

transforming lives after spinal cord injury

Impact report 2020/21



Welcome



This past year has been difficult for everyone. The severity of the Covid-19 pandemic has left so many of us unable to do the things we all love and enjoy; shopping, exercise and spending quality time with our friends and families.

Spinal centres and hospitals around the UK have also operated differently for most of the year, with some having to give up beds and facilities in response to the pandemic. This has made it even more difficult for people to adjust to a life-changing spinal cord injury. Centres have either been severely restricted or completely closed to visitors, leaving those newly injured without a support system in place and unable to be visited by their loved ones and charities like us.

Normally, we would have been delivering face-to-face services to in-patients; patient education sessions, wheelchair skills training or just providing a listening ear. We've continued to stream vital information straight to centres, and we launched our first ever virtual course, 'What Next?', but without a physical presence we've found it much harder to reach newly injured people.

We knew we would need to adapt to support people and despite some challenges we've had amazing feedback from service-users about our new digital services; The Back Up Lounge has a thriving community, our chatbot, The Back Up Bug, signposts people to the information they need, and our wheelchair skills app has helped multiple people learn new skills or hone existing skills further.

We continue to be blown away by the support shown from our generous donors; individuals, fundraisers and corporate partners. In a difficult year you've helped us rise above and face challenges head on, enabling us to continue supporting people affected by spinal cord injury in new and exciting ways. Thank you to each and every one of you.

Yes the year has been difficult, but the stories in this report prove that the Back Up community is stronger than ever and that our services remain such a vital lifeline.

Abigail Lock | CEO

The impact of Back Up's work in 2020/21

The coronavirus pandemic left us rapidly adapting our work, but we have continued supporting people affected by spinal cord injury albeit in different ways - throughout 2020/21.



Our range of services were accessed over 3000 times in 20/21



119 family members registered for family support, with 53 matched with a trained mentor to help them make positive changes in their lives. 96% of those achieved their personal aim



17 children and young people with a spinal cord injury were supported at different stages of their education, and all of them told us they felt happier after receiving Back Up's support



Our online forum, The Back Up Lounge, welcomed **1178 attendees** this year, with 84% telling us they've felt more connected with the spinal cord injury community



The Back Up wheelchair skills app has been downloaded 362 times, allowing people to practise essential skills from the comfort of their own home



Streaming 59 essential patient education sessions straight to spinal centres to support 258 **people** newly injured people with a spinal cord injury





645 people were supported by telephone on topics like relationships, travel, work and bladder management, with 87% more aware of the possibilities available to them after these calls



138 people with a spinal cord injury were matched with a trained mentor, and **98%** of mentees achieved their personal aim



Ellis

Thriving at any age

Prior to my injury I was an international competitive swimmer. But just two weeks after my 17th birthday I had a fall, causing a T12 incomplete spinal cord injury. I am now a full-time manual wheelchair user. This absolutely changed my life - I had to relearn everything.

Everyone has felt isolated due to the pandemic, but in hospital that feeling was magnified. I spent weeks without my parents and it took a toll on me. I felt lonely. There weren't a lot of other people with a spinal cord injury on my ward. I wanted to meet others and I needed to know I wasn't alone.

My mum got in touch with Back Up. When I left hospital, they paired me with a young mentor similar to me – only two years further down the line.

"Mentoring showed me that life could be positive after spinal cord injury"

I also had the opportunity to have very honest conversations, discussing challenges and proving there are always ways to deal with them and carry on. We talked about literally any question I had, no matter how random.

I also joined The Back Up Youth Lounge – an online group for under-18s with a spinal cord injury. It's great because you can meet other young people across the UK in similar situations. We reflect on the difficulties of living with a spinal cord injury together and guest speakers talk to us about things like university, sport, and holidays. It's given me a sense of companionship, and has helped me realise the opportunities out there.

I am feeling very positive for the future, which didn't seem possible even a few months ago! I hope to do more wheelchair racing, and complete my A Levels. I'm studying Maths, Chemistry, and Biology. After that, I may go to university. When I was first injured I thought I wouldn't go but now, through Back Up, I've met some other people with a spinal cord injury that have studied. I'm leaving my options open, and I feel hopeful and excited.

Chris

I have Guillain-Barré Syndrome. It's a rare condition that affects your whole nervous system. 1500 people a year get it, but most can walk after six months. I only know one other person who has had long-term paralysis as a result.

