

strategy 2021-2025 Transforming Lives

Executive summary

For 35 years Back Up has been at the forefront of helping people adjust positively to spinal cord injury.

We are led by the needs of people affected by spinal cord injury. Over 300 people have helped create our strategy through workshops, surveys and focus groups.

Our service users, volunteers, and supporters have helped us carve out the three goals that underpin our strategy; goals that matter to those we support.

- Living confidently ensuring people with a spinal cord injury have the confidence and practical skills to live a full, independent life.
- **Thriving at any age** ensuring all people with a spinal cord injury can reach their full potential. •
- **Staying connected** ensuring everyone affected by spinal cord injury can connect with someone in a similar situation, helping them achieve the goals that matter to them.

This strategy is a living document designed for you to view in different ways; either as a whole, goal by goal or through our short three minute video. We will be reporting each year with how we are meeting our yearly objectives. You can find out more and follow our progress here.

Thank you to all supporters, volunteers, partners and patrons for your continued support, and if you are new to Back Up, we hope our strategy inspires you to join us in making our goals a reality.



Abigail Lock | CEO



Jo Wright | Chair of Trustees





$|SS| \cap |$

Embrace challenge Have fun Build inclusive communities Ambitious for each other

Staying connected

Everyone affected by spinal cord injury is connected with someone in a similar situation helping them achieve goals that matter to them.

- Driving efficiency and effectiveness
- Volunteers at our heart
- Compelling communications
- Committed to collaboration
- Open and accountable



66

I didn't know where to turn to after my injury and Back Up were there waiting for me. Talking with Back Up and their support has felt like a family coming out of the woodwork.

Our strategy is focused on finding better ways to support more people affected by spinal cord injury at times when they need us the most.

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.

We offer:

- an accredited peer mentoring service
- proactive telephone support
- life skills and activity courses
- support for family members

Back Up's vision is:

a world where people with spinal cord injury can reach their full potential.

- support for individuals looking to
 - return to work, volunteering or education
- wheelchair skills training
- online services designed to overcome isolation

Our mission is to:

deliver services that build confidence, independence and inspire people affected by spinal cord injury to transform their lives.

What is spinal cord injury?

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. It is protected by the bones (or vertebrae) that make up the spine, and by spinal fluid.

Your brain and spinal cord are vital for controlling your bodily functions. The spinal cord is responsible for communicating twoway messages to and from the brain to all parts of the body; your muscles, organs and your skin. We are able to feel pain and move our arms or legs because of these messages or impulses.

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 the loss of control of your bladder, bowel and sexual function.

Most injuries cause loss of movement and feeling in the parts of the body below the level of the injury. If you damage or break your spinal cord close to your neck, this will cause paralysis in a larger part of the body than damage to your spinal cord lower down your back. As well as the physical impact of a spinal cord injury, there are also emotional and psychological effects on the person concerned – and their family.



The need we are addressing:

Every year approximately 2,500 people

in the UK will sustain a spinal cord injury. That is more than one person every four hours.

It could be as the result of an illness. an accident or something as simple as falling down the stairs. Spinal cord injury can affect anyone at any time. It could affect you.





It is estimated that there are around people living with spinal cord injury in the UK.





and young people will sustain a spinal cord injury each year.

Less than a third of people with a **spinal** cord injury are in employment.

Rates of Suicide are higher among

people with a spinal cord injury than the general population, especially in the first ten years post-injury.

Our strategy will help us to achieve our vision and will guide everything we do today, tomorrow and to 2025.

We have three goals to address our mission. These are:



Thriving at any age:

all people with a spinal cord injury are able to reach their full potential.



Living confidently:

all people with a spinal cord injury have the confidence and practical skills to live a full, independent life.



Staying connected:

everyone affected by spinal cord injury is connected with someone in a similar situation, helping them to achieve the goals that matter to them.

Back Up values



We embrace challenge

Challenge is central to our learning and growth; it helps us gain knowledge and skills. By finding ways to overcome challenge and move forward we gain a sense of achievement, supporting us to realise our full potential.

We have fun

We believe that having fun allows us to connect with others whilst opening up opportunities to develop, achieve and get the most out of life, showing that there is a positive future after spinal cord injury.

2.

4.

3.

We build inclusive communities

We achieve more for people affected by spinal cord injury when we work together. We are collaborative and inclusive in our approach. We embrace diversity, working with, and supporting individuals, groups, and the wider spinal cord injury community.

