

Understanding the Impact of COVID-19 Restrictions for people with Cerebral Palsy February 2021

Context

Last year Cerebral Palsy Scotland carried out two surveys in May and September 2020 to understand how lockdown restrictions were affecting people in Scotland with cerebral palsy (CP), their families and carers at that time. Recently we repeated our survey which was open on Survey Monkey throughout February. We were keen to understand what had changed and to hear the issues and challenges our population continues to face as we approach the first anniversary of COVID-19 restrictions being imposed. Continued input has given us an extremely helpful, if concerning, picture of the issues people with CP continue to face.

42% of responses came from families of children with CP, 58% were from adult respondents. We received input from people who live in 10 out of the total 14 health boards in Scotland. There was a 90% completion rate.

Headlines

- The negative impact restrictions are having on people's mental health has significantly increased to 60%.
- Decline in wellbeing was not restricted to the person with CP but 44% felt that it had also impacted on other people in the family.
- 43% of people are reporting that their physical health continues to deteriorate.
- 63% reported that their care arrangements had still not returned to pre-Covid levels.
- 53% feel that their family has become more isolated
- Most people have either already been vaccinated or want to be vaccinated. Only 12% reported that they did not want to be vaccinated.
- 82% said that they wanted everyone who lives with them and cares for them to be vaccinated as soon as possible.
- 83% were happy with the level of support they were receiving from Cerebral Palsy Scotland, even though the imposition of restrictions has delayed input for some groups.

Main Themes

Health and Wellbeing

As restrictions have continued and particularly during the lockdown since 26th December 2020, 60% of people with CP and families reported an increased deterioration to their mental health and wellbeing. Mental health has now overtaken concerns about deterioration in physical health, which was reported by 43% of survey respondents.

"I feel very lonely and isolated and am finding it harder mentally"

"Barely left home since March. Mostly in my room"

"Lack of physical therapy lead to a decrease in physical condition, leading to medical intervention and decrease in mental health"

"Lack of routine and boredom has affected me"

"As a parent I have found my mental health has declined through Covid due to uncertainty and stress"

For some respondents there have been positives:

"I am able to take adapted exercise classes on Zoom. I'm in better shape than pre-lockdown"

"Working from home has been beneficial. My confidence has improved with remote working rather than face to face"

Care Arrangements

63% of respondents reported that any care arrangements they had in place previously were not yet back to the levels they were before Covid-19, which is a slight improvement from the 71% reported in September 2020. However, there remains over 41% who remain totally reliant on family carers.

"I worry that the support that I had will not get back to normal and that I will stiffen up and not be able to get fully mobile again"

"It's a really worrying situation for my mother who's been doing all my care for 11 months"

"There is uncertainty as to whether we will get a worker and often we are left to manage alone."

"My family provided most of my care pre-COVID but there was support in place for me to attend my part time job and for socialising outside my family"

12% continue to report that they do not want people coming into their house at this point because they remain concerned about the virus.

The restrictions were also directly blamed for the lack of access to care:

"Support workers have been told to stay within their region, so agency workers won't travel to me"

Community Assets

The strain of community services continuing to be closed, including for children the closure of schools, and the limited availability of respite or other opportunities to stay connected to their community has a greater impact for people with CP and their families than compared to the wider population due to the reliance on these services for people to be able to stay fit and well. These community facilities are vital in order for people to be able to maintain social and professional connections, such as volunteering, and to successfully self-manage their own condition or support their family member.

"Before Covid I was a part time wheelchair user and I could walk short distances, however due to Covid I am no longer able to go to the gym and continue my swimming which has affected my walking and I now struggle to walk even short distances"

"There's nothing open in my area or available for me to access to exercise to maintain my physical health"

"Less access to things which help pain, e.g. swimming, pilates classes"

"Day services closed for almost a year"

"Limited respite"

"Lack of activities, unable to get out and about in the community. Limited input from the outside environment and family"

"Lack of community support and opportunity. All day centres closed. Prior to lockdown just started to look at volunteering again but most can only be accessed if I attend to support my daughter. No 26 year old wants their mother with them all the time. Feel centres should be given the same priority as schools"

Schooling

For parents of children with CP the closure of schools has had a huge impact on their care arrangements.