I ran a business from 2005 to 2016 which altered wheelchairs for outdoor activities. When the company wound down, I struggled to get my direction back work-wise. I thought the Back Up to Work course could boost my confidence after a few years of unemployment.

I was accepted onto the course in 2020, but it was cancelled due to coronavirus. This year, I was offered a place on the virtual Skills for Work course. It was fantastic. I wasn't sure what to expect from a virtual course, but I was impressed from day one. A portion was focussed on selling yourself, writing CVs, and cover letter preparation.

More than anything, I learned how to become confident again, especially when talking to the other participants. When you see a lack of confidence in someone else, you often also see their potential. You have to be able to turn this back on yourself, and realise that you have something to give too.

"The course has made me feel much more confident, and happier to approach employers"

It came at the right time for me and it was great to have something to focus on during the pandemic. I was really impressed by how Back Up picked the speakers for this course and the effort they put into tailoring the course around people's needs. I spoke to an engineering recruiter, perfect for my background.

Since the course, I've signed up to become a STEM ambassador to motivate young people into engineering. I'm also doing some consultancy work with some specialist adaptive sport equipment providers. My mindset has shifted from being negative about returning to work, to realising I have something to offer.







Sarah

Living Confidently

I've had Lupus for 20 years. It's an autoimmune disease where your body can attack healthy cells. In June 2020 my husband took me to A & E with a painful suspected UTI. Three hours later, my legs went from under me. My Lupus caused Transverse Myelitis, damaging my spinal cord and causing a T6 complete spinal cord injury.

Being in hospital during lockdown was honestly difficult. I was grieving over what happened to me, and I had no physical contact with friends and family. FaceTime is good, but it doesn't give you a hug when you need it. After a few weeks bawling my eyes out, I started wanting to get on with it. Following my initial treatment I moved to a spinal injuries unit, where I found out about Back Up. I spoke to Michael virtually. He was so helpful, and he recommended I get a mentor through Back Up. I did, and she was fantastic!

Then, I signed up to the virtual two day What Next? course to learn more about living with a spinal cord injury. We were split into different groups, so we could hear from people in a similar situation and how they found solutions to problems. When you leave hospital after spinal cord injury, it can be hard as you aren't surrounded by people who understand. What Next? reminds you that there is still support outside of the hospital.

One module was all about travel. It covered things like going away on holiday and going to the cinema for an evening. It showed me that if I plan ahead, ask for help and laugh at myself, I can live life after spinal cord injury. It won't always be smooth sailing, but I know support is out there.

I wasn't 100% clear on what I needed before going on this course, but I knew I needed to hear from people who understood. This course helped me develop a positive mental attitude and I'm now back in employment, working at Harrods to ensure their supply chain is sustainable.

"I now know that there's nothing I can't do - I just need to plan ahead"

Will

Sustaining my spinal cord injury was life-changing. I was doing a charity triathlon nine years ago when a stick caught in my bike's spokes. It stopped the wheel dead, and I went over the handlebar. I damaged my spinal cord at the C4 level.

As soon as I was off the ventilator, my priority was figuring out what I could still do. Fortunately, my mum found out about Back Up and I was paired up with a very positive mentor who taught me what was possible.

I use a chin controlled chair. At first, I didn't want to use it. I just thought "what is the point?". I had no motivation and felt like the chair limited me. My mentor convinced me otherwise – giving me the boost I needed and within a few weeks I found myself learning power chair skills with Back Up.

I've been a power chair skills trainer since 2018. Volunteering gives me purpose. It's so rewarding to show people, like an older gentleman I remember, how independent they can be in their chairs.

I was scheduled to teach powerchair skills in spinal centres at the start of the pandemic, but we couldn't go in due to the risk of coronavirus. This inspired the creation of the Back Up wheelchair skills app, providing digital support when we can't be there face-to-face.

The app gives people something in the palm of their hand so they can still practice using a wheelchair. I've created some short videos for it, and the app's had great feedback with people finding it easy to use and helpful to be able to practise their skills in their own time.

Back Up is so important, because they offer support and encouragement.

"They show you that there are still possibilities and life can still be lived to the full after spinal cord injury"

It may have taken a pandemic to create these digital services but I hope they continue when things are back to normal – they've been so positive for so many people.







Hayley

Staying connected

My husband Vince has had a spinal cord injury since 2018. He has a C4/C6 level incomplete injury which he sustained after falling from a pushbike. It was when the pandemic hit that I really got involved with Back Up. In the early days I struggled to find a routine. I was working from home, so I was managing my team at work as well as Vince's wellbeing. The Back Up Lounge looked like a place where I could see how others were coping.