We are ambitious for each other

We are driven by the needs of people with a spinal cord injury and their families. We are passionate, striving to be the best. We set high standards, and we work hard to reach them. We are proactive, push boundaries, try new approaches and we learn quickly. We recognise that failure doesn't have to equal loss, rather an opportunity for growth. We listen to what people affected by spinal cord injury want and we seek innovative responses based on their feedback.

Looking back o all we have achievec

First wheelchair skills trainers taught

Going forward we will continue to build upon the services which Back Up is known for - evolving and finding innovative new ways to make a difference.

Created our Spinal Injury liaison and **Telephone Support** . team liaison

people into employ 2009

Schools inclusion service developed to support children and young peopl

2007

We run our first work

skills course to support

Youth Advisory Group formed to influence and shape our U18s services

> 2017 Permanent base established in Scotland with first Scotland-based coordinator

2020

We adapted to deliver services virtually through our online forum. The Back Up Lounge and building the Back Up Wheelchair Skills app



Goal with a s one live a ful

Living confidently: all people with a spinal cord injury have the confidence and practical skills to live a full, independent life.

Setting the scene

Spinal cord injury changes your life in an instant. The impact can be catastrophic affecting every area of your life from your bladder, bowel and sexual function to your career and relationships, and how you age.

Adjusting to spinal cord injury can be overwhelming, but we believe it shouldn't stop anyone from getting the most out of life. Our services, including wheelchair skills training, activity courses and vocation service, challenge preconceptions and show people affected by spinal cord injury what is possible.

Over the lifetime of the strategy, we will build on our existing services in order to help more people gain the skills and confidence they need to live life independently.



What did people with spinal cord injury tell us?



"Be there EARLY for everyone affected."

"I think Back Up's focus on practical skills, psychological stability and learning **how to have fun again** is completely on target. I also found everything Back Up does seems to be really professionally run. **It's made a huge difference for me.**"

"Keep your focus upon assisting independence and showing newly injured people that **there is a** way forward."

What we will achieve by 2025

We will reach all newly injured people in the UK, including all children and young people. By providing support from the beginning of the adjustment process we can make sure people have the skills and confidence they need to live life independently.

We will be more inclusive, expanding the number and range of our transformative courses and virtual resources for people who cannot access specialist support in spinal centres – making them accessible wherever they may be in the UK.

We will be leaders in supporting people with spinal cord injury in getting back to work and volunteering, working collaboratively with businesses, the NHS and other organisations where we can achieve more together to provide even more opportunities.

Thriving at any age: all people with a spinal cord injury are able to reach their full potential.



Setting the scene

Goal

Spinal cord injury can affect anyone, at any age. Whether you sustain a spinal cord injury aged one or 101, Back Up is there for you. The support that an individual and their family needs will differ according to their life stage and the length of time that they have been living with an injury. Our focus will be on helping people at the period of greatest need. In many cases this will be the early stages after an injury as people learn new skills, get back to school or work, and rebuild their confidence.

We are the only charity in the UK who provides dedicated support for children and young people with a spinal cord injury. Each year around 100 children and young people sustain a spinal cord injury. We believe that children and young people with a spinal cord injury should have the same opportunities as any other young person. Our children and young people services strive for equal access to education, opportunity, and advancement for all children and young people with spinal cord injury, from early years through to the transition to adulthood.

Just as children and young people face unique challenges, those sustaining an injury later on in life will face a different set of challenges. The majority of people who sustain spinal cord injuries will be adults. Over 40% of people sustaining injuries are over 60 years old. Whilst our courses and services are open to people of all ages, over the course of the strategy we will better tailor our offer to older people.

What did children and young people with a spinal cord injury tell us...



"Back Up is there for the serious times and the fun ones."

"Teach parents about spinal cord injury kids and how to cope."

"Find your limits and push them."

What did older people with a spinal cord injury tell us...

"I have developed 'new' problems that it would be good to talk through. **The courses are also probably more relevant now than they** were early in my injury."

"After living with a spinal cord injury for over 25 years without any support, **I found the services that Back Up offered have been invaluable** in helping me to adapt and cope with the changes I am now going through due to living with a long term spinal cord injury."

"I'm quite an old paraplegic-26 years- so I've adapted.... Learning skills after 20 years was however an eye opener and **increased my independence further**."

