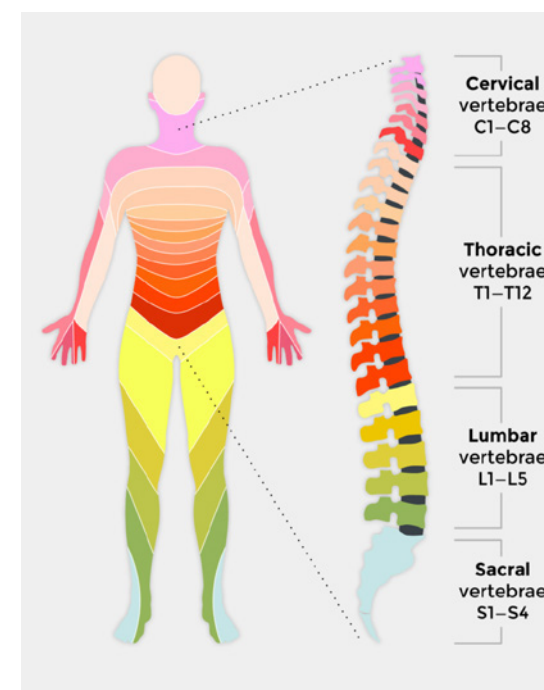
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What is a spinal cord injury?

There are an estimated 60,000 people in the UK living with a spinal cord injury and each year over 2,000 people are newly injured.



The spinal cord is a bundle of nerves and other tissue which extends from the brain's base at the top of your neck down the length of your back.

If the spinal cord is damaged or injured, some of the 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 limbs and your internal organs.

Visit www.backuptrust.org.uk/spinal-cord-injury/what-is-spinal-cord-injury to find out more.



Leonie's story

Leonie's daughter Lucille was an adventurous 5-year-old when she sustained a T9 level spinal cord injury in a road accident.

“Being plunged into a bewildering new reality was really difficult. Lucille had been a very adventurous and active child before the accident, and I struggled to cope with her potentially losing that.

We first met Back Up on the children's ward. They were very positive, which is what is needed, but initially I didn't want to be part of that world.

Later on, I did contact Back Up when I felt overwhelmed by the transition process. I was paired with a mentor who helped me to see that Lucille can achieve whatever she wants. To hear that was such a relief, and it was remarkable to share the pain and even laugh at times with another parent who understood. Back Up have supported Lucille at school too, and this has been hugely significant for her. Every child should feel they have a future full of opportunities, and Back Up gave this back to Lucille.

We are still rebuilding our strength, but we share a lot of very happy moments together. ”

Mirka's story

Mirka's partner, Martin, sustained a C6/7 level spinal cord injury in 2014 when he was involved in a crash cycling home from work.

“ When Martin came home from hospital, I called Back Up. I had been functioning fine till then but I really wanted to know the practical stuff, and how other people dealt with what we were going through.

I got put in touch with a great mentor who didn't sugar coat things. They were living a fully functioning life, but they still had their struggles.

When she said, “it does get better,” something just clicked. When you're in a rut and you have no one to talk to, someone who has gone through it saying that to you is so important. That's when things started turning around.

I did have counselling in the early days, but it didn't work for me - the lady didn't have experience of spinal cord injury. It makes a huge difference when you speak to someone who knows what you're going through.

Before his accident, Martin and I lived separate lives. We have become much closer and stronger. We've also just had our first daughter. We were really lucky that the IVF worked for us. She's given us such a boost. ”





Pip's story

Pip's sister Holly was 23 and teaching at a surf school in Morocco when she fell from a terrace and sustained a T8/9 level spinal cord injury.

“ Holly injury rocked our whole family. We're a tight-knit unit of six and I'm one of four sisters – Holly being the youngest. We visited her regularly during her rehabilitation, but I just remember this overwhelming sense of guilt all the time. I felt guilty when I didn't go to visit Holly, and guilty when I went home after the visits.

A few years later, I applied to become a family mentor. The training weekend was the first time I had ever met anyone else who had a loved one with a spinal cord injury. I felt I could talk openly about Holly for the first time, and it has really changed our relationship for the better. I wish I had just found Back Up sooner because that weekend had such a positive impact on me.

Life is so fulfilling for our family now. Everything that felt overwhelming and totally daunting has become so normal. We no longer think that spinal cord injury is something that destroyed Holly life. Back Up made us realise that. We always find ways to get around things and life is full of fun and laughter. ”

Sarah's story

In early April 2012, Sarah's mum woke up to an unusual pain in her back. Within days, Sarah's mum was in surgery to remove a tumour from her spine which damaged her spinal cord at the C6-T5 level.

“ Mum was very active and in control, so the injury changed everything. Initially it was hard for us all because mum was used to looking after me and my brother, and that role was flipped dramatically.

It was Mum who suggested I get in touch with Back Up. I mainly called up just to stop her worrying about me, but it turned out to be a really positive decision. It was great to have a mentor who understood the situation first hand and knew exactly what it's like to be a child of someone with a spinal cord injury.

I was reluctant to seek help at first, but I realised that I wouldn't be able to help my mum and family if I wasn't also looking after myself.

