

Transform

For everyone affected by spinal cord injury

Autumn 2018

“We spoke about work, university and having an invisible disability. It was so useful.”

Shelley

Have a listen to our charity appeal on the BBC Radio 4 Appeal website at www.bbc.co.uk/programmes/b006qnc7

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Who is Back Up for?

Back Up is for everyone affected by spinal cord injury and their family members, regardless of age, level of injury or background. Our services aim to build confidence and independence and include:

- Mentoring
- Wheelchair skills training
- Residential life skills and activity courses
- Support to make sure children and young people are fully included in their education
- Support with going back to work

We understand a spinal cord injury can be devastating, but we believe it shouldn't prevent anyone from getting the most out of life.

To find out more call us on **020 8875 1805**
or visit **backuptrust.org.uk**



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Welcome to our Autumn 2018 edition of Transform. It has been a very busy year at Back Up, not least in Scotland where many people have seen the benefits of having a coordinator based there (page 20). We've formally accredited all our residential courses – making volunteering an essential part of people's professional development (page 12). Our fantastic supporters and fundraisers like Paula (page 16) have been working hard too, raising vital funds towards our work. We're very excited to celebrate all these achievements at our annual Back Up Ball on 17 November, and I do hope to see you there.

Best Wishes,

Sarah Bryan

Chief Executive, Back Up
sarah@backuptrust.org.uk
or **020 8875 1805**.

Latest News



London to Paris: Riding in Danny's memory

This July, 40 cyclists – including six handcyclists – took on the London to Paris ride in memory of former Back Up trustee, Danny Turnbull, who sadly passed away in 2017. Stewarts Law supported the challenge and their team of riders helped us to raise over £138,000 for Back Up.

“As the enormity of what we’d achieved started to sink in, the tears flowed, and we remembered why we had signed up to this. We challenged perceptions and showed there are no limits to what’s possible.” (Andy Adamson, handcyclist)



Young volunteers receive Diana Award

Two of our young volunteers, Sam Appleton and Kevin Walker, received the prestigious Diana Award this year. Both play a huge part in delivering Back Up’s under 18s services.

“Kevin and Sam are dedicated and enthusiastic volunteers, sharing their ideas, skills and experiences to influence the services we offer for children and young people. It is brilliant that they’re being recognised for their contribution.” (Ella Provan, Under 18s Manager)



Cushman & Wakefield raise over £75,000

In June, Cushman & Wakefield took on their Kayak Attack challenge. Over 100 of their employees kayaked through 13 miles of London’s canals over eight long, gruelling hours, and they raised over £75,000 for Back Up.

“Everyone at work knew about the support that Back Up had given me when I was in Pinderfields hospital. Choosing to support Back Up was easy as I knew the money would make a real difference to people’s lives.” (James Campbell, partner at Cushman & Wakefield)

Back Up launches new online shop

We recently launched a new online shop which will sell a range of branded clothing items and products to raise funds for our work.

Our Head of Fundraising, Sean McCallion, explains: “Back Up is a community made up of people with a spinal cord injury, their family and friends, hundreds of volunteers, supporters, donors and fundraisers – all of whom play a part in making Back Up such an amazing organisation. Setting up an online shop felt like a great new way for people to engage with us and show their support.”

The shop will sell cycling and running vests, t-shirts, Christmas cards and more. We will also sell gift cards, offering people the chance to buy a life-changing experience for someone with a spinal cord injury in a friend or loved one’s name (read more about

our gift cards on page 11).

Alongside our sports clothing and fundraising items, we plan to sell a small number of products which will be useful for anyone but particularly helpful for people with a spinal cord injury. We’ll be selling reusable straws and insulated coffee cups, and we hope to expand our selection in the future so that we can be a one-stop shop for lots of useful products.



You can visit our online shop now at www.backuptrust.org.uk/shop

Young people have a voice

Our youth advisory group (YAG) is a forum for children and young people to develop our under 18s services. We recently spoke to Hannah about why she decided to become a youth advisor.

