Annual Review
2020•21

cerebral
palsy
scotland

2020 • 2021

A YEAR LIKE NEVER BEFORE

Joint statement from our Chairman and CEO

This year has been like no other for all of us. At the end of March 2020 we had no idea how the pandemic would affect people with cerebral palsy (CP) or our organisation.

What we did know was that cerebral palsy was being highlighted as making people more vulnerable to the effects of Covid. Very quickly we all had to adapt to lockdown and restrictions. Our physical contact as we knew it, with people and with services and even our board meetings, changed to online. We are extremely grateful that funders were quick to provide emergency funding to ensure that we could pivot our services to meet the new and different demands.

Providing trusted information and interpreting the changing guidance relevant for people with cerebral palsy became an essential part of our support, as did ensuring that we kept in touch with families and those who were experiencing increased anxiety and isolation as so many other services and opportunities shut down.

We have shared expertise and evidence from our lived experience surveys to ensure that policy makers and the wider community take the needs of people with CP into account.

Changing our name to Cerebral Palsy Scotland recognised a long held strategic aim to further raise awareness of cerebral palsy and enable us to reach everyone affected by CP across the country. We pledge to continue this work in the coming year and be led by doing what will most benefit and improve the lives of people in Scotland with CP.

Ian Johnstone
Chair of Trustees

Stephanie Fraser
CEO Cerebral Palsy Scotland

What is cerebral palsy?

Cerebral palsy (CP) affects a person's ability to control their movement, posture and balance.

Cerebral palsy is the most common physical disability in children. Around 1 in 500 births will result in a diagnosis of CP and in Scotland around 150 children are diagnosed each year.

No two people experience cerebral palsy in the same way. How someone is affected will depend on the type of cerebral palsy a person has and how much of their body is affected. As well as affecting movement, cerebral palsy can affect other areas of function.

Of those people living with cerebral palsy

1 in 4
is unable to talk and uses alternative methods of communication

3 in 4
experience pain

1 in 4
has epilepsy

1 in 2
has a learning disability

1 in 4
has bladder control problems

1 in 5
has a sleep disorder

1 in 5
has saliva control problems

1 in 3
is unable to walk

In Scotland, there is not enough specialist support and services for people with cerebral palsy and their families. Cerebral Palsy Scotland exists to close this gap.

Our mission

We provide specialist therapy and other opportunities to help people with cerebral palsy build skills, knowledge, confidence and relationships. We advocate for the cerebral palsy community to have life-long access to knowledgeable, compassionate services and support.

Our values

Our values describe what we stand for, and how we work.

We see the whole person

We listen to and work alongside the person with cerebral palsy, their family, and those around them. We understand that people with cerebral palsy are unique individuals and we create personalised approaches.

We are always ambitious

We enable people with cerebral palsy to pursue achievement at all levels and in whatever way they choose to define it. We aim to open people's eyes to the next opportunity.

We are kind

We are unapologetic about putting kindness and compassion at the heart of our work. Supporting emotional health and wellbeing can have as big an impact on people as supporting function.

We stay practical

We use our knowledge and expertise to work in practical, direct ways. We create useful services that reflect what people with cerebral palsy want and need. Our growth is guided by what's best for the cerebral palsy community and not what's best for Cerebral Palsy Scotland.

We build relationships

We want to reduce the number of people who "know no one like me". We build relationships with and between people with cerebral palsy and their families. We enable the cerebral palsy community to network, share and collaborate. We work positively with health and education professionals, organisations and government to get the best outcomes for people with cerebral palsy.

How we helped

Over the past year, Cerebral Palsy Scotland adapted existing services, and created new ones, to respond to the needs of the cerebral palsy community as the pandemic progressed.

- Working within the context of Covid restrictions, we continued to provide therapy sessions throughout the pandemic. Between July 2020 and March 2021 we treated a total of **107** individuals either in person, online or as a home or school visit. This included:
    - **342** sessions delivered since mid-July in the centre
    - **272** CP Connect sessions offering free therapy and support to children and adults with cerebral palsy during the Covid outbreak
    - **104** virtual sessions
    - **21** home visits
- We shared information and guidance on Covid relevant to the cerebral palsy community on the Cerebral Palsy Scotland website. Between 16 March 2020 and 31 March 2021, Covid-related content on our website was viewed **8000** times.
- Between April 2020 - March 2021 we sent **26** e-newsletters to over **1500** people in our community, including weekly e-newsletters at the height of the pandemic.
- Regular advice and support by telephone and email throughout the past year.

