



back[↑]up

transforming lives after spinal cord injury

A GUIDE TO OUR SERVICES

2021-2023

Welcome



You're not alone. Every service described in these pages has been designed to help you adjust to living with a spinal cord injury.

We're here whenever you need us, be it days after diagnosis or years. Whether you're the person with the injury or illness or a family member. Whether you want to get to the local shop or abseil down a rock face, get back to work or get back to being you. Any age, any ability, we're here for you.

If you'd like to find out more, get involved or simply talk to someone who understands, call us on **020 8875 1805**, visit **www.backuptrust.org.uk** or scan the code below to register.

Kevin Filby, **Director of Services**



“Why me?” “I’m scared.”

“How am I going to live my life?”

Adjusting to life with a spinal cord injury is tough. We know because at Back Up all of our services are run and delivered by people who are affected by spinal cord injury. At some stage, we've asked ourselves these same questions.

Why we exist

Back Up is a national charity that inspires people affected by spinal cord injury to get the most out of life.

We support people across the UK to rebuild their confidence and independence.

Our services are designed and delivered by people affected by spinal cord injury, delivering vital support to individuals and families in a similar situation.

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Outreach Team

We understand that the transition from hospital to home can be challenging.

Back Up's services are available to everyone with a spinal cord injury and their family members. Our outreach team all have a spinal cord injury so they understand the challenges faced. Every member of our family support team has a family member with a spinal cord injury.

Having 'been there' ourselves, we use our own experiences to listen, offer helpful advice and work with you to achieve your goals.

Using personal experiences and decades of knowledge of living with a spinal cord injury across the team, we can provide you with advice on travel, driving, bladder and bowel management, work or leisure or anything else you may want to ask. We can recommend other Back Up services we think you may benefit from, including our mentoring service and courses, we can also signpost you to other resources that could be helpful from our partner charities.

If you just need to talk to someone who understands what you're going through, we're here and ready to listen.

**Our phone lines are open from
9am-5pm, Monday-Friday.**



93% of people
receiving outreach
support felt more
positive about the
future as a result of
the contact.



"It's always good to get a call and hear from someone who's been through this (spinal cord injury) too. A bit of support when needed the most."

Ex Glasgow patient

"Helpful to be able to bounce ideas about stuff with somebody you can talk to easily and has lived experience. Not being pushy, which is great. Strongest part of the support is that it's delivered by peers who have a spinal cord injury themselves."

Ex Sheffield patient



Call the outreach team on 020 8875 1805 or email us at outreachandsupport@backuptrust.org.uk

Mentoring



Adjusting to life with a spinal cord injury is hard. A mentor can help you to move forward.

You can connect with someone who has been in a similar situation to you with our award-winning mentoring service.

The service will connect you to a volunteer mentor who has a spinal cord injury via our online platform. Mentoring is available to people of all ages, all over the UK and takes place over the telephone.

Your mentor will have been through a similar experience to yourself and will have been trained by a clinical psychologist. Your mentor is there to listen, offer advice, and support you to make positive changes in your life.

We have mentors of all ages, genders and levels of injury. This includes people who can walk as well as manual and power wheelchair users. They are all ready to offer you life-changing support. We also have a dedicated mentoring service for family members, please see page 8 for more information.

98% of mentees
feel more able to cope
with their situation
after mentoring



"A lot has changed since I started speaking to Carley, both externally and in my understanding of my thoughts and emotions. I struggle with less anger than when we began and talked through different coping mechanisms for some of the feelings, which have helped since implementing them. I have also started to be less harsh on myself and my achievements which is all thanks to Carley."

Giselle, mentee

"It's given me the realisation that I am not alone and that people are in a similar position and have overcome different challenges. My mentor just gave me a channel to ask questions and get advice from someone who has been living with a spinal cord injury for a long time."

Mark, mentee



To find out more about mentoring please contact us on 020 8875 1805 or email: mentoring@backuptrust.org.uk

Supported by



Family Support

Supporting family members of people with a spinal cord injury.

We understand that a spinal cord injury affects the whole family and we are here to help. The aim is to check in with you regularly – both during your family member's time as an inpatient, and once you are all home. Our family support service is here for you – regardless of where your loved one is receiving their rehabilitation.

We offer family support sessions at the spinal centres, where you will learn all about spinal cord injury and how it will affect you and your family member's life moving forward. You will meet and hear from our volunteers who also have a family member with a spinal cord injury. Working alongside the healthcare professionals, our family volunteers can give you a 'real life' picture of living with a spinal cord injury, useful information, and advice from their own personal experiences.