In 2013, Hannah, now 17, underwent an operation that went wrong. While she was recovering, she contracted meningitis which caused fluid to leak into her spine – damaging her spinal cord and leaving her with a permanent injury at the T10 level.

While she was at Sheffield Children's Hospital, a nurse mentioned Back Up to Hannah. She got in touch and went on one of our YAG weekends. "It was really fun with so many different activities across the two days."

Since that initial meeting, Hannah has gone on to become a youth advisor – a volunteer who helps to shape our under 18s services. "I really enjoy helping the charity. We get a say in how things are organised, and it gives



us more independence."

For Hannah, one of the most important things about getting involved is meeting other young people who understand her experiences.

"Every time I come back from a YAG weekend, I feel more confident. I've made friends with people who have gone through similar situations to me. It makes me feel better to know that I'm not alone."

To find out more about joining the YAG, please get in touch with Ella at ella@backuptrust.org.uk. Our next YAG weekend will be taking place 1-3 February 2019.

MEMBER DISCOUNT

To celebrate our new partnership, we are offering you a 10% discount on the value of a brand-new **RGK** wheelchair

- To claim simply contact RGK and ask to arrange a product demonstration or assessment with one of our experienced and friendly mobility advisors
- Mention you have a Back Up voucher to apply
- Present the voucher to your mobility advisor during your assessment for completion
- Receive your quotation with 10% discount added

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Getting support from people who can understand

As a person with a spinal cord injury who can walk, Shelley often felt like she didn't fit in. Through Back Up, Shelley met a community of people who understood how she felt.

In 2013, Shelley was involved in a car crash that left her with an incomplete spinal cord injury. She walks without aids but experiences pain, fatigue and poor temperature regulation – issues that people can't necessarily see. "People don't get that I can't turn my head, that I can't carry things far, that I need to know where the toilets are," Shelley says.

Luckily, Shelley found Back Up online and got in touch with our

mentoring team in 2015. She was matched with a mentor who could walk and had been through similar experiences.

"I wanted to speak to someone who understood the psychological adjustment I'd gone through. We spoke about work, university and having an invisible disability. It was so useful," Shelley adds.

Shelley then went on our Next Steps course, designed by and for people with a spinal cord injury who can walk. It was the first time she'd met

“It was a safe space to talk through all these problems”

a group of people who were all facing the same challenges.

"It was amazing. It was a safe space to talk through all these problems and to meet people who, like me, had gone through a trauma."

Two years later, Shelley is now a mentor and volunteering as a group leader on the Next Steps course – sharing the experiences and advice that she'd found so helpful. She also qualified as an occupational therapist (OT) in 2017.

"Having a routine, something to get up for and have a lot of pride in, is so important. It all helps me feel like I'm just getting on with my life."

With a full-time job, volunteer work, and friends and family to see, Shelley recognises that taking care of her health is incredibly important.

Shelley explains: "I learned to speak up for myself and be honest with my friends, family and colleagues about my limitations. I ask for help when I need it, which can take a bit longer, but then people get a little insight into how an injury affects you."

Shelley also makes sure that she saves energy so she can go out and enjoy herself. "You don't want to spend all of your time doing the things you have to do and have no time or energy left to do the things you'd like to do."

“I learned to speak up for myself”



Shelley with friends at the 2016 Back Up Ball

If you'd like to find out about our services for people with a spinal cord injury who can walk, please contact our outreach and support team at outreachandsupport@backuptrust.org.uk or call 020 8875 1805.

Get involved with Back Up at Christmas

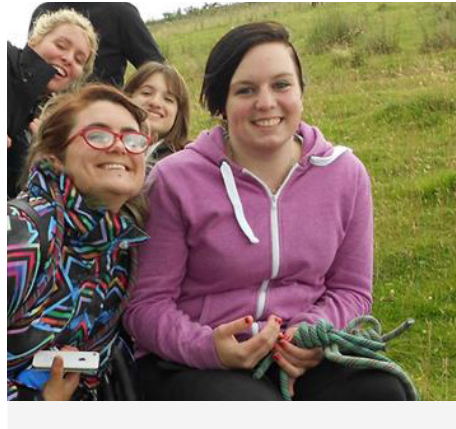


Back Up Christmas Cards

This year, we're selling seven different Christmas cards to raise funds and awareness of our vital services for everyone affected by spinal cord injury. Make sure to order early to avoid disappointment.

