

Spring 2023

NEWSLETTER

**My name
is Zoe and I'm
37 years old.**

“ I work for a disabled access charity called Euan’s Guide. I work with them 12 hours a week at the moment and I really enjoy it.

I’ve been coming to Cerebral Palsy Scotland since 1995. I’ve always found that therapy here has helped me both physically and mentally.

As a child with cerebral palsy you get a lot of input from the NHS to try and improve things like posture and coordination, and to be more active or mobile.

But when you reach the age of 18 you seem to drop off the end of the earth and no one really knows what to do with you. I think that’s partly because cerebral palsy isn’t really recognised as a long-term condition generally so people don’t have the knowledge of how it affects an adult fully.

I always find it really frustrating because I know that the NHS generally is a fantastic service and everyone is grateful for it. But as an adult with cerebral palsy I’ve had very different experiences of being treated as an adult with a long-term condition.

I have had problems with hip dysplasia and pain in my hips for a long time. I started to notice it in 2012 but it wasn’t until 2021 that I finally got a hip replacement operation, after I found a surgeon who was willing to give me a hip replacement rather than remove my hips completely.

The surgeon opted to give me this type of operation, so I could maintain my self-transferring. Then, in 2022 I got a second hip replacement operation.



Following the surgery I wasn’t getting the rehab support I needed from the NHS.



The physios I worked with told me I shouldn’t be standing, I shouldn’t be walking and I shouldn’t be trying to self-transfer. I got to the stage that I didn’t know where to turn anymore. Wherever I went it felt that someone was closing the door in my face and saying, “No you can’t do that, so we won’t even try”. I felt like I had been put on the scrap heap. I know that sounds dramatic but that is how it felt.

I know that, as an adult, I’m not as mobile as I used to be. You realise that you need extra help in order to function in everyday life. You may have been able to do something at one stage and now you can’t do it as easily anymore. That is really difficult to deal with mentally – it’s hard to come to terms with.

But, even though I know my abilities are changing as I get older, and although I’ve had two hip replacements, I still want to keep trying, and try to function to the best of my ability.

Continues inside...



At Cerebral Palsy Scotland, all the therapists are willing to try different things. They genuinely want to help and make a difference. They never say, "That is over ambitious" or "that's not realistic" - they take note of it and say "let's work towards it". It is that kind of optimism and willingness to help that I think makes such a big difference, especially when you are in such a lost situation.

In my sessions last year at Cerebral Palsy Scotland, the motivation was to maintain the mobility that I have and the movement I have.

The therapists are specialised and have knowledge of cerebral palsy; they understand what works and what doesn't and understand how your body reacts to certain movements. They understood how much pain I was in. All that really helped physically and mentally.

Some of the things we have worked on in recent sessions are things that I've always had problems with. For me the first sessions were to work on my back issues, which gets rid of a lot of the pain which was the first goal. Then from there it is learning to move properly - so trying to learn how to move to stop the same problems from happening again.

One of my longer-term aims is to get back to standing transfers on and off the toilet. In the last sessions I used the hoists in one of the rooms to try and take some of my weight so I can focus on how to transfer my weight to be able to walk a couple of steps.

The first time I got in the hoist and started to move I started crying, because I never thought I would ever get to this stage because of all the feedback

I got from the hospital. Being able to transfer from one place to another was great. In the last session we practiced rolling over, because I thought maybe if I learn how to roll over I can learn how to get out of bed. It's a big step but a step in the right direction. It is giving yourself small goals which add up to bigger things.

I thought the other day about what would be different about my life if Cerebral Palsy Scotland didn't exist, and I got quite emotional. There just wouldn't be the same appreciation of how cerebral palsy affects people. There wouldn't be people going the extra mile.

Without Cerebral Palsy Scotland the world for people with cerebral palsy here would be a much more difficult and challenging place. ”

Cerebral palsy awareness month

March 2023

This year we are launching our biggest-ever social media awareness campaign to raise the voices of people with cerebral palsy in Scotland.

We are collaborating with a group of volunteers who have lived experience of cerebral palsy to design content about things that are important to them. Look out for the stories on our social media platforms throughout the month of March.



Go Green for CP

This cerebral palsy awareness month, join us and #GoGreen4CP.