- Produced five 'therapy tips' videos to support both adults and children with cerebral palsy to keep moving during lockdown.

- Hosted weekly virtual 'coffee and chat' Zoom sessions for adults. Attendees felt socially isolated and the informal sessions helped to provide peer support and information sharing.

> **It was great, because at first it was the only time I saw people and I could catch up with my friends, even in lockdown. Seeing a friendly face helped me a lot every week." (Marion)**

- Carried out three surveys with the cerebral palsy community in Scotland. The results of these surveys were used at national level to highlight and raise awareness of the negative impact of restrictions on the physical and mental health of people with cerebral palsy and their families.

- Welcomed over 100 participants to our online conference held on 1 October. Supported by Digby Brown Solicitors, the event focussed on information sharing and discussion.

Providing therapy during a pandemic
CP Connect

It was immediately clear that the pandemic, and the restrictions that came with it, would negatively impact the physical and mental health of people with cerebral palsy and their families.

People experienced a reduction in the services they would typically receive, with appointments cancelled and support moving to telephone and virtual consultations.

Providing hands-on, face-to-face therapy using the Bobath concept is at the heart of what we do at Cerebral Palsy Scotland, so the charity had to act quickly to find new ways to reach people and offer much-needed help and advice.

Our response was to create CP Connect. With support from the Scottish Government and other funders, we created a service offering free therapy and support to any child or adult anywhere in Scotland with a diagnosis of cerebral palsy.

Over the past year, we have completed...

272
CP Connect sessions in total

which included

125
adult sessions

147
child and family sessions

At the outset, therapy sessions were offered virtually. By July 2020, we were able to re-open our Glasgow centre to offer in-person support, whilst adhering to strict protocols. Virtual consultations continue to be available as long as they are needed, allowing us to help people who cannot access the Glasgow centre.

Most people using the CP Connect service have between four-six sessions. The most pressing issues continue to be physical, particularly chronic pain and stiffness, due to the general fitness and mobility issues faced by people with cerebral palsy and which have been exacerbated by the lack of access to usual support and services.

The service has also assisted people with mental health and wellbeing, with specialist support provided by our Consultant Clinical Psychologist, Dr Joy Nisbet, who has both directly supported individuals and provided the psychological context for co-ordinating services and next steps.

Whilst CP Connect has not provided the longer intensive blocks of therapy we have traditionally offered, it has supported many people and families at a time when statutory services have not been at their normal levels of operation. We look forward to building on our experiences to understand how we can continue to develop responsive and supportive services.

Meet some of the people we've helped

Ella Rose and mum Charlene

"Because of Covid we hadn't been getting as much therapy input, so we came to Cerebral Palsy Scotland for some CP Connect sessions. Ella Rose is three – she's able to use gestures and make sounds, but she was getting frustrated not being able to get her message across as well as she would like.

"In our first session, Claire introduced a **PODD book to Ella Rose** – it's full of words and symbols organised into topics, so it opened up a lot of new vocabulary.

"We weren't sure how Ella Rose would do with the communication aids or whether she was ready for it, but she proved us wrong because she took to it so well.

"She uses her PODD to choose meals, let us know when she's hungry, for bedtime routines, or to choose games. She's getting independence. **She's a different wee girl; she's so much happier now** she's not getting that frustration."

Jennifer and mum Crystal

“Jennifer is 20 now, but she’s been coming to Cerebral Palsy Scotland since she was a wee girl.

“Jennifer had six major operations in the space of a year when she was 12 and the trauma from that meant she developed selective mutism, so she only speaks with me and her sister.