All cards come in packs of ten with envelopes included and cost £4.50. The message inside reads "With Best Wishes for Christmas and the New Year".

To buy your cards online, please visit our new online shop at www.backuptrust.org.uk/shop

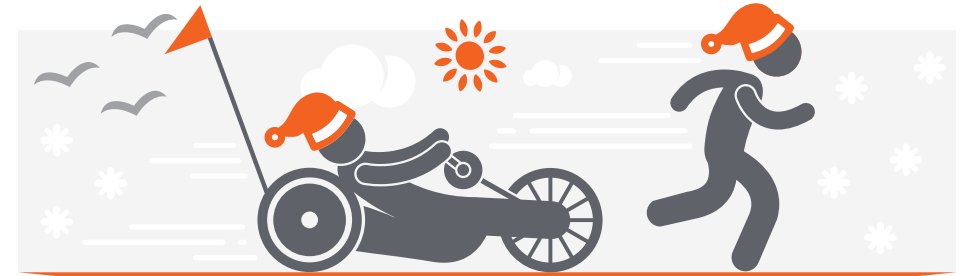


Back Up's Christmas Appeal

Our Christmas campaign this year focuses on how we supported Eleanor to attend her chosen course at university, which took place in an inaccessible building. Last Summer, lifts and ramps were fitted so Eleanor could finally start her textiles course.

"It has taken 18 months and it's been hard but so worth it. I couldn't have done it without Back Up."

You can read Eleanor's story and make a donation at www.backuptrust.org.uk/get-involved/xmas



Back Up Gift Cards

Looking for an unusual and uplifting present - something that's guaranteed to raise a smile? You should take a look at our range of charity gift cards!

Instead of soap and socks, you could buy a kayaking lesson for someone adjusting to life with a spinal cord injury, or a camping and bushcraft experience for a child on one of our exciting outdoor activity courses. Your gift could transform someone's life.



Buy a gift card today at www.backuptrust.org.uk/shop

Accessible Santa run and Jingle Mingle event

If you're based near London, why not join the Back Up team for a festive 5k Santa fun run/push on 8 December in Battersea Park. We'll also be hosting our first Jingle Mingle party afterwards at the Lighthouse pub nearby which is open to all supporters

Find out more at www.backuptrust.org.uk/get-involved/special-events/back-ups-jingle-mingle

Hold a festive event for Back Up

If you want to plan your own event to support Back Up this Christmas, Janet, our Fundraising Manager, is here to help. You can email her at janet@backuptrust.org.uk or call 020 8875 6760



Volunteer opportunities for nurses and PAs

This year, we formally accredited all our residential courses with The Continuing Professional Development (CPD) Certification Service. This means that volunteering for Back Up is now not only a rewarding experience, it's also an essential part of your professional development. We recently spoke to Susan about what she gets out of volunteering for Back Up.

Susan always knew that she wanted to work in care, especially as she had spent some time looking after her grandfather. She eventually trained as a nurse and specialised in spinal cord injury – an area she finds hugely rewarding.

She says: "It's so brilliant being able to help people see that there is life after something as devastating as spinal

cord injury. I love my job because you form amazing relationships with patients and their families."