What we will achieve by 2025

We will provide support to every child and young person with a spinal cord injury who wants our help, to ensure that they are fully included in their education and that their voice is heard in this process. We will be there for any teacher, school, college or university that needs our support around inclusion and meeting the needs of a child or young person with a spinal cord injury, to ensure they have a positive education experience.

■ We will provide specialist advice and information to children and young people so that they can access care, equipment and social support they need. We will work in collaboration with the NHS to ensure that all children and young people with a spinal cord injury receive the treatment that they deserve through the established Children and Young Person's Pathway.

Our support will be targeted at times of greatest need. We will continue to help people affected by spinal cord injury overcome barriers they may face in their education, career, family life, hobbies and social life, so that they can live the life they want. We will have increased our resources for people who are ageing with spinal cord injury, and have established a course for newly injured people who have sustained a spinal cord injury later in life.





Staying connected: everyone affected by spinal cord injury can connect with someone in a similar situation to themselves, to overcome challenges and achieve the goals that matter to them.

Setting the scene

Adjusting to spinal cord injury can be overwhelming both for the person with a spinal cord injury, and their family. People can often feel isolated and alone, thinking no one could possibly understand what they are going through. No one should have to face living with a spinal cord injury alone. At Back Up, most of our services team have a spinal cord injury or are a family member of an injured person. This includes all members of our outreach and support and mentoring teams. We understand, because we have been there ourselves and we use these experiences to ensure people reach their goals.

Over the past five years, inpatient rehabilitation times have decreased. This means that recently injured people spend less time learning from others in a similar situation. Many other people with spinal cord injury will never receive inpatient rehabilitation at a specialist Spinal Cord Injury Centre. Typically this can be people with co-morbidities, those with Cauda Equina Syndrome or people with lower level injuries who can walk.

Back Up has been providing mentoring since 2005 - we know first-hand that connecting with others in a similar situation can positively influence the adjustment process of living with a spinal cord injury, both for the individual and their family. It can make the difference between surviving or thriving and that is why we will be expanding our mentoring service and developing new offers to bring people together.



What did people affected by spinal cord injury tell us?

"It was hard coming home and not knowing what was accessible in our area. We have had to find out through our own research and sometimes disappointment. When my husband was at **Stoke Mandeville he was surrounded by people with spinal cord injury,** but when he came home he was the only one."

"It has been so beneficial to be able to meet, receive support from and chat to other people with a spinal cord injury."

"Offer follow up sessions with your mentor at potentially difficult times in the future, e.g. on the anniversary of your injury."

What we will achieve by 2025

We will provide more in-depth oneon-one support to those who are really struggling, increasing our capacity to mentor three times more people with a spinal cord injury and their family members. We will also establish a parent support programme and parent mentoring. This will involve sharing experiences and parents being provided with practical support to help them come to terms with what has happened, and adjust positively to life post-injury.

We will offer a 'family rehab service' that supports family members of those with a spinal cord injury. This begins with the acute phase through information and advice online and in-person at relatives' days, to postdischarge, from the hospital through peer mentoring and dedicated courses.

We will be integrated into the NHS's spinal services rehabilitation pathway in order to increase access to the firsthand knowledge that comes from living with a spinal cord injury. We will work in partnership with the spinal centres' multi-disciplinary teams for inpatient support and with the outreach and out-patient teams to support those with a spinal cord injury in hospital as well as in the community.

What we will achieve by 2025

Goal

2025 Year Aims

By 2025 we will reach all newly injured people in the UK, including all children and young people. By providing support from the beginning of the adjustment process we can make sure people have the skills and confidence they need to live life independently.

Living confidently:

people with a spinal the confidence and practical skills to get the most out of life.

By 2025 we will be more inclusive, expanding the number and range of our transformative courses, online resources and services for people who cannot access specialist support in spinal centres – making them accessible wherever they may be in the UK.

By 2025 we will be leaders in supporting people with a spinal cord injury in getting back to work and volunteering, working collaboratively with businesses, provide opportunities.

Thriving at any age: reach their full potential.

By 2025 we will provide specialist advice and information to children, young people and their parents in order for them to access care, equipment and social support to help them live well. We will work with the NHS to ensure that all children and young people with spinal cord injury receive the treatment that they deserve through the established Children and Young Person's pathway.