In the family lounge, we come together on Zoom every fortnight to talk things out, discuss challenges, and share how our weeks have been. It has helped me put some of our bad experiences in the past.

"The Back Up Lounge has made me see that it's not all doom and gloom - it's helped Vince and I look to the future"

These new digital services suited my needs perfectly. They have brought people together from all over the country. I live down South, but now I can talk to people from the Midlands and the North who I wouldn't speak to otherwise. It also means I don't even need to leave my house to get support - I can finish work and join the Lounge straight away!

The pandemic has been hard on family members of those with a spinal cord injury. I know many who have had to shield, and I found it very difficult in the beginning too. Thankfully, The Back Up Lounge makes you realise you're not alone. It surrounds you with people who have had similar - and different – challenges after spinal cord injury. It's good to talk it out, learn from others, and offer advice too.

Vince's injury has been life-changing in many ways. There have been negatives and challenges, but we now have a bright outlook for the future. Going forwards, I will definitely keep being involved with Back Up. I'm now a qualified volunteer mentor. I'm looking forward to my first mentoring relationship.

Stephen

I wouldn't say I was isolated during the pandemic, but The Back Up Lounge was something I looked forward to during lockdown. We couldn't see people for weeks on end, so the Lounge really helped me connect with others. It's been very positive for a lot of people with a spinal cord injury.

I attend the walker's lounge. It's an open forum where no topic is off limits. We share solutions and tips about problems we are facing, such as pain, medication, and exercise. It can be light-hearted too. We share pictures and stories, showing what can be done after spinal cord injury. It's good to show that you can still push boundaries.

There are certain sides to my health that you can't see. When you can walk with a spinal cord injury it can be tricky to explain things like dexterity and bladder and bowel management to people who don't understand. That's why it's good to have the Back Up Lounge - it means you can share experiences with others. You get a lot of empathy and understanding out of it.

As well as The Back Up Lounge, I volunteered on What Next? - Back Up's first online course. I spoke about pain management and walking after spinal cord injury. These new virtual services have been easy to use. I think Back Up has done a really good job switching to digital.

Face-to-face services are good, but the digital offerings have been a great substitute. I hope they continue in the future – having people all over the country getting together online is fantastic.

Under the circumstances, Back Up has been marvellous. They have put in so much effort to support people during the pandemic. I can't fault them.

"Back Up can help you understand that life goes on after spinal cord injury"





Plans for the future

We have set ourselves some ambitious targets as our new <u>Transforming</u>. <u>Lives strategy</u> sees us focusing on finding better ways to reach all newly injured people in the UK, including all children and young people with spinal cord injury.

We remain in constant communication with all spinal centres and have recently resumed our face-to-face services on the front-line. Returning and delivering these crucial services are vital to us achieving our goals. 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.

The coming year sees the start of a three-year partnership with NHS Spinal Centres, integrating our services into the spinal cord injury rehabilitation process to support newly injured people to build confidence and independence.



The difference our volunteers make

Our vital work is always made possible by the support of our passionate volunteers, whose contribution is felt at all levels of the charity. Back Up was founded by volunteers and, to this day, volunteering remains at the heart of everything we do, even in this difficult year. Last year, we estimate that our volunteers contributed the following hours to our work



Volunteer mentors spent **1900 hours** supporting others to make positive changes to their lives



Office volunteers gave 2368 hours of their time to provide fundraising and administrative support



Our family volunteers gave us **204 hours** of their time to support family members of people with spinal cord injury



Back Up's mentor trainers committed **120 hours** to deliver comprehensive training and guidance to mentors



Our fundraising volunteers gave 170 hours planning our special events, sourcing prizes for events and supporting our work



Our youth advisers and education advocates gave **114 hours** of their time to support children and young people with a spinal cord injury through mentoring, videos and our Youth Lounge

In total, we estimate that our unbelievable volunteers contributed around **8424 hours** to our work this year. This works out **at almost** 351 days, or almost a year's worth of time. We are extremely thankful for the amazing pro-bono support offered to us and for the valued contributions our volunteers make.



Our trustees dedicated **750 hours** to govern Back Up and shape the charity's future

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How we raised our money

In 2020/21, we raised £1,880,463 including income from the furlough scheme. We anticipated a drop in income due to the coronavirus pandemic, so we adapted our fundraising approach by launching an emergency appeal, delivering virtual events and adapting how we contacted and pitched to corporates, trusts and foundations.