If your loved one's spinal centre doesn't offer family support sessions or you would like to talk to someone who understands after the event, our family support team is here for you. All of the team are relatives of someone who has sustained a spinal cord injury, so they know what it is like in the early days.

We also offer a dedicated family mentoring service. Our trained mentors are parents, partners, siblings and children of people with a spinal cord injury.



This genuine understanding means they can share advice and offer much needed support to others in a similar position on many different topics. These include sex, relationships, emotions, employment, managing personal care (including bladder & bowels), pain, or anything else related to spinal cord injury.

You will be matched with someone who suits your needs and who can help you to work out the best way to move forwards.

97% of family mentees achieved their personal goal



"Since speaking with Sam, I feel so much more positive about the future with my partner Phil. I feel more clued up about what to do in quite a few situations such as going on holiday, what to do if something goes wrong, help regarding care packages and what to expect. This is definitely a fantastic scheme and I am so thankful and grateful to the Back Up team and the mentors for offering their time and experience to help me get through probably the most frightening time I've ever had to face. Knowing I wasn't alone and being able to talk to people who understood what I was going through and to tell me where to go and what to do in some situations was such a weight off my shoulders."

Natalie, partner

"When I heard Pete and his son's experiences, I was saddened at times as we (my family) haven't had the same opportunities or confidence. Pete is a lovely guy and he helped me to get things in perspective. His tone and his words were supportive and challenging. I was sad when it finished but I am in a better place and this has put my son in a better place too. Things are better because of my mentoring. As a family, we have hope for the future."

Ali, parent



To find out more about family mentoring please contact us on 020 8875 1805 or email familyoutreach@backuptrust.org.uk

Wheelchair skills training

For manual and power wheelchair users.

Having the skills and confidence to get around using your wheelchair is vital to living the life you want to live. Getting on a bus or train, going out to your local cinema, playing with your children or grandchildren in the park, or something as simple as safely carrying a cup of tea from the kitchen to your living room - these are all skills we can help you learn.

All skills sessions are tailored to the needs of each individual group. Sessions are inclusive of all injury levels and the skills we teach match what you want to learn. We run both manual and power wheelchair training sessions, and all of our wheelchair skills trainers have a spinal cord injury. This means we can draw from our own experiences to find the best way to teach you what you need to know.

We run our wheelchair skills training across three stages:

1. **Wheelchair skills** – sessions in all spinal centres and some general hospitals to introduce you to the basics.
2. **Wheelchair skills extra** – follow up sessions held in towns and cities where you can refine and practise your skills to build confidence when out and about.
3. **Courses** – follow up sessions held on one of our residential courses where skills can be honed further and more life skills can be learnt, such as transferring safely into your car.

Back Up's Wheelchair Skills app features a whole range of videos to help you become more confident using your wheelchair. Covering both manual and power chair skills, search for 'Back Up Wheelchair Skills' in the App and Google Play stores today.

Our wheelchair skills trainers have also produced a range of videos demonstrating certain skills, in lieu of our regular face-to-face training sessions at spinal centres. These are available on our YouTube channel.

To download the Back Up Wheelchair Skills app please scan the below QR code



SCAN ME

App store



SCAN ME

Google Play

To find out more about these sessions and to watch our video collection scan the QR code to the left or visit the wheelchair skills page on our website.



"I am so proud to have been pushed to learn new skills. Most importantly working with others and back wheel balancing. Loved the team and my day. Thank you so much." **Sam, wheelchair skills extra participant**

"The best thing for me was learning how to use a wheelchair to perform everyday tasks such as kerbs, reversing and how to handle the wheelchair. Even though every move in the wheelchair is daunting, it is a wakeup call that we as users need to know what to do to be independent and to be able to go out alone." **Sue, wheelchair skills training participant**

90% of people
found their
confidence increased
after a Back Up
wheelchair skills
session

**Wheelchair skills extra
sessions are supported by**



Courses

Challenge yourself in new ways.

Our UK-wide residential courses are for people of all ages, backgrounds and levels of injury – whether you have a complete or incomplete injury, use a wheelchair or walk, there is a course for you. We also run specific courses for children and young people.

All of our courses aim to increase confidence and independence in a supportive environment. Like all our services, they're led by people who have a spinal cord injury themselves – allowing participants to learn from others who have been there and understand the issues and difficulties faced.

Our courses challenge your perceptions of what's possible in everyday life through a wide range of life-affirming indoor and outward-bound activities that are all fully adapted, so that you can participate as independently as possible. Our courses are also a brilliant opportunity to have fun with others and make new friends. The full programme of courses includes:

- **City Skills** – explore a new city and learn new skills to rebuild your confidence. Experience using public transport, and learn how to tackle different terrains as a wheelchair user.