“Jennifer had had surgery on her knee a couple of years before, but then during Covid she suddenly started to get real problems with it again and she became terrified to stand. She couldn’t stand at times and she was asking me **“Why are my legs not working?”**

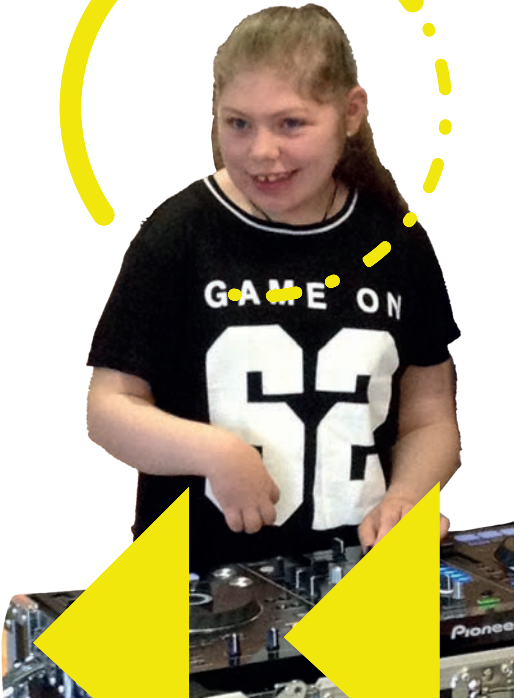
“That was when Sandra and Lesley from Cerebral Palsy Scotland came to the rescue.

“It took a wee while, but the shakiness in her legs started to calm down, and she gradually started to become less frightened. She listens to Sandra and Lesley. They are absolutely fantastic.

“They also put us in touch with a clinical psychologist, to help Jennifer with her anxiety.

“And they also support me too, because I have my own health issues.

‘I’m really grateful to Cerebral Palsy Scotland, they gave us a lifeline, and they helped us both at a really difficult time.”



Fraser and mum Kirstie

“At the beginning of the pandemic Fraser (age three) was put on the shielding list, so during the lockdowns face-to-face things just stopped for him. It was stressful for all of us. Normally he is such a happy, lively wee thing, but over lockdown there was no life about him at all – the spark was gone. Fraser just wasn’t Fraser anymore.

“We began to struggle to get Fraser to do physio ourselves. **His physical side and his emotional side had gone right downhill.**

“That’s when we approached Cerebral Palsy Scotland – **we were at utter panic-stations to be honest.**

“At the beginning of the first session with Leen, Fraser didn’t want to engage. But by the end of that session she was getting him up on his feet and using his standing frame. He’s loving it now – standing up, smiling – you start to see your wee boy come back again.

“We had got an adapted trike for Fraser, and Leen also got that set up for him so it was suitable.

“We also got lots of fresh tips from Claire about using his eye gaze communication aid, as well as advice from the team about selecting a new specialist seat for Fraser.

“Going to Cerebral Palsy Scotland gives us fresh ideas and a bit of hope.”

Adam and mum Katie

“Adam is four. He was born prematurely and we were told shortly after he was born that he had sustained quite a large brain bleed. After an MRI scan, we found out Adam had hydrocephalus and had sustained a stroke. He had a shunt put in when he was ten months old, and when he was about two and a half Adam was diagnosed with cerebral palsy.

“We first contacted Cerebral Palsy Scotland during the Covid outbreak. **I felt I was letting Adam down a bit** because he wasn’t getting as much physio as normal.

“We had about six sessions at the Cerebral Palsy Scotland centre through CP Connect and **Adam instantly took to Sandra, the Occupational Therapist. It was a lovely bond they had.**

“The sessions were all play-based, so in the first session Sandra had a mini washing machine and Adam just loved that.

“By the end of the sessions, I had noticed at home that he had reached out with his left hand to get something a few times. **It was wonderful to see.**

“We all benefitted from the sessions because it was great for me and my husband to bring home all the ideas and incorporate them in everyday life. Because half the time Adam doesn’t even know we’re doing physio things - we’re just playing.”

Kirsty's story

Kirsty Colquhoun is a consultant geriatrician and has cerebral palsy.

"I work as a consultant geriatrician in Glasgow. This means that I look after older adults, particularly those who are frailer. Covid, for the group of patients I care for has been catastrophic.

"This year has been exhausting and brutal, physically and emotionally, but whatever I have felt has never been as bad as what my patients and their loved ones have gone through. There has been tragic stories like people losing both of their parents within days of each other, that is heart-breaking to witness, and I will never forget those patients and their families.

"The first patient I successfully discharged home from my Covid ward was an older lady with cerebral palsy, we were all delighted when she got home, as we were for all our patients.