We want you to wear green to raise awareness of cerebral palsy during the month of March but particularly around 25 March – cerebral palsy awareness day.

Encourage your friends, family, school or colleagues to make a donation and join you as you #GoGreen4CP.

If you would like collecting cans or buckets, or balloons please get in contact with us at GetInvolved@cpscot.org.uk.
#CerebralPalsyAwarenessMonth



Join our Walk 'n' Roll virtual challenge.

Get moving this March in a way that works for you. Join our Walk 'n' Roll virtual challenge using your wheelchair or powerchair, walking frame, frame running bike, trike, feet, or body!

Set yourself a challenge and raise vital funds to power our work so that every person with cerebral palsy in Scotland can reach their full potential.

All you need to do is:

- Sign up and set your goal
- Join our Walk 'n' Roll Facebook group
- Get your free t-shirt

Find out more at: cerebralpalsyScotland.org.uk/event/walk-n-roll-march-challenge



How we're raising awareness of cerebral palsy

Across 2022, our campaigning and policy work raised awareness of the changes that need to be made so that every person with cerebral palsy has access to the support and healthcare they need to make the most of their abilities.

Building on the publication of the Neurological Alliance's '1 in 6' report, on 15 November we attended a debate in the Scottish Parliament on 'Improving Outcomes for People with Neurological Conditions' and a further meeting with the Minister for Public Health, Maree Todd MSP. The Minister confirmed that the funding to deliver the remaining two years of the Framework for Action for Neurological Conditions remains available and we look forward to working through the

National Advisory Committee for Neurological Conditions to ensure that services and support for people with CP remain part of this implementation work.

Our annual conference on 6 October - World Cerebral Palsy Day - was a fantastic day and an opportunity for the cerebral palsy community in Scotland to come together, raise awareness and share information and knowledge.



In November we hosted a reception at the House of Lords by invitation of the Lord Speaker. The event considered how we can build a better future for people with cerebral palsy and everyone in the room committed to working towards real change.



Firewalkers feel the Burn

On Burns Night 30 brave souls helped to power our work by taking on a firewalking challenge to support children and adults with cerebral palsy in Scotland.

The fantastic evening couldn't have been made possible without the amazing team at Allied Mobility who kindly gave us the use of the Glasgow Tigers Speedway track as a venue for the event and provided delicious food for the firewalkers and their supporters.

The event raised a total of **£6,564**. Thank you to all our firewalkers who braved the coals!





Meet Mirren and Kerin

Mirren's mum Kerin talks about their experiences of coming to Cerebral Palsy Scotland and the impact therapy sessions have had.

“ Our daughter Mirren is two years old. She has an older brother and two sisters, and we live in Newton Stewart.

I wouldn't change Mirren for the world. She's very affectionate. She just wants cuddles all the time. I would say she's just such a content wee soul now considering the amount of things that she can't do for a typical two year old.

Getting the diagnosis has opened up a whole new life

From birth we thought there was something wrong with Mirren. She wouldn't settle, she didn't like anything really. We noticed she didn't seem to use her right side. As she got a bit older, she wouldn't swallow or chew properly. But we kept being advised that it was because of reflux, or that some babies favour one side, or that some are slower to wean.

When she was seven and a half months, she was eating something and I noticed she flung herself forward and her eyes started rolling. We took her to the GP and the doctor was brilliant. We were sent to Glasgow for an EEG and they diagnosed infantile spasms. She was put on medication while we waited for an MRI scan.

After the MRI, that's when the doctors told me what had happened. They told me she's had an antenatal stroke and they said there's a high chance that Mirren could have cerebral palsy and a high chance she could have autism. They said all of this would have a big impact on her development and she might never walk, she might never talk. So I was trying to take this in myself, not expecting a diagnosis that day. I came home in an absolute mess.

At times I've felt like I was grieving for a child that was still alive. I feel like I'm waiting on the unknown. I constantly feel like I'm watching her to see what's coming.

But getting the diagnosis was good because it's opened up a whole new life really. We understood; we had answers. And the medication made a big difference to her mood. She was like a different baby, which made it so much easier for all of us.