- **Next Steps** – A course for people with a spinal cord injury who can walk, designed to boost confidence and teach skills for living independently.
- **Skills for Independence** - A course with an intensive focus on your wheelchair skills and general life skills to help make everyday life more manageable and improve your independence.
- **Multi activity** – Do you have a love of the outdoors? Have you always wanted to try abseiling or canoeing? Then our multi-activity course may be for you.
- **Ski courses** – Experience the thrill of travelling and discover the freedom of life on the slopes whilst boosting your confidence and independence in a challenging and exciting environment.

100% of participants
achieved their personal
aims for the course



"The course reminded me of what it was like to feel joy and live for myself. The realisation that I had been stagnating at home terrified me and with the help of my group leader and the Back Up volunteers I came up with a realistic plan to make lifestyle changes when I got home. My husband noted immediately on my return home that I looked healthy and happy. I feel like I have found my pre-injury self and am ready to take on any challenge life presents me."

Charlotte,
Multi-activity course participant

"Absolutely amazing. I've grown in confidence. Wheelchair skills have increased and I am able to go out on my own. The whole course was a big adventure from the start to finish."

Janina, City Skills participant



If you would like to register your interest for any of our courses, please call the courses team on 020 8875 1805 or email courses@backuptrust.org.uk

Vocation service

Skills for Work is about equipping you with the knowledge and confidence you need to work towards your employment goals.

Working is an important part of most people's lives. The benefits that come from working are not just financial – work can be mentally stimulating, offer a sense of purpose and provide vital social interaction, especially when working as part of a team.

We understand it can be incredibly daunting to go back to work or apply for jobs after sustaining a spinal cord injury. Our Skills for Work course gives you the skills and confidence you need when looking to secure work. We can also advise you on how and when to declare your disability, so you receive the necessary adjustments you may need.



If you're thinking about returning to the workplace this course is perfect for you.

- Market yourself more effectively by honing your CV and revealing your talents
- Practise your interview techniques with eight-minute speed interviews
- Receive advice on job hunting
- Get in touch with specialists for benefits and financial support and advice

We want you to learn from others, so listening and supporting each other is encouraged for a shared experience. After the course, tailored one-to-one support covering your goals and aspirations is available to support you further on your journey.

100% of people who have attended a **Skills for Work** course achieved their personal aims for the course



"The course was of a very high quality – I have been on many courses including management training, leadership skills and so on. This was easily one of the best I have attended, with fantastic hospitality from the host company, an incredible venue and interesting and engaging content from start to finish."

Kierson,
Skills for Work participant

"The course was great, I feel much more confident in myself and have been spending time updating my CV and changing my personal profile."

Mariam,
Skills for Work participant



We run several Skills for Work courses around the UK. To find out more, please give the team a call on 020 8875 1805 or email vocation@backuptrust.org.uk

What Next?

‘What Next?’ is a Back Up course which takes place completely online.

It is an online guide combined with live Q&A Zoom sessions and workshops throughout the week.

We know that sustaining a spinal cord injury is just the start of a new journey and that returning home can be lonely and confusing, especially if your rehab has been affected by Covid-19 restrictions.

You will have the opportunity to learn more about spinal cord injury and how to best move forward with life, all in the company of people who know what you’re going through.

The Online Guide is full of information about living well with a spinal cord injury. It will cover the following topics:

- Continence (bladder & bowel care)
- Health and wellbeing
- Mobility
- Relationships
- Accessing support in the community



We will also support you to develop a goal planning document to take away from the sessions throughout the week, which you can work on and refer to beyond your ‘What Next?’ course.

You will be invited to join live Q&A interactive sessions to discuss any questions you may have throughout the week. These sessions will be led by professionals in their field, as well as people with a spinal cord injury who have lived experience of what you are going through.

This course is free and takes place virtually meaning you can join from the comfort of your own home.



"I loved the fact that there were experts available that had the training and the volunteers who had personal experience. People who had lived it. The experts are trained but they don't live with it. Having that range of experience from the volunteers, [was] gold.

"Meeting people who had freedom gave me more hope. I know I can be happier now. Seeing people struggling with their emotions, none of us were alone. "

What Next? Participant



If you would like some further information please call the courses team on 020 8875 1805 or email us at courses@backuptrust.org.uk

The Back Up Lounge

Our online forum open to everyone affected by spinal cord injury where no conversation topic is off-limits.