My mum appreciated the fact that I sought support too. In a strange way, it helped give her peace of mind. Our relationship was strong before the injury and still having that closeness is really important to me. ”





Family support

Our family support team are here to help you to adjust to your loved one's spinal cord injury. Working with volunteers across the UK, we visit spinal centres and provide support to family members.

The team are also available to listen, support, or offer advice to anyone who gets in touch. We can share our own experiences and advice on all sorts of different topics like taking time for yourself, or travelling with your family member.

Family mentoring

Our family mentoring service matches the loved ones of people with a spinal cord injury with trained mentors who have been through similar experiences and can understand the challenges faced. They're here to listen, offer advice, and support you to make positive changes in your life.

We have trained volunteer mentors who are parents, partners, siblings and children of people with a spinal cord injury, and we will match you with someone who has been through similar experiences. Whether you want to discuss looking after yourself or you need practical advice, we'll pair you up with someone who can genuinely understand and who can help you work out the best way to move forwards. You can refer yourself directly for mentoring via our website: www.backuptrust.org.uk/support-for-you/mentoring



**To find out more,
please contact our
family support team
at [familysupport@
backuptrust.org.uk](mailto:familysupport@backuptrust.org.uk) or
call us on 020 8875 6721**

Other services

As well as our support for families, we offer a wide range of services for people with a spinal cord injury. Whether your family member wants to find out more about returning to work, improving their wheelchair skills or just to speak to someone in a similar situation, Back Up is here to help.



Wheelchair skills:

From pushing technique, getting over obstacles and up kerbs, to back wheel balancing and transfers, our manual and power chair sessions are tailored to help people with a spinal cord injury live the life they want.

Courses:

We offer a variety of different residential activity courses which help people learn new techniques and develop confidence in a supportive environment. We also offer an online 'What Next' course for people in the early stages of life with SCI.

Outreach and support:

Back Up provide proactive telephone support from people with a spinal cord injury who can empathise and understand.

Back to Work Service:

Returning to work is evidenced to be good for health regardless of level of injury. If you would like support talking to your relative's employer, give us a ring.

Young people:

We offer residential activity courses specifically for under 18s that give them the opportunity to challenge themselves and become more independent in a safe environment – all while having a lot of fun.

Education support:

Back Up supports children and young people with a spinal cord injury to settle back into education, and at any point when support may be needed.

Mentoring:

Our mentoring service is available to people with a spinal cord injury as well as family members. Our trained mentors can support your family member to move forwards with their life.

Back Up Lounge:

The lounge is an online forum open every other Wednesday from 6pm-7pm for everyone aged over 18 (also separate youth lounges) affected by spinal cord injury, where no conversation is off limits. At each lounge there is a specific family breakout room.

If you'd like to find out more about the support we can offer your family member with the injury, please contact our outreach team at outreachandsupport@backuptrust.org.uk or give them a call on 020 8875 1805



Frequently asked questions

What sorts of things can I speak about?

The team at Back Up are more than happy to talk about anything related to spinal cord injury, and we will endeavour to offer advice and support on a wide range of issues.

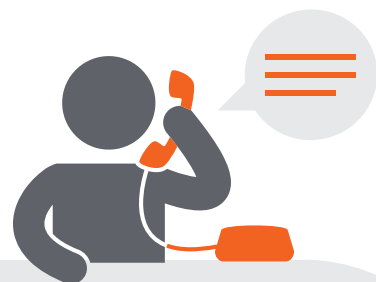
On occasion, we may need to refer you on to other organisations if they provide more appropriate support in an area outside of our remit.

More than one person in my family would like help. Can you support us both?

If two or more people in your family want to access our support, that's absolutely fine. We won't share what is discussed between you, so you can talk as openly as you want.

How much does it cost?

The family support service is completely free to anyone who needs to use it.



I don't have any specific questions, but I want to speak to someone. Can I still call?

Yes. We understand that you may just want to have a chat with someone in a similar situation. The conversation doesn't have to have a specific agenda.

Is everything I say kept private?

All conversations with members of Back Up's team are confidential, except if there is a safeguarding concern about serious harm to you, or someone else. In this case, we may need to involve other services, such as your GP.

I don't think I need help, can you support my loved one?

If you are interested in exploring support for yourself or anyone else in your family, you are welcome to get in touch. We cannot contact anyone without their consent, but

we can talk about what options may be available so you can discuss them together.

It's been a while since my loved one was injured. Can I still call?

Yes. At Back Up, we know that managing a spinal cord injury can throw up different questions at different stages of your life. Whether your family member sustained their injury recently or thirty years ago, we are happy to talk about anything you wish to discuss.



Get involved

If you'd like to support Back Up, there are many ways you can get involved and make a vital contribution towards our work.

You can have fun and develop new skills by becoming a Back Up volunteer. All our volunteer roles are challenging, fun and incredibly rewarding. You could use your experiences to support other family members, help out on our courses, or assist the team in the office.

You could also raise funds for our work by taking on a challenge, raising money in your community, or attending one of our fundraising events.

If you'd like to find out more about fundraising or volunteering at Back Up, please visit our website at www.backuptrust.org.uk/get-involved or call us on 020 8875 1805



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