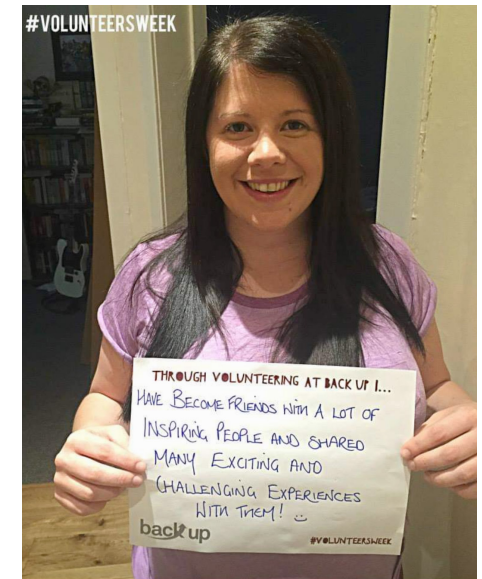
Susan was working at the Queen Elizabeth National Spinal Injuries Unit in Glasgow when she went along to the Stoke Mandeville Games with some of her patients. The physiotherapist leading the activities was a group leader for Back Up. "She talked to me about the work Back Up does and put me in touch with the courses team. The rest is history."

Since meeting Back Up in 2011, Susan has been a volunteer nurse on many of our courses, providing support and assisting course participants with their personal care. She finds that the most rewarding aspect of volunteering on these courses is seeing participants achieve things that they didn't think were possible – especially when newly injured.

"It's wonderful watching people discover new wheelchair skills and learning that they can do things like skiing and abseiling if they want. Seeing the look on people's faces after the course because they now have a different perspective is always amazing."

Merryn, our Interim Courses Manager, says: "We really wouldn't be able to run our life-changing courses without our volunteer

nurses and PAs. For some course participants, it might be their first time away from home since sustaining a spinal cord injury. The care team play an important part in making them feel at ease as they know their personal care needs are being met. In the office, we love hearing about volunteers taking the skills they've developed on a course and passing their knowledge on to their patients or clients."



To find out more about volunteering as a PA or nurse on one of our courses, please get in touch with Merryn at merryn@backuptrust.org.uk

Courses calendar

February 2019

Saturday 2 – Tuesday 12 | Sit Ski course, Colorado

April 2019

Monday 8 – Friday 12 | Multi-activity course, Exmoor

May 2019

Saturday 18 – Saturday 25 | Multi-activity course, Lake District

June 2019

Monday 17 – Friday 21 | Multi-activity course, Exmoor

July 2019

Tuesday 16 – Saturday 20 | Moving Forwards 18-25s, Leeds

August 2019

Monday 29 July – Friday 2 August | U13s multi-activity course, Lake District

Monday 5 – Friday 9 | 13-17s multi-activity course, Lake District

September 2019

Monday 9 – Friday 13 | Over 50s multi-activity course, Lake District

October 2019

Friday 4 – Tuesday 8 | Skills for Independence, Coventry

Thursday 26 September – Tuesday 2 October | City Skills, Edinburgh



To find out more, visit our website at www.backuptrust.org.uk/support-for-you/life-changing-courses



fittleworth

fighting Fit

Fittleworth Medical participated in this year's 2018 Snowdon Push. This is Back up's toughest yet most exhilarating fundraising event and it tested our team to the max. Fifteen people from Fittleworth and Tate Fletcher, our wheelchair user, made it to the top of Mt Snowdon and back again in just over 5 hours, climbing 3,560 ft.

Our sincere thanks to the amazing team at Back Up and Tate for a very memorable event.



"Reaching the summit of Snowdon was so amazing, something I never thought I'd do. The memories of it help me through the tough days and remind me that with help anything is possible." Tate Fletcher



Taking on Mount Snowdon

The Snowdon Push is Back Up's most exhilarating fundraising challenge. It involves teams of between 10 and 16 people aiming to conquer the highest mountain in England and Wales, Mount Snowdon. One member of the team must be a wheelchair user, and together they push, pull and climb towards the summit and back again.

This year, our 12 teams raised almost £70,000 – all of which goes towards our work supporting people affected by spinal cord injury. Paula Clarke, 54, decided to take part and was matched with the ACG Cliffhangers team – an architecture firm from Basingstoke.