The majority of respondents on behalf of children sent their children to a mainstream school. Apart from one exception, all had accessed school or nursery in person between August and December 2020 whether they were in mainstream or attending a special school. However, 71% of children have not attended school for any time during the week in their school or nursery setting since the beginning of 2021. Of those that are able to access school or nursery this may be due to the parent having key worker status, but very few have been able to access school or nursery full time.

Around 53% of children are reported to be coping with home learning and support from schools seem to have improved since the first lockdown. Many reported that schools have been a great support.

"Some days are better than others... he does struggle to do work for me"

"He isn't doing as much work as he would in school though"

There are the challenges for parents who are trying to work from home as well as caring for dependent children.

64% of parents reported that they did not feel they were coping with home learning. Only 27% were receiving any additional support to help their children in their home learning, but some of this seems to be online only.

"It's impossible to carry out home learning"

"Very demanding trying to teach one child who needs one to one support with other special needs children in the home"

"It's a huge commitment for us as parents"

"As time goes on you realise the impact on their learning. We are currently considering whether our 8 year old with CP should repeat the year"

Family Life

Whilst 22% of families report that they have become closer, 53% feel that they have become even more isolated and whilst the restrictions have certainly impacted on the mental health of the person with CP, 44% report that they have also impacted on other people in the family. People are missing being able to access the support of wider friends and family due to travel restrictions.

"The whole year has been really difficult and we've all struggled in some way with mental health as well as physical health"

"My main concern is that I miss something that could have an impact on my son because we are not being seen regularly"

"Lack of support has led us to feeling overwhelmed and forgotten about"

"We can't travel between regions. We don't see each other"

"I live with my mother but it has been difficult having restricted contact with my sister and her family"

"Missing my family who live abroad. Haven't seen them for over a year now"

Accessing Healthcare

70% of respondents have been able to access healthcare either for their CP or for other issues. The majority of this (65%) is either online or via telephone, 17% had accessed healthcare in person. 12% reported that they had not been able to see or speak to their GP or other healthcare professional.

Only 18% reported that they had had difficulty accessing support for mental health, but this may be a reflection that people have not tried to seek help for their wellbeing from healthcare professionals. 30% say that appointments with the health professional they normally see about their CP have still not resumed. 55% have had difficulty support for their physical health (physiotherapy, occupational therapy and speech and language therapy) and 13% had been unable to resolve equipment issues. It seems also that surgery planned pre-Covid is yet to be rearranged.

"Unable to see consultant psychiatrist. Not able or confident to use Zoom which may be available. Struggle to communicate even when face to face"

"I have accessed neurology and found the telephone call which lasted 4 minutes in total was very poor. I'm not convinced that a new potential neuro related condition can be assessed in the space of 4 minutes"

"There's not a CP specialist in my area either"

"Appointments with rehab service (spasticity management) were stopped prior to pandemic and not been renewed"

"Timely access to WESTMARC wheelchair service has been the biggest issue"

"Routine hospital appointments for June already cancelled due to Covid"

"Lack of access to therapy such as hydrotherapy and physio input has seen a deterioration in her physical health"

"I feel that support was better during the last lockdown – we were receiving regular phone calls from physio, OT and SLT. This lockdown has been much quieter in terms of pro-active contact"

Only 25% of respondents said that they have been able to access all the support they need from health professionals and only 23% reported that equipment needs were being met. 25% of the survey respondents confirmed that cancelled appointments have been rearranged. It is likely that this may vary across different geographical areas.

"You realise how varied support can be and varies from professional to professional"

"Consultant appointments in hospital have continued essentially unaffected by Covid-19 other than the necessary precautions"

"Delayed appointments for Botox injection but do eventually get them"

"I speak to my GP about general health but not CP related stuff as don't feel they know enough"

Vaccinations

With the roll out of the vaccinations, we asked respondents to let us know how they felt about being vaccinated.