We launched the Back Up Lounge in April 2020 as a result of the Covid-19 pandemic closing our face-to-face services in UK spinal centres. Held over Zoom, this volunteer-led service, was initially created to tackle loneliness and connect people affected by spinal cord injury with other like-minded individuals during this difficult time.

The Lounge has been a massive success because you drive the discussion. You are given a choice of lounges, but what you talk about in there is up to *you*. So, whether you are looking for recommendations for Netflix shows to binge, tips on nailing your back wheel balance, a frank conversation on bladder and bowel management or just fancy a chat, the choice is yours.

Topics have included:

- Catch up corner
- Wellbeing
- People who can walk
- Parent network
- Family support
- Exercise



What makes the Lounge truly special is our attendees. They've found that they are helping each other grow in so many unexpected ways, but are still keeping the fun environment Back Up is known for. This service will run indefinitely, so you can still join us if you would benefit from some additional support.



"I wasn't going to come - I thought the first time I came I was just going to turn the camera off and just listen. I got here and thought "yeah, they're just normal people." We've been in this situation forever and you tend to think there is no one else like me, but this has made me realise that this is other people's lives too, not just our own. Now I come every week!"

Kay, partner

"The support and friendship I get from this group is incredible. We share stories, laughter and the difficulties of living with someone with a spinal cord injury. This is the only place I can really share this with others in my situation."

Nicky, family member



To find out more about the Back Up Lounge, please visit our website or email serviceteam@backuptrust.org.uk

Volunteering

Our services are strengthened by our peer led support and passionate volunteers.

Back Up was founded by volunteers and volunteering remains at the heart of everything we do. Their contribution is felt throughout the charity, and we simply wouldn't be able to operate our life-changing services without them.

Could you join our amazing team? Whatever your background we have a range of opportunities to suit your interests. Our roles are challenging, fun and rewarding – volunteering with us could change your life!

Become a Back Up mentor

If you or a family member has a spinal cord injury, why not volunteer as a Back Up mentor? You could help transform someone's life by sharing your experiences and providing a listening ear. We need Back Up mentors of all ages, and from all parts of the UK.

Become a family volunteer

Are you a family member of someone with a spinal cord injury? Do you want to help family and friends of newly injured people adjust to life after spinal cord injury? Then we have the role for you! We're seeking volunteers to support others and talk at our family support sessions at spinal centres around the UK.

Become a Back Up wheelchair skills trainer

If you're interested in becoming a skills trainer, and volunteering with us – whether it's face-to-face sessions at UK spinal injury centres, taking part in our virtual training sessions or training on our residential courses – we'd love to hear from you.

Become a Back Up courses volunteer

There are many volunteering opportunities with Back Up on courses – whether as a group leader, a wheelchair skills trainer, a buddy or a personal assistant/nurse – we're always looking for volunteers from all pathways of life to support us on our courses.

Become a Back Up education advocate

Our education advocates visit nurseries, schools and universities around the UK to ensure all children and young people with a spinal cord injury are heard and feel included in their education.

**To find out more please call
020 8875 1805 or email
volunteering@backuptrust.org.uk**



Become a Back Up fundraiser

We rely entirely on the efforts and generosity of our supporters to survive and continue our work. Could you help us support more people with a spinal cord injury by taking on a challenge, attending an event or getting your friends and family involved?

Youth volunteering

We know the best people to support children and young people are often young people themselves - that's why we make sure that they are involved in the design and delivery of our services for them.

"Having benefited from Back Up's services, I wanted to give something back and help people come to terms with their new situation. Volunteering as a mentor was an obvious place to start and it is hugely satisfying helping people when they need it most."

Dave, volunteered as a mentor

"The highlight was seeing the participants really grow in their skills and confidence, ready to get on with their lives and genuinely motivated and excited about the future."

Gavin, volunteered as a city skills buddy



There are loads of ways to volunteer and support us here at Back Up. To find out more please call 020 8875 1805 or email volunteering@backuptrust.org.uk

Services for children and young people

Dedicated services for young people.

We understand that life with a spinal cord injury can be hard. As a child or young person, it's important to get support that takes into account your age as well. Growing up with a spinal cord injury can bring its own challenges and it can be helpful to spend time and learn from others with similar experiences.

Back Up are the only charity in the UK with dedicated services for children and young people affected by spinal cord injury. We support children from birth through to school and university.

We have a separate information brochure specifically for children and young people. Please do get in touch with the team for one of these, and for more information about how we can support you directly. Here is an overview of what support we offer:

Education inclusion service

You have a right to be included in every part of your education and we can support you with this. Whether you're starting nursery, returning to school or preparing for college, we can help staff and students better understand spinal cord injury, ensure your voice is heard and that the right support is in place for you to participate fully.