"We have tried to continue as much of our other non-Covid work as possible. For example in the work I do with older cancer patients we have been using virtual means. Covid has given us an opportunity to change the way we work and some of that may be for the better.

"Sadly Covid has supercharged already pre-existing inequalities. You are more likely to die of Covid if you live in a deprived area. For some there is a view that if you are older, have a disability or a chronic health condition you are somehow less valuable. That is wrong and we must push back against that mind-set. I would fall into the category of having a disability, it seems to surprise some that someone with a disability could work (more than full time) as a consultant, particularly work in Covid wards. But why, disabled people are working in all areas of society, just like everyone else. I can assure you my life is no less valuable than the next persons, nor those of any disabled person.

“A surprise challenge for me has been the physical impact the pandemic has had on my cerebral palsy. I normally carefully balance long working hours with a mix of marathon outdoor swimming, Pilates and weights. But all that disappeared. I was standing longer at work, sitting longer at home and doing less of the things that keep me on my feet. I was in much more pain than usual and my function had deteriorated to a level I cannot recall as an adult. It is at that point that you realise there really are no services easily available for adults with cerebral palsy except if you go to the private sector or the charity sector. I have to admit I was scared, scared that this was my new normal, and that the independence and career I had worked so hard to achieve was changing.

“I have privately had to see a musculoskeletal physio, who has been a great help. However, I have had my first session with Cerebral Palsy Scotland. I have had a full top to toe MOT by a Cerebral Palsy Scotland Bobath physio.

“Everything from the way I sleep to the way I stand has been looked at. I know I will not only come out the other side of this as I was but have the opportunity to come out better.

People with cerebral palsy need and deserve the same access to specialist services as anyone else would who have a health condition or disability.”

Kirsty Colquhoun: Consultant Geriatrician in NHS Greater Glasgow and Clyde, Subdean Glasgow University Medical School for Glasgow Royal Infirmary, Fellow of the Royal College of Physicians and Surgeons – Physician Representative of the Inclusion Advisory Board, Secretary for the British Geriatric Society Oncogeriatric Specialist Interest Group, Trustee Cerebral Palsy Scotland. Has Cerebral Palsy, Diplegia.

Meet some of the team

Anna Hunter
Communications Manager

"I first came to the charity as a parent - my eldest son has quadriplegic cerebral palsy. The team here really kick-started his communication. When he was two, Claire was the first person that showed us how my son could communicate using symbols and eye-pointing. They showed us what he was capable of. He is now nine, attends mainstream school and uses an eye-gaze communication aid to talk. I will never forget the critical role the therapists here played in that journey.

"Now I'm a member of staff, part of my mission at the charity is to try and show as many people as possible just how great the services at the charity actually are.

"You cannot underestimate how important it is to have a place like Cerebral Palsy Scotland to go to; a place where you can get additional support from the therapy team and benefit from their time, knowledge and expertise. That can be the game-changer you need. Surely every parent who has a child with cerebral palsy has a right to get the help they need so that their child can achieve their potential."

Leen Van Gestel
Physiotherapist

“Over the past year, I have mainly been able to work with clients coming in for sessions as part of the CP Connect programme. This has offered an important opportunity for many to get back on track and keep them going until Covid restrictions eased off again.

“When talking to families and adults with cerebral palsy, it was clear that Covid has put an enormous strain on services and support in the community.

“One of the big positive things Covid taught us is the resilience of people and how quickly we can adapt to new circumstances when there is no other choice. I have developed a deep love-hate relationship with my webcam! Let’s all hope in the near future we can welcome these people and families into our centre and work safely with them face-to-face and together to achieve their goals and improve their participation in real life.”

Petra Mikesková Gurd Occupational Therapist

"There have been a lot of changes to the way we work with clients over the past year. Covid restrictions meant we transferred therapy to online consultations for a while. Once we were able to start seeing clients face-to-face again, we had to limit the number of people in the centre and the session, which made our multidisciplinary approach more challenging.

"Many adult clients I have spoken to really struggled through the pandemic, especially for those people who rely on special services such as carers, wheelchair accessible pools, gyms, clubs and groups. Parents of babies and young children experienced reduced NHS therapy input and turned to us worried that they were missing precious opportunities to support their child's development.