For Paula, the opportunity to return to the top of Snowdon – a climb

“Never in my wildest dreams did I believe I'd see the top of that mountain again!”

she'd made five years before – was too much to miss out on. Paula adds: “Never in my wildest dreams did I believe I'd see the top of that mountain again! I soon began to feel the excitement of all that lay ahead.”

When the day arrived, Paula felt confident in her team and supported throughout the entire challenge. “I learnt to put my trust in people I barely knew, but they were very caring and considerate, always checking that I was OK,” Paula says. It was a fantastic moment for the entire team to reach the top of Snowdon and realise what they had all achieved together.

“Reaching the summit was exhilarating. The weather was gorgeous and the views from the top were stunning. I could still see the orange Back Up t-shirts of all the other teams, vibrant against the backdrop of the mountainside.”

As they descended the mountain and realised they were nearing the end, Paula and her team made one last push to reach the finish line where they were greeted by a sea of Back Up supporters, clapping and cheering them on. “We had done it! I

felt so emotional and proud to have taken part,” Paula adds.

Not only were ACG Cliffhangers the third-fastest team, they raised the most money and received the top fundraiser award. Paula says, “The whole experience was so amazing and one of my biggest achievements since my spinal cord injury two years ago. It was emotional, tough, fun, challenging and so rewarding. One of my most memorable days ever.”



If you'd like to take part in The Snowdon Push in 2019, please get in touch with our Events and Challenge Fundraiser, Alex, at alexandra@backuptrust.org.uk or call her on 020 8875 1805.

Fundraising calendar

November 2018

Saturday 17 | Back Up Ball

Tuesday 27 | Giving Tuesday bucket collection

December 2018

Saturday 8 | Back Up's Jingle Mingle

Friday 14 | Christmas bucket collection

March 2019

Thursday 21 | Front Row

Sunday 24 | London Landmarks Half Marathon

April 2019

Sunday 28 | London Marathon

May 2019

Thursday 2 | City Dinner

Sunday 12 | Salford Dragon Boat Festival

June 2019

Saturday 22 | Snowdon Push

Monday 30 | Kayak the Great Glen

July 2019

Saturday 6 | No Limits Dover to Brighton ride

August 2019

Sunday 4 | Ride London



To find out more, visit our website at www.backuptrust.org.uk/get-involved

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Expanding our reach in Scotland

In December 2017, we were thrilled to appoint our first outreach and support coordinator with a spinal cord injury in Scotland who has made a huge impact in his short time there.

Since Rich Osborn has been in post, he's grown our Scottish volunteer base considerably. This has allowed us to run more wheelchair skills sessions and contribute to more patient education talks than ever before



at the Queen Elizabeth National Spinal Injuries Unit in Glasgow. We've established closer working relationships with the staff there and with our colleagues at Spinal Injuries Scotland (SIS) too.

Seonagh, a support nurse who works at Glasgow's spinal unit, was delighted to see us introduce a coordinator dedicated to our work in Scotland. Seonagh explains: "Rich's increased presence within the unit allows him to provide invaluable help and advice from someone with real-life experience of living with a spinal cord injury. Our patients continually tell us that this is fundamental to their rehabilitation."

Rich has also increased knowledge and awareness among staff and patients about Back Up's peer-led services. Seonagh adds, "Staff are better equipped to inform patients and relatives of the ongoing support available to them. Rich is also able to keep in contact with our patients post discharge after meeting them in the unit and establishing a rapport."

This means we can stay in touch with



Rich (right) leading a Back Up wheelchair skills session at Glasgow's spinal unit

those people who, following their rehabilitation in Glasgow, return to rural locations where they have limited access to support. Rich can now contact these people in isolated areas and offer support from his own experiences as well as refer people through to our services and other organisations that can help.

As well as increasing our presence in Glasgow, Rich has been in contact with general hospitals in Aberdeen and Inverness – educating people about Back Up's services and looking for opportunities to work together. Our early conversations with these hospitals have been very encouraging, and we hope to pilot wheelchair skills sessions at both

these locations soon.