My goal for the therapy sessions was to have Mirren standing

I first found out about Cerebral Palsy Scotland through my local physio and occupational therapist. They asked me if they can refer her for the outreach sessions Cerebral Palsy Scotland were doing in Dumfries.

My goal for the Cerebral Palsy Scotland therapy sessions was to have Mirren standing. Because she wouldn't put her legs down at all.

Lesley and Sandra – the therapists from Cerebral Palsy Scotland - showed me how to use a bench and distract her with a toy so I could then discreetly encourage her to weight-bear on her right side, and use her right hand to lean on. Because, at that time she wasn't using her right side much at all.

I remember the first night when we came home, Mirren started lifting her right hand and looking at it, as if to say, "Oh, ok, you're

there". Because before that she hadn't even acknowledged it.

They showed me things like blowing bubbles and then taking her left hand and hiding it behind her back, so that she had to pop them with her right hand. And they showed me to put toys on the right of me, so that she would grab them from the right hand side.

We had five sessions with Cerebral Palsy Scotland – the last one was in December. And literally, in January she started standing. She started pulling herself up one day, onto the toy box. And she just got up and I was like, "Oh my God!"

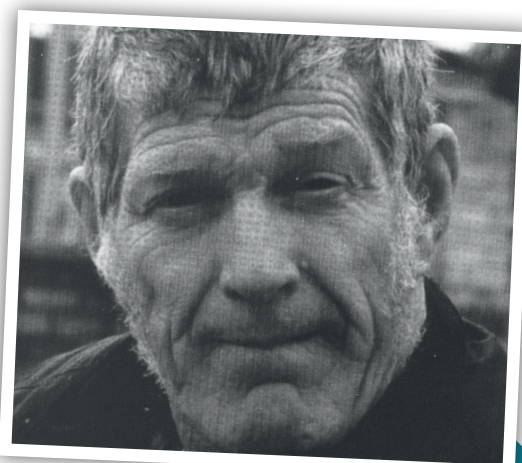
The things that the Cerebral Palsy Scotland team taught me and taught Mirren - I definitely learned things I would never have thought of doing.

Lesley and Sandra were great, they were so calm with her. If things didn't work, they would try something else. They wouldn't give up until they found something she liked and she was happy with what was being done.

There were so many different ways that they showed me. I was totally amazed. They played a big part in her becoming aware of her right side, and her doing what she's doing now. ”

The outreach sessions to Dumfries and Galloway were funded with thanks to National Lottery players and The National Lottery Community Fund.





Edward Stanton leaves a lasting impact

Leaving a gift in your will can have a life-changing impact for people with cerebral palsy in Scotland and their families.

We are grateful to Edward Stanton, who decided to leave a legacy to Cerebral Palsy Scotland in his will. Below, Edward's friend Peter writes about Edward and what motivated him to donate in support of people with cerebral palsy.

“ I'd like to tell you about Edward Stanton, a man I am proud to have called my friend. Born in 1939 he was diagnosed soon after with cerebral palsy. In keeping with the times he was considered uneducable so did not attend mainstream school. Worse still, at the age of seven he was removed from his family in Glasgow to Caldwell House near Lugton in Renfrewshire and later to Lennox Castle Hospital, Lennoxtown. Deliberately placed out of sight it took a lot of effort using public transport for his family to visit. That determination was shared by Edward and reflected in his irrepressible spirit and the opportunities that he took to enhance his prospects and those of others.

Edward stayed in Lennox Castle until he moved back to live with his family in 1967. A life-long Celtic fan, let's just say that was a very good year. Gradually he built up his own way of living and took on the family tenancy.

To say Edward embraced life with both hands would be an understatement. His sense of

fun meant he was always up for an escapade, the hairier the better. At the same time he was a powerful advocate for others and as opportunities arose for him to access support to live in the way he wanted so he encouraged and educated others on how to do so too. Through rights based campaign work, direct action and group advocacy he enthused and emboldened others. He took part in training events with nursing and social work staff and students not to mention regular letters to Scottish Ministers and local councillors. His persistence and determination to find a way was clear.