Courses

Do you fancy abseiling in your wheelchair, racing your friends in a canoe, relaxing with others by the campfire toasting marshmallows, or exploring a new city? On our residential courses you can give all these things a go. These courses are designed to build confidence and independence in a safe environment.

Mentoring - speaking to another young person

You are not alone. If you want to talk to someone who understands what it's like to have a spinal cord injury, we can find the right person for you. Whether you have questions about school, travelling, learning to drive or anything else, we can put you in touch with someone who can help and share their experiences.

Wheelchair skills

Confidently getting around using your wheelchair or powerchair so you can live the life you want – that's what wheelchair skills training is all about. Our wheelchair skills sessions can teach you the skills you need to use your chair independently, from carrying a drink one-handed to getting up and down kerbs and on and off the bus.



Youth Break Out Lounge

The first Tuesday of each month, we host a virtual meet up via Zoom to 'meet' other young people, chat and share experiences. We regularly have guest speakers who have a spinal cord injury too, who have a variety of experiences including sports and travel.

We are here for children and young people of all ages, from birth right up until teenage years. Do get in touch to find out how we can individually support you.

"Back up have helped me make new friends, taught me new skills and built my confidence."

Kevin

Back Up is here to help you get the most out of life.

Sometimes that can involve us signposting you to other support services, including those from other charities.



Our partners at Aspire run a range of vital, practical services which we recommend you get to know about too. With your permission we will put you in touch with Aspire so you can get all the services you might need to make things work.

Move from injury to independence with practical support from Aspire

Housing • Independent Living Advisors • Patient Education • Assistive Technology • Welfare Benefits Advice • Money Matters

When you have a spinal cord injury there's a lot to take in and deal with. Which is where we come in. Aspire offers a range of services that can help you lead an independent life.

We are experts in **Housing** rights and issues, and also have specially adapted houses around the country which you can live in while permanent, accessible accommodation is being arranged.

Our **Independent Living Advisors** – all of whom have a spinal cord injury themselves – offer practical support and advice to spinal cord injured people and their families.

We also provide **Assistive Technology** facilities at Spinal Injury Centres which help you use computers, whatever your level of injury. If you have any concerns about your **Welfare Benefits** you can talk to our experienced Welfare Benefits Advisors and if you would like advice about your financial situation you can speak with our **Money Matters** Specialist.



You'll find loads of information about us at aspire.org.uk

Email info@aspire.org.uk or call us on 020 8954 5759

Association for Spinal Injury Research, Rehabilitation and Reintegration
Registered Charity Number 1075317. Scottish Registered Charity Number SC037482.
Republic of Ireland Registered Charity Number 20150181. Registered Company Number 3744357.

Aspire



Back Up's award-winning practical services presented in this brochure are there to show people affected by spinal cord injury what is possible through challenge and fun. We are there for people with a spinal cord injury and their loved ones from the very beginning.



Support Back Up

Back Up is entirely charitably funded by donations, fundraising activities, events and grants. If you want to help make a difference, don't hesitate to get in touch. By making a donation, you can help us transform lives.

Remmond's Story

Read on to discover how Back Up helped Remmond live confidently after spinal cord injury.

There wasn't one single incident that caused my spinal cord injury that I recall. My condition got worse over time. At one point I started limping. Eventually after a full back scan in hospital they discovered a protrusion on the T5/T6 level of my spine.

After the surgery to decompress my spinal cord I was a bit naïve. I thought I would be back on my feet after a few weeks. It was only when I started rehab that I learned I may never walk unaided again. At this point my mentality was to do my upmost to live in this new situation.

My physiotherapist gave me a leaflet about Back Up's services. At the time I didn't know anything about spinal cord injury, but I was determined to build myself up again. I got in touch with Sophie at Back Up who told me all about the mentoring service, and said she found me a perfect match. I was paired up with my mentor, Kevin, and we instantly hit it off. Kevin showed me that there is a lot I can do with my life, even with a spinal cord injury. He answered all the questions I had - covering topics like sleep, relationships and work.

Mentoring made me understand so much about my injury. I was the only person on my ward with a spinal cord injury, I was mainly with stroke and brain injury patients, so mentoring proved there are other people like me out there living well.

I've recently reached out again to Sophie to find out how I can get involved with Back Up. I want to give back in the future by volunteering










Back Up
4 Knightley Walk
London
SW18 1GZ

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

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Contact our services team today

020 8875 1805 or
serviceteam@backuptrust.org.uk