We're excited to build on these successes and reach more people in Scotland in the years to come. "In less than a year, we've managed to build a stronger volunteer base, establish better relationships with spinal unit staff members, and increase our presence outside of Glasgow and Edinburgh. I'm so proud of all we've achieved so far," Rich adds.

If you'd like to find out more about our work in Scotland, please contact Rich at rich@backuptrust.org.uk or call 07738276731.



Managing pain

Dr Jasmine Hearn is a chartered psychologist and lecturer, specialising in pain management for people with a spinal cord injury. She shares her views and experience with us.

“Studies vary on an exact number, but around 50% of people with a spinal cord injury experience neuropathic pain. People describe this pain as sharp and sudden, like a burning or electric sensation. The brain sends messages down to the legs and feet, but it doesn't receive

an appropriate response – causing the brain to interpret this as pain. That's not to say that the pain isn't real. It's just that the brain is misinterpreting the signals.

When it comes to managing its effects, research shows that acceptance of living with pain can make a big difference. People are often looking for complete pain relief, but by seeing that pain is a part of daily life, not something that can be erased, they often become more resilient. Treating depression can also help to alleviate pain, as can cognitive behavioural therapy (CBT) and mindfulness. There's no one-size-fits-all solution though and you just have to see what works for you.

Back Up can support people who experience pain by matching them with a mentor who can listen and discuss the challenges faced. Having that peer support from someone who's been through something similar themselves is really important. ”

Our full Q&A with Dr Jasmine Hearn will soon be available on our website. If you'd like to speak to someone about your experiences of pain, please contact our services team on 020 8875 1805

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The impact of Back Up's work in 2017/18



939

We registered **791** new people with a spinal cord injury and **148** new family members to receive our support



624

people were trained in wheelchair skills in hospitals



90%

of people felt more confident in their abilities after a Back Up wheelchair skills session



92%

of family members felt more supported after attending one of our relatives' days



82

people attended one of our residential courses which help you to learn new skills and develop your confidence in a supportive environment



140

people were matched with a trained mentor to help them make positive changes in their lives



95%

of people achieved their personal aims for their mentoring relationship



578

people were supported by telephone on topics like travel, relationships, bladder management and work



100%

of people who attended our Back Up to Work course felt that work with a spinal cord injury is more manageable



38

children and young people with a spinal cord injury were supported at different stages of their education and all of them felt happier after receiving Back Up's help

Family mentors provide invaluable support



When Caroline's son, Tim, sustained a spinal cord injury in a skiing accident in 2004, it took a long time for her to process what had happened. "It took me several years to even say the word 'paralysed'. I have a background in nursing and I went into that kind of coping mode which helped me deal with it."

Tim first met Back Up almost a year after his accident when he went on one of our sit ski courses. Caroline was anxious about how he'd manage the trip, especially as he had sustained his injury through skiing in the first place. "I was so worried while he was away, but it

was clear that he'd had such an amazing experience when he came back. It led to other opportunities for him, and I realised that Back Up was transforming his outlook and what he was able to do."

A few years later, Caroline decided to volunteer as a Back Up family mentor because she really wanted to offer support and encouragement to other parents of people with a spinal cord injury. "In the early months after Tim had his accident, there was no one for me to talk to – no one really understood everything that family members go through when someone has a spinal cord injury."

What does volunteering as a mentor involve?

- Providing up to ten sessions of telephone support
- Enabling people to work through their challenges using personal experience, problem-solving techniques and goal setting
- Having experience of spinal cord injury, being a good listener, compassionate, and non-judgmental



Caroline with her son Tim

For Caroline, being able to offer others the support that she found helpful is very rewarding. "I always knew that I could ring up Back Up and ask for help. It's good to know that I can offer that to someone else."

Our Family Mentoring Senior Coordinator, Charlie, says: "Caroline and all our fantastic mentors offer invaluable support based on their own experiences. Without them, we could not run our mentoring service."

Our next training weekend for family mentors is taking place 25-28 Jan 2019. Applications are open to all family members. To apply, get in touch with Charlie at charlief@backuptrust.org.uk or call 020 8875 6763.



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