



**back**  **up**

transforming lives after spinal cord injury

## **A GUIDE TO OUR SERVICES**

2021-2023

SUPPORTED BY **CliniMed**<sup>®</sup> **SecuriCare**<sup>®</sup>

# Welcome



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

Andy Masters, **Head 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 & delivered by people who are affected by spinal cord injury. At some stage, we've asked ourselves these same questions.

CliniMed and Securicare are sister companies, providing specialist healthcare products and services. CliniMed supplies innovative products for continence, stoma and skin care. Their products are used widely throughout the NHS in hospitals and on prescription for continued use at home. SecuriCare is a friendly, free home delivery and support service for continence and stoma supplies. They deliver all makes and brands of prescription products and through their in-house pharmacy, Pharmicare, they also deliver prescription medicines.

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# Telephone support

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

Back Up's [telephone support service](#) is available to everyone with a spinal cord injury and their family members. Our outreach and support team all have a spinal cord injury so they understand the challenges faced, and every member of our family outreach 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 & 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, and 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 telephone support felt more positive about the future as a result of the calls.

"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 and support team on 020 8875 1805 or email us at [outreachandsupport@backuptrust.org.uk](mailto: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 [mentoring service](#), accredited by the **Mentoring and Befriending Foundation**.

The service will link you to a volunteer mentor who has a spinal cord injury. 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 the changes you want to make.

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 since implementing have helped. I have also started to be less harsh on myself and my achievements which is all thanks to Carley.

**Ciselle, 27, T12 inc- walks**

“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, 44, C4 inc**

! To find out more about mentoring please contact us on: **020 8875 1805** or email: [mentoring@backuptrust.org.uk](mailto:mentoring@backuptrust.org.uk)

Supported by **Aspire Law**  
Spinal Cord Injury Solicitors

# 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 as to where your loved one is receiving their rehabilitation.

We offer relatives’ days 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, the 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 relatives’ days, or you would like to talk to someone who understands after the event, our family outreach 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 (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, 30, partner**

“When I heard Pete & his sons 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, 50, Parent**



To find out more about family mentoring please contact us on: 020 8875 1805 or email [familyoutreach@backuptrust.org.uk](mailto:familyoutreach@backuptrust.org.uk)

# Wheelchair skills training

## For manual and power wheelchair users.

Having the [skills and confidence](#) to get around in 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 in your wheelchair. Covering both manual & power chair skills, search for 'Back Up Wheelchair Skills' in the [App](#) & [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 find out more about these sessions and to watch our video collection scan the QR code to the left or visit <https://www.backuptrust.org.uk/support-for-you/wheelchair-skills>




"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, 25, T8/9**

"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, 50, L1**

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



SCAN ME



SCAN ME

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

Wheelchair skills training sessions are supported by **SHOOSMITHS**

Wheelchair skills extra sessions are supported by **Coloplast**

**IM** irwinmitchell

# 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. They 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.



- **Moving Forwards 18-25s** – Are you thinking about moving away from home, living independently, heading to university or developing life skills? This course, designed by young adults for young adults, is the right choice for you.
- **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](mailto:courses@backuptrust.org.uk)

# Vocation service

**Back Up to 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 [Back Up to Work service](#) is hosted in the office of one of our corporate partners, and we offer courses to give 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.



"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, 42, 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, 32, Back Up to Work participant**

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



**We run several Back Up to 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](mailto:vocation@backuptrust.org.uk)**



# Next Steps



## A course for people with a spinal cord injury who can walk.

Our **Next Steps** course is for you whether you walk with or without aids, or use a wheelchair some of the time. This course is all about what you want to learn and what would improve your independence. Our aim is to give you the confidence to lead a more enjoyable and healthy life.

Over a long weekend the course will cover life skills, such as using public transport, making a meal and getting around a busy city. You'll also have an opportunity to share experiences and talk about different issues related to being able to walk following a spinal cord injury. The topics often discussed include pain, fatigue management, invisible disability, guilt and other issues.

Group leaders and skills trainers will be people with spinal cord injury who are able to walk themselves.

"As a person with spinal cord injury who can walk, you sometimes feel stuck in a halfway house, not as severe as someone who is a permanent wheelchair user but you definitely have a disability. This is the perfect course where you get to share with others in the same situation and realise that you are not alone with what you are going through. A life changing experience that will leave you with light bulb moments that you can take forward into everyday life. I am so glad I took the plunge and would wholeheartedly recommend this course!"

**Kevin, 42, participant**



We run two Next Steps courses a year. To find out more, please give the team a call on 020 8875 1805 or email us at [courses@backuptrust.org.uk](mailto: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 coronavirus 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.

**Different topics have included:**

- Catch Up Corner
- Wellbeing
- People who can walk
- Parent Network: lockdown with little ones and teens
- 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's known for. This service will run indefinitely, so if you think you could benefit from some additional support and you haven't yet joined us you still can!

"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 spinal cord injury; this is the only place I can really share this with others in my situation."

**Nicky, family member**



**To find out some information about the Back Up Lounge, please visit <http://bit.ly/BUlounge> or email [servicesteam@backuptrust.org.uk](mailto:servicesteam@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.

To find out more about mentoring please email [mentoring@backuptrust.org.uk](mailto:mentoring@backuptrust.org.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 relative days at spinal centres around the UK.

To find out more, please call **020 8875 1805**,

or email [familyoutreach@backuptrust.org.uk](mailto:familyoutreach@backuptrust.org.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.

To find out more, please call **020 8875 1805**, or email [outreachandsupport@backuptrust.org.uk](mailto:outreachandsupport@backuptrust.org.uk).

### 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.

To find out more, please call **020 8875 1805**, or email [courses@backuptrust.org.uk](mailto:courses@backuptrust.org.uk).

### 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 [schools@backuptrust.org.uk](mailto:schools@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 spinal cord injury by taking on a challenge, attending an event or getting your friends and family involved?

To find out how you could help, email [fundraising@backuptrust.org.uk](mailto:fundraising@backuptrust.org.uk) or call **020 8875 1805**.

"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, 48, volunteering 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, 30, volunteering as a city skills buddy**

! **There are loads of ways to volunteer and support us here at Back Up. If you would like to find out some information on volunteering with Back Up, please call 020 8875 1805 or email [admin@backuptrust.org.uk](mailto:admin@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 in 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.



#### 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.

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, 14

## 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](http://aspire.org.uk)  
Email [info@aspire.org.uk](mailto:info@aspire.org.uk) or call us on 020 8954 5759

# Aspire

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.

At CliniMed® and SecuriCare®, our aim is to help people live their lives more comfortably. We have almost 40 years experience in supplying continence, stoma and skin care products direct to your door.

Alongside our range of innovative products and tailored, trusted home delivery service, our friendly team offer free samples, specialist advice and support.

To see how we can help you, contact our **Careline Team** today on **0808 2741 409** or visit [www.clinimed.co.uk](http://www.clinimed.co.uk) or [www.securicaremedical.co.uk](http://www.securicaremedical.co.uk).



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

We receive no government funding. 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.








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## Contact our services team today

020 8875 1805 or  
[serviceteam@backuptrust.org.uk](mailto:serviceteam@backuptrust.org.uk)



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