Edward used his story to encourage others. He had several versions of his biography and he didn't let his lack of formal education get in the way. He typed out a version of his story on computer using one finger, words, dictated to him letter by letter by letter. During a difficult time at work I asked him how he managed to get through all those years in institutional care. His reply "I just had to believe that one day it would be better" embodies all those qualities.

Edward died in July 2021 having taken ill when watching his beloved Celtic. He asked in his will that a donation be made to Cerebral Palsy Scotland. I am pleased to be able to carry out his wishes in a tribute to his sense of generosity and justice. ”

If you would like to discuss leaving a gift in your Will or making a donation in memory of a loved one. Please get in touch with Kelly Kolatowicz on **0141 352 5000** or **Kelly.Kolatowicz@cpscot.org.uk**

Kiltwalk superstars

Huge thanks to our superstar supporters who put on their kilts and walking boots for the Kiltwalk's Wee Wander, Big Stroll and Mighty Stride challenges in Edinburgh. We had 15 walkers take on the challenge to support people with cerebral palsy in Scotland. It was another record breaking event for us raising an incredible total of...

£15,225!

With distances between 3 and 26 miles there is something for everyone. Come join us for Kiltwalk 2023. Registration is now open so sign up and join us at

cerebralpalsyscotland.org.uk/event/kiltwalk-2023-glasgow



Save the date: Dragon Boat race day 2023.

The annual Dragon Boat race day for Cerebral Palsy Scotland is taking place on 3 June on the shores of Loch Lomond.

Dragon Boat racing is a fun-filled, team water sports competition – no experience is needed to take part.

Could you be part of the team that can work through the heats and emerge as the overall winner?

Register your interest now by getting in touch with Hester Lee on **0141 352 5000** or GetInvolved@cpscot.org.uk.



A few words of thanks

A massive thank you to Jo MacMonagle and Team Bailey who raised an amazing **£2,609** by taking part in the Paisley 10km and fun run.

Thank you to Vivian Maeda who raised **£1,400** by completing the Scottish half marathon.

Special thanks to Gillian Scott who completed the Great North Run, her 19th London Marathon and held her annual charity ball, raising an incredible **£4,000**.

Huge thanks to Glasgow YouTuber Ryan Fitzsimons for doing a 12-hour sponsored stream for Cerebral Palsy Scotland. Ryan's stream was watched by over 9,000 people and raised a wonderful **£375**.

Jack Ovenden and his friends did a 40-mile sponsored cycle ride in honour of Jack's brother, Matthew, who attends the centre. This is the boys second sponsored ride, they did a fantastic job and even increased their distance from last year! They raised **£1,810**.

We also want to say a heartfelt thank you to all our wonderful Facebook birthday fundraisers and everyone else who has given their time over the last few months to fundraise and improve the lives of children and adults with cerebral palsy Scotland.

THANK YOU



Festive fun

In December we were delighted to bring people with cerebral palsy and their families together through hosting a festive family party and an adults' lunch. At the family party, we had ornament decorating, a visit from Santa, a Christmas jumper competition and a Christmas film screening. Marion Burns organised a fantastic quiz for the adult lunch and there was a huge spread of food.

It was great for everyone to get a chance to catch up after a long time away and it was lovely to see the centre full of activity before the holiday.



Mental health and wellbeing update

We are delighted to announce that we are recruiting for a part time clinical psychologist to provide psychology support to people with cerebral palsy when they need it most.

This would not be possible without the support of People's Postcode Lottery, Scottish Children's Lottery, Pixel Fund, Hospital Saturday Fund, James and Grace Anderson Charitable Trust.



How you make a difference

Because of your generous support over the past year

We have delivered **1069 hours** of therapy

and supported **129 children and adults** with cerebral palsy



Become our Friend with a regular gift

As a Friend of Cerebral Palsy Scotland your regular donation will provide vital physical and emotional support so that every person with cerebral palsy in Scotland can reach their full potential.

Scan here for more information



Lotto

Glasgow Community Lottery is a fun way to support Cerebral Palsy Scotland and be in with a 1 in 50 chance each week to win a prize, with a top prize of **£25,000!**

Tickets for the lottery cost £1 per week and 50% of the funds come to Cerebral Palsy Scotland with the remainder going into the prize pot and supporting other great charities in Glasgow.

To take part, visit our website:



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