Due to the incredibly generous support of our donors we were able to rebuild our income effectively this year to deliver vital services to people affected by spinal cord injury. Our individual supporters, including 372 committed regular givers, donated £364,878 to Back Up. We received **£4,163** from gifts in wills and **£10,144** in donations in memory of loved ones



37 companies volunteered over 2081 hours of time to help us deliver our services and raised over £420,000 through sponsorship, corporate events and office fundraising

Over 600 households attended our new and exciting virtual events, including wine tastings from across the world, quizzes, and our In The Cloud festival. These events collectively raised over £128,696



61 charitable trusts. including The National Lottery Community Fund in both England and Scotland, generously gave us a total of **£591,175** to fund our services

940 people took part in our challenge events including the Spinal Circuit, #NoLimits cycle ride, the 2.6 Challenge and skydiving, raising £208,873 on behalf of Back Up

In 2020/21, we raised an incredible £1,880,463.

Every donation counts - big or small, they help us support people affected by spinal cord injury. To all the individuals and corporations who have contributed to Back Up, we would like to say a massive thank you on behalf of all those you have helped in this past year. We simply could not do what we do without you.







We received £4498 from schools and clubs and **£27,792** from people holding their own events

How we raised our money

How we spent our money



Although the majority of our income goes directly to our services, we wouldn't be able to function as a charity without spending on fundraising and governance to ensure the sustainability of our services for future generations. We recognise that going in to 2022 there is still a high degree of economic uncertainty which is why we have increased our reserves policy to four months, but more importantly this surplus will enable us to immediately invest more in our services in the coming year to deliver the commitments we have made within our ambitious Transforming Lives 21 – 25 strategy.

Lockdown restrictions meant for large portions of the year we weren't able to deliver our services in person, so we developed new ways to reach people. However, this meant our overall spend on services decreased.

We already have plans underway which will see us reaching even more people, providing more intensive support to those who have been injured during the pandemic and expanding our services to meet demand.

Acknowledgments

We value the support of every individual and organisation who supports us, but we'd like to mention a few who have gone over and beyond this year to support us.

Trustees

Helen Cooke

Mona Dhanjal David Fraser

Anne Luttman-Johnson

Christopher Morgan (3 February 2021 - present)

Ben Parker (3 February 2021- present)

Martine Petetin

Richard Rawstron (3 February 2021 – present)

Tom Roberts

Richard Smith

(Hon Treasurer)

Ben Sneesby

Rebecca Stevenson

Dr Clair Turnbull

Joanna Wright (Chair of Trustees)

Patrons

Mike Nemesvary Konrad Bartelski Martin Bell Barbara Broccoli Sophie Carrigill Eric Lanlard Sophie Morgan Valerie Singleton

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Aspire Law Bank of Montreal **Bath Amphibians Big Yellow Storage** Clarasys CliniMed Ltd Cognizant Coloplast Cyclone Mobility **Eversholt Rail** Fittleworth Fletchers GRX Life Hayman's Gin Hollister Hotchillee Irwin Mitchell ITC Global Security Limited Jackson Boyd IMW

Leigh Day Lynn Murray & Co M&S Monday Charitable Trust Novia Financial **Origin Care** PageGroup RAPP Redbrain **RGK Wheelchairs** RSA Russell Cooke Savills Shoosmiths Stewart Investors Stewarts Law Taylor Rose Wellspect

Trusts and Foundations

We would also like to thank all charitable trusts who helped fund our life-changing services this year, including

Alice Ellen Cooper Dean Charitable Foundation **BBC** Children In Need The National Lottery Community Fund - Reaching Communities Bruce Wake Charitable Trust Edith Lilian Harrison 2000 Foundation Garfield Weston Foundation Henry Smith Charity James Tudor Foundation John Horniman's Children's Trust Medicash Foundation Pom Charitable Trust **RS Macdonald Charitable Trust Rothschild Foundation Ryvoan Trust** Sovereign Health Care Shanly Foundation St James's Place Foundation William Allen Young Charitable Trust 29th May 1961 Charitable Trust

Celebrities and individuals

We would like to thank all the celebrities who supported our Heels for Wheels campaign and all the individuals who generously enable us to continue transforming the lives of those affected by spinal cord injury.





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We'd like to thank our amazing photographer Chris Marchant for providing the majority of the photographic images used in this impact report.



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