"One of the positives is how well and quickly people were able to adapt to online consultations and therapy. Online therapy is far removed from hands on and face-to-face therapy, but it is an option to get people seen. People got used to using computer technology during the pandemic and for many it opened up the possibility of connecting with others and with us.

"We are slowly getting back to multidisciplinary sessions which is great for our clients and for us as we missed working alongside each other."

Financial Review

Cerebral Palsy Scotland seeks to ensure that as many people in Scotland with cerebral palsy, families of people with cerebral palsy, carers and professionals that support people with cerebral palsy have access to our services and advice. We concentrate on need, not ability to pay. We are therefore extremely grateful to all those who have supported and continue to support our work in order to ensure we can help all those who need it most.

During this most extraordinary year the income of the charity from all sources was **£598,415** whilst total expenditure was **£501,435**. Our surplus is entirely down to the support of the UK Coronavirus Job Retention Scheme which has enabled us to backfill the staff costs, particularly when social distancing and infection control measures mean that we are only able to operate at approximately 50% capacity.

We spent **80%** of our total expenditure **(£401,555)** on our charitable activities. Because of the pandemic we were unable to develop services as planned and instead focussed during the year on strict cost control and ensuring that our condition-specific expertise is available for anyone of any age with cerebral palsy either online or in person.

Income: £ % of total

Trusts and Grants	**(70%)**
Charitable Activities	**(8.5%)**
HMRC Job Retention Scheme	**(6%)**
Individual Supporters	**(6%)**
Community Fundraising	**(5%)**
Rental income	**(3%)**
Corporate	**(1%)**
Events	**(0.5%)**

Expenditure: £ % of total

Charitable activities	**80%**
Raising funds	**20%**

Fundraising

Helping people with cerebral palsy and their families though the pandemic simply wouldn't have been possible without all the people and organisations who dug deep at a time of crisis to make sure that specialist support and information was available to everyone with cerebral palsy in Scotland who needed it.

The many people who supported Cerebral Palsy Scotland last year through their own donations and fundraising have also made a huge difference. From the 2.6 challenge, to virtual marathons, head shaves and anonymous gifts, each gift or sponsorship matters. These funds have provided a lifeline for families.

By far the largest percentage of our funding during 2020/21 came from charitable trusts and foundations. We are deeply grateful to all those organisations who changed restrictions on funding to ensure that we could focus on what was most important and urgent. We would like to thank all those trustees, grant making staff and advisors for their support through a challenging year. Some of the key grants received during 2020/21 include:

HSF The Hospital Saturday Fund

The Scottish Government
Riaghaltas na h-Alba

Community Fund

White Top Foundation

The Ryvoan Trust

The Hugh Fraser Foundation

Foundation Scotland
Response
Recovery
Resilience

The RS Macdonald Charitable Trust

Garfield Weston Foundation

The Baily Thomas Charitable Fund

Crerar Trust

and many more.

Thank you!

Next steps...

Develop our services in close collaboration with people with cerebral palsy, so that we can better understand and become more responsive to the needs of the cerebral palsy community.

Understand how we can offer the right mixture of face-to-face, virtual and outreach services, so that we can help more people across Scotland with cerebral palsy.

Ensure the needs of people with cerebral palsy are taken into account by policy makers and statutory services, particularly in relation to the longer term impact of Covid on the cerebral palsy community.

Raise awareness with people with cerebral palsy and their families of how Cerebral Palsy Scotland can help.

cerebral
palsy
scotland

Chief Executive

Stephanie Fraser

Trustees

Auditors

Hardie Caldwell LLP
Chartered Accountants
Registered Auditors
Citypoint 2
25 Tyndrum Street
Glasgow G4 0JY

Bankers

Bank of Scotland
836 Crow Road
Glasgow G13 1ET

Clydesdale Bank
30 St Vincent Place
Glasgow G1 2HL

Solicitors

Mitchells Robertson
36 Hanover Street
Glasgow G1 2AD

Photography

Sean Purser

Design

dmu design
dmudesign.co.uk

Bradbury House,
10 High Craighall Road
Glasgow G4 9UD

Tel: 0141 352 5000
Email: info@cpscot.org.uk
cerebralpalsyscotland.org.uk

OSCR
Scottish Charity Regulator
www.oscr.org.uk
Registered Charity
SC022695

We're committed to
GOOD FUNDRAISING

Registered Charity number
SC022695

follow us on