Goal

Thriving at any **age:** all people with a spinal cord injury are able to reach their full

Staying connected:

spinal cord injury can

in a similar situation

to themselves, to

matter to them.

connect with someone

2025 Year Aims

By 2025 we will ensure our support will be targeted at times of greatest need, helping people affected by spinal cord injury overcome barriers they may face in their education, career, family life, hobbies and social life, so that they can live the life they want. We will have increased our resources for people who are ageing with spinal cord injury and have established a course for newly injured people who have sustained a spinal cord injury later in life.

By 2025 we will provide support to every child and young person with a spinal cord injury who wants our help to ensure that they are fully included in their education and that their voice is heard in this process. We will be there for any teacher, school, college or university that needs our support around inclusion and meeting the needs of a child or young person with a spinal cord injury, to ensure they have a positive education experience.

By 2025 we will provide more in-depth one-on-one support to those who are really struggling, increasing our capacity to mentor three times more people with a spinal cord injury and their family members. We will also establish a parent support programme and parent mentoring. This will involve sharing experiences and parents being provided with practical support to help them come to terms with what has happened, and adjust positively to life post-injury.

By 2025 we will offer the family of each newly injured person a 'family rehab service'. This begins with the acute phase through information and advice online and in-person at relatives' days, to post-discharge from the hospital, through peer mentoring and dedicated courses.

settings, and in the community.

Find out more about our objectives

https://www.backuptrust.org.uk/about-us/the-back-up-strategy

By 2025 we will be integrated into the NHS's spinal services rehabilitation from living with a spinal cord injury. We will work in partnership with the spinal centres' psychology, physiotherapy and occupational therapy professionals for in-patient support. We will work in partnership with the outreach and out-patient teams to support those with a spinal cord injury in other hospital

Components of success



We have clear goals and a set of values to guide how we will achieve them.

Our success will be built on:

1) BEING PEER DRIVEN

The majority of our team either have, or are affected by, spinal cord injury. This lived experience shapes every service we offer and our approach. We will continue to engage with people affected by spinal cord injury about what matters to them so that we can ensure that Back Up provides the right support at the right time.

2) GROWING FUNDRAISING TO MEET OUR AMBITION

Our strategy is ambitious. To achieve our goals, we will need to significantly increase our investment in our charitable objectives. We will implement a sustainable fundraising plan that adds £1million to our income per year by 2025. By making better use of our data we will gain new insight into our donors and improve our donor journey. We will diversify our income streams offering flexible ways for people to support us.

3) DRIVING EFFICIENCY AND EFFECTIVENESS IN ALL THAT WE DO

We will continuously look for ways to become more efficient so that we can reach more people and have an even greater impact. We will improve the quality and understanding of our data to support our fundraising and to ensure we maximise the impact of our services. We will drive down our ratio of charitable to noncharitable spend from 65: 35 to 70:30

4) HARNESSING TECHNOLOGY

Using new technology we will innovate to increase impact, by creating digital versions of our key services so we will be able to reach more people virtually. These will complement our face-to-face services and increase our insight of the changing needs of our service users. We will build on learnings from virtual events to offer a mix of ways people can engage with Back Up and pilot the use of new platforms to drive competitive fundraising in challenge events.

5) DEVELOPING AND EMPOWERING OUR PEOPLE

We will embrace a learning culture to increase knowledge and performance. We will do this through peer-to-peer learning experiences, encouraging staff development through innovative working practices and creative thinking. We will align our staff development plans with our strategy and business plans to ensure our staff have the skills and tools they need. We will learn openly from mistakes, celebrate success and apply these principles to our wider volunteer team and board of trustees. We will actively continue to ensure that wellbeing is central.

6) VOLUNTEERS AT OUR HEART

Back Up was founded by volunteers and volunteering remains at the heart of everything we do. The contribution of our team of over 400 volunteers is felt throughout the whole organisation in all aspects of our work. We will find more ways for our volunteers to get involved across all departments, and strengthen the journey from service user to volunteer, ensuring volunteers are supported with the training and resources they need to succeed.

7) BEING INCLUSIVE

We want Back Up to be a place where everyone feels welcome. We will do more to reach a diverse range of people affected by spinal cord injury and ensure that we are more reflective of the population we serve. This will be reflected in the stories, images and videos we use for communications and marketing, as well as in our partnerships and volunteer recruitment.