- At the time of the survey only 3% had received their vaccination. Another 3% had received their appointment time and were waiting to be vaccinated
- 82% said that they wanted to be vaccinated as soon as possible, but they hadn't been contacted yet.
- 12% said that they didn't want to be vaccinated. For some this was because children don't qualify and others had concerns about allergic responses or the lack of long term data regarding people with CP.
- Some parents commented that they wanted their children to receive the vaccine as soon as possible but they recognised that as yet, the vaccines have not been approved to be given to children.
- 82% of people said that they wanted everyone who lives with them and cares for them to be vaccinated as soon as possible.

"I feel the vaccine is a hope to get back to some kind of normality"

"I'm really disappointed that people with CP but no other health issues are not on the priority list for the vaccine"

"My daughter and her PA have been vaccinated but not me who lives with her which seems a bit bizarre"

"I feel that a lot of pressure is being placed on people with underlying conditions to be vaccinated with very short term data available"

"I would rather everyone around us was vaccinated as neither my son or my daughter will be able to be vaccinated"

"Very important carers are vaccinated – who looks after the person with CP if we become ill"

"I'm less worried as the jag is on its way"

Support from Cerebral Palsy Scotland

83% of respondents felt they were getting enough support from Cerebral Palsy Scotland.

"I have only been in contact since January 2021 and feel very supported. Thank you"

"Up to date information relating to people with CP gathered in one place"

"By providing face to face therapy for my little boy you have improved our quality of life"

"Currently chasing up my status as an unpaid adult carer using links from CP Scotland information sheets"

Whilst some people have had planned activities paused due to Covid, 73% felt that the information provided by Cerebral Palsy Scotland covers what they needed to know. Some still had questions, regarding their personal situation and medication issues, but most felt well informed.

"It's always nice to know we can contact you if need be"

"Cerebral Palsy Scotland is my 'go to' first port of call for appropriate Covid-19 information"

"The support I have got from Cerebral Palsy Scotland right through this time from information about the virus to the Zoom chats have been great so thank you for being there for me"

Conclusions

The three phases of our survey, in May 2020, the follow up in September 2020 and most recently in February 2021, show the serious impact that the Covid restrictions are having on people with CP and their families. With increased deterioration in mental health on top of increased isolation, feeling unsupported, there is a general sense that disabled people are being forgotten and ignored.

"As time goes on I'm generally disappointed about the level of care and input disabled people are receiving during Covid. There is a sense of nonchalance about caring for this group, which are often vulnerable. Government and health professionals should be doing more, not less, during the outbreak."

The continued closure of community facilities has a significant impact for people with cerebral palsy, particularly as they may rely on accessing gyms and swimming pools to be able to stay well and may not necessarily be able to exercise outdoors or just go for a walk. If people cannot exercise and keep fit and active in a way that works for them this will not only affect their physical health but will also influence their mental health. As reported, this negative impact is felt not only by people with CP but also by their families.

"No school. No social contact. No activities. Causes acute social isolation, anxiety, self-harm, separation anxiety. Lack of motivation"

"My physical health has deteriorated due to not being able to go swimming to exercise. My mental health has deteriorated slightly due to being stuck in my flat all day everyday"

Cerebral Palsy Scotland have seen an increase in enquiries from people with mild to moderate CP who, pre-Covid, were able to successfully self-manage their condition within their community. We believe that this is a direct result of the continued closure of community assets and the resulting decline in physical health and wellbeing that people are therefore experiencing.

We continue to note with concern that evidence of decline in condition is not being recognised or understood by professionals, (difficulty in accessing physiotherapy, appointments postponed, lack of access to specialists in cerebral palsy).

We are committed to ensuring that Cerebral Palsy Scotland continues to provide support for anyone, with any form of CP, of any age and from any area of Scotland, through our CP Connect programme. The programme is designed to identify needs, treat and support as required and to co-ordinate onwards referrals as required.

We note that virtual or telephone appointments, which are often being relied upon during the restrictions by many services, are not suitable or appropriate for many people with CP and therefore believe that our continued ability to provide face to face appointments, as well as virtual and telephone support, is essential.

CP Connect is designed to address the identified mental health, wellbeing and physical needs for the CP population to directly tackle the impact of lockdown and when remobilisation is possible, to reconnect people with their communities and to rebuild strength, mobility and confidence.

For more information please contact: info@cpscot.org.uk