Impact of COVID-19 Restrictions for people with Cerebral Palsy

May 2020

Response rate

The survey was open from 11th – 25th May 2020 and was accessed via Survey Monkey. We received responses from across Scotland and from all Health Board areas (except for Highland, Orkney and Shetland). There was an 81% completion rate for the survey with an average completion time of just over 6 minutes. 50% of the respondents were on behalf of children with cerebral palsy. 47% of respondents classified their (or their child's) cerebral palsy as being "severe", 34% as "moderate" and 19% as "mild" cerebral palsy.

Key Statistics:

- 70% of people with CP, and their Carers, believe that the current situation is impacting negatively on their physical health.
- 54% reported that the current situation is impacting negatively on their mental health and 49% responded that the mental health of their carer was being impacted negatively.
- 69% of respondent have had medical appointments cancelled.
- 15% reported that planned surgery had been cancelled.
- 58% reported that both shielding and practicing social distancing was affecting their lives "a great deal" or "a lot".
- 42% are either finding it hard to make contact with health professionals or don't feel they are getting enough support.
- 41% had equipment needs that required attention and adjusting.
- 56% of people reported that they had not been able to access PPE.
- 34% of respondents reported that they were happy with the level of support they were receiving from health professionals.
- 69% of respondents felt they were getting enough support from Cerebral Palsy Scotland.
- 75% valued the weekly email update of cerebral palsy related issues.

Main Themes

Shielding vs Social Distancing

68% of the survey were adopting "social distancing" and 32% are currently "shielding". 58% reported that both shielding and practicing social distancing was affecting their lives "a great deal" or "a lot". Many reported shielding because they were coping with their co-morbidities in addition to having cerebral palsy, or that a family member was also living with a long-term condition or was vulnerable. Some people had chosen to shield, although they had not received the official letter and others illustrated some confusion over what exactly was meant by "shielding" an about why they weren't able to or "allowed" to shield.

"Would shield as have chronic kidney disease and hypertension as well as cerebral palsy but as a frontline healthcare worker am not allowed to as I fall in the vulnerable range."

"Both parents are frontline so shielding is impossible."

"I have not received a shielding letter but have chosen to shield myself and where possible my parents as they are both pensioners."

"I'm staying indoors because I find I can't keep a sufficient distance from people even though I wear a mask when out."

Isolation

A great many comments picked up on a widespread sense of isolation and in particular the lack of contact with regular support networks, at school or through seeing family. People living in residential homes reported that visitors had not been allowed for some time and therefore contact with family members had been extremely restricted.

"Very socially isolated, not got a large friend group."

"I am really missing my friends and my sister."

"I live on my own and feel isolated."

"No day service or contact with regular people who support"

People responding on behalf of children reported that the lack of socialization opportunities was having the most negative impact on their lives.

"he keeps asking to go to school and for his teacher"

"my daughter needs social interaction, it's the only thing that's important to her".

"my son is really missing school"

"The main thing it is affecting is socialisation. Not being able to see other children or extended family. Also not having the option of our child being looked after by other people is affecting the whole household and our ability to work."

"Lack of therapy input, swimming, physio etc. Also massive additional pressure on myself as I am a single parent with two children and am also trying to work from home."

"I am having to work whilst caring for our son with CP and his 4 year old sister. Home therapy is reduced to juggling work, siblings etc. and as a result I feel our son is missing out (that's not considering him missing physio, OT, hydrotherapy and other appointments)."

Care Arrangements

The picture regarding care arrangements for people with cerebral palsy is complex. (Many people have little enough help with care regardless of the impact of Covid-19). Overall 46% of people reported a negative impact on their care arrangements. The picture varies for adults rather than families of children. This was mostly due to children being looked after by their parents, although adults too rely on increasingly elderly parents for their care. Parents in general highlighted the strain that the lack of additional care was putting on them.

"The stress is unbearable dealing with my daughter fulltime."

"It has been challenging as we are not getting any break from providing support as family members have been unable to visit and help out."

"Normally grandparents would take our child once a week when he is not in nursery."

"My mother is coming over to assist when she can but is not supposed to".

"My mum is doing all my support and she is over 70."

"My partner has been assisting me on her own throughout lockdown. She has been doing this in addition to working from home, parenting our child and household tasks. I usually have a PA who assists with my needs and also allows me to take a more active role in the household."

Some reported that their care packages had been cut:

"We have been offered 2 hours a week from our usual 24."

"We are unable to use our usual respite centre as it is closed and one of our paid carers is shielding so we are not receiving any respite care."

"I have not had PAs since lockdown started due to a lack of access to PPE and an absence of guidance for disabled people who control their own support."

"I still have my home care but not my support workers."

Others have adapted their care:

"We have had to adapt how my PA works and have had to source our own PPE."

"Working from home has made it easier."

A number of respondents voluntarily chose to reduce their care because of the risks of Covid:

"From a friend's advice who lives in Italy we stopped what little support I was getting in March. No one has been in our house."

"We have not had carers since the start of March due to virus and have concerns about having carers in the house again."

PPE

56% of people reported that they had not been able to access PPE. For some this was because they did not have carers coming into their house. However, for others this was due to shortages and confusion over what might be required. Many had simply resorted to sourcing and funding their own PPE privately. However, Carers' Centres had helped some respondents access PPE.

"There are no guidelines on how to access PPE if you are a PA employer."

"Was allowed to use SDS to pay for [PPE]. In an emergency if ran out could from hub if completed a form."

"I have only this week been able to arrange to get some PPE by contacting the PPE helpline."

"After 8 weeks of lockdown we are now getting limited supplies of PPE."

"We haven't asked for anything yet, although I know we probably should."