Find out more about our components of success https://www.backuptrust.org.uk/about-us/the-back-up-strategy

Our newly established Diversity and Inclusion group will work to remove barriers which prevent people from engaging with Back Up. Our board will continue to have at least 50% representation of people affected by spinal cord injury. We will continue to ensure our calendar of fundraising and services events are inclusive for all those we serve.

8) COMPELLING COMMUNICATIONS

Engaging and targeted communications tell the stories of those we support and help to raise national brand awareness. We will focus on our digital and social media presence, encourage user generated content and initiate high-profile PR campaigns which positively challenge the perceptions of all that is possible with a spinal cord injury.

9) COMMITTED TO COLLABORATION

We will learn from others and work with partners to develop our services. By introducing share and learn sessions we will learn from other organisations about their experience of what works. By working more closely with other charities, the spinal cord injury centres and other organisations which can help us achieve our mission we will reduce duplication of effort and be able to target resources where needed.

10) OPEN AND ACCOUNTABLE

We will be transparent, measurable and accountable in all that we do. We will embrace our values in our day-to-day work, and keep the needs of people affected by spinal cord injury central to all we do.

What the Back Up community tell us

In order to deliver our vital services, we rely on our amazing supporters and fundraisers. These quotes are from just some of the charitable trusts and fundraisers that have recently supported our work. They help ensure that Back Up is there for everyone affected by spinal cord injury.

Our supporters

"I like Back Up because it is so important for wheelchair users to get the support and teaching that they need to be able to use their wheelchairs properly and get around confidently and safely. The sessions help build courage and confidence, as well as friendships from meeting others who've been in the same position, and seeing how they are managing to rebuild their lives. It is such a lovely and well thought-out service in the way that it covers such a wide range of needs and issues so nicely, so that everyone who can participate will surely get a lot more out of the sessions besides improving their wheelchair skills." Anonymous trust

"Back Up has established a clear footprint in Scotland, providing both support and practical advice to newly injured Scots when they are facing huge changes to their lives. It was also great to read that you are successfully working with the NHS and charity partners in a joined-up way to offer a range of support to patients." Anonymous trust

"Oh my goodness, how do I effectively express my gratitude for the opportunity to share this experience with such wonderful, selfless people. It proved such a huge challenge but each member of the team stepped up and gave it their all. Each time I close my eyes I see that sea of happy, exhausted, supportive and jubilant faces. I'll always hold onto and treasure that memory".

Susan Mould, Snowdon Push participant

Our trustees

Back Up is governed by a board of trustees. These are the people responsible for ensuring we reach our goals. We aim to make sure that 50% of the board have personal experience of spinal cord injury.

"It is an honour to be a trustee of this fantastic charity, which goes from strength to strength. Every year we help more people and develop or enhance our services. Even during the pandemic, the charity adapted and found new ways to help people with spinal cord injury. The team has implemented new digital services like the Back Up Lounge, so we can still reach people affected by spinal cord injury even when our face-to-face services are suspended. Let the Back Up Force be with you!"

Anne Luttman-Johnson, Back Up Trustee, who has lived with a spinal cord injury since 1984.

The people we support

Our services are influenced by the needs of people affected by spinal cord injury. Feedback from the people we support proves just how life-changing our services are.

"Back Up has really good people, staff and volunteers who really do know how it feels, unlike some who continually say they know what you mean, when there's no way they do. I really respect the knowledge, help, and experience Back Up staff share, which helps lots in an awful situation."

"Multi-activity courses, city skills and wheelchair skills training are really beneficial and empowering."

"The attitudes of the people who work and volunteer at **Back Up are positive** and they always find solutions to difficult (and sometimes embarrassing) situations. Nothing is too much or too personal to ask which has given me no end of confidence and reassurance."

"The best thing about Back Up has to be the positive attitude when people are struggling to come to terms with a life-changing injury. Seeing people who have been injured for longer and are getting on with life makes you believe you can do it too!"

Help us **make it happen**

Thank you for reading our Transforming Lives strategy. We can only achieve our ambitions with the help of supporters, volunteers and partners who share our vision.

If something in this strategy has inspired you to get involved please do contact us, we would love to hear from you.

You can help us transform even more lives affected by spinal cord injury in the future. **Visit our website to make a donation towards our** <u>life-changing services</u>.







Back Up 4 Knightley Walk London SW18 1GZ

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

6 backuptrust



Obackuptrust

Contact our team today

020 8875 1805 or admin@backuptrust.org.uk