Impact on Family Life

The stresses for people with cerebral palsy on their family life have been immense. Many people reported having to cope with many other family issues in addition to dealing with cerebral palsy. 54% of people with CP reported a negative impact on their mental health and 49% of carers felt the current situation was detrimental for their mental health.

"We are finding it difficult, we are hardly out the house."

"Not able to work from home effectively due to care responsibilities."

"As parents we are exhausted, no respite or support."

"Child is becoming frustrated at not getting out for daily walks and only having immediate family for company."

"We simply miss family and the additional family support. We also miss our therapists. Simple things such as keeping on top of housework is a struggle."

Schooling

50% of respondents (which corresponds to the % of respondents who were responding on behalf of someone under 18 years old) reported that school closures were affecting them "a great deal" or "a lot". Their children are clearly missing school and this is a source of regular and much valued opportunities for children to socialise as well as accessing specialist education and healthcare provision. As related above, the demands on families to cope with the physical and emotional aspects of their children's care requirements on top of learning requirements is leading to significant stress for families with a child with CP.

"His learning is full on, he needs support to access the learning and complete the tasks. It takes us all day to complete 1 or 2 tasks."

"Our son has lost almost all his social interactions without school. He often says he misses his teachers. He needs a lot of attention to help him do any school work and as we are working full time at home, it's very difficult to find enough time to do this so we're very worried about his education."

"She feels more lonely."

"We are getting stuck in a bit of a rut. Especially school work. I haven't got the confidence to teach them and they are the same age as twins but with 1 disabled they are in such different places and I have a 1 year old too."

"We appreciate the 2 short days our son is currently being given but he is missing the specialist education and healthcare provision he usually receives at school."

"I'm really nervous about how shielded children can go back to school but I'm also so worried for our son's emotional development and education if he doesn't go back to school soon."

Accessing healthcare

69% of respondents have had appointments cancelled and 15% have had planned surgery cancelled. There is widespread understanding as to why this is the case, but a worrying number report that planned alternative appointments have not been forthcoming. 42% are either finding it hard to make contact with health professionals or don't feel they are getting enough support.

"SALT, OT and physio have promised us video appointments but these have yet to be arranged."

"No support from local GP surgery."

"Had no contact from GP or social work."

For some, they have been in contact with some health professionals but are fearing deterioration in their wellbeing due to the lack of access to other services.

"Our community team have contacted us to offer support but its equipment that's our main issue."

"Consultant and physio good, but missing Botox injections."

"I used to get my teeth cleaned at the dentist so I am missing that."

"I need podiatry appointments as I have sore toenails."

"My son's physio and OT have been in touch but orthotics cancelled."

"Our child is due to start school this year and no news from professionals as to how his transitions might be discussed."

"I'm worried about the impact this situation will have and whether he will ever get the same level of input again?"

Others reported some positive aspects to health professionals being in touch:

"We've done a couple of phone appointments instead of planned outpatient appointments. For certain things this actually works well and it's good to have this option in the future."

"I had to contact the physio and they called me back that day and arranged a video appointment."

34% of respondents reported that they were happy with the level of support they were receiving from health professionals.

Wellbeing

70% of respondents reported that they were worried that the current situation was impacting negatively on their physical health.

54% of respondents felt that the current situation was negatively impacting on their mental health and wellbeing.

Lack of access to community services combined with lockdown restrictions has meant there are fewer opportunities for people to stay physically active. People are reporting a deterioration in what they are able to do. (For example people are walking less and using wheelchairs more). Carers also reported the physical strain constant caring was impacting on them.

"I am worried that I am developing mobility difficulties and I won't be able to recover the strength in my legs."

"Walking any distance is extremely limited. Need to constantly sit down. No strength in arms and frozen shoulders are impacting on my wheelchair use."

"I'm very worried about our son's emotional and mental health. He's spending so much time on his own and is getting quite withdrawn."

"Tone has become very stiff."

"Usually attend the gym and hydrotherapy."

Many of the issues highlighted were to do with equipment provision.

"My son has outgrown his lycra suit. This really does affect his posture and therefore his ability to use his communication aid. His wheelchair needs adjusting and his AFOs are also needed looked at. Our physio has flagged this up to the relevant teams but appointments aren't possible at the moment."

"My son is waiting on a chair from occupational therapy."

"We are struggling with the standing frame, which is something that used to be a favourite. We need a new headrest for chair but unable to have assessment and application to SCTCI hasn't been processed."

Support from Cerebral Palsy Scotland

69% of respondents felt they were getting enough support from Cerebral Palsy Scotland. 75% appreciated the weekly email update of cerebral palsy related issues.

"The support which our family have received from Cerebral Palsy Scotland is and has been skilled, helpful and generous beyond compare."

"The contact and reaching out to say you are there has been valued even though I haven't accepted any help yet. I know you are there until I am ready."

Many have not required to be in contact with Cerebral Palsy Scotland. People reported that they valued the condition-specific information and have valued seeing what Covid-19 means for people with cerebral palsy.

"Info on Facebook has been good and informative."

"You have been a great support and Zoom chat has been good with adults."

Many have looked to the website for information and have found that it covers all the things that they would want to know.

"It's the only place that's providing this collection of info."

"The information provided has been helpful and supportive."

"Sensible up to date information available on website."

"I have enjoyed hearing about other people's experiences."

"Lockdown therapy sessions" via NHS NearMe/Attend Anywhere with Cerebral Palsy Scotland have been particularly appreciated by those who have accessed them.

"Excellent remote physio sessions!"

"Virtual appointments have been excellent and have provided much needed advice."

"You have been the only health organisation to provide help and support during lockdown."