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# Covid-19 and Parent Carers. Survey #1

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March 2020

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FVP Parent Representatives

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Family Voice Peterborough have conducted a short survey of parent carers in Peterborough in order to gather the thoughts, feelings and fears of those who are affected by the current global pandemic Covid-19. The survey was launched on 17th March 2020, and gathered 94 responses in total. The survey closed on 20<sup>th</sup> March, and a summary of issues raised was passed on to Peterborough Local Authority.

Of parent carers responding, areas of need relating to their child/young person were varied, including: Autism, Learning Disabilities, Cerebral Palsy, Hydrocephalus, Complex Health needs including chronic heart and lung disease and Downs Syndrome (non- exhaustive.) The ages of young people represented ranges from 1 year - 24 years.

How worried are you about the current corona virus pandemic?

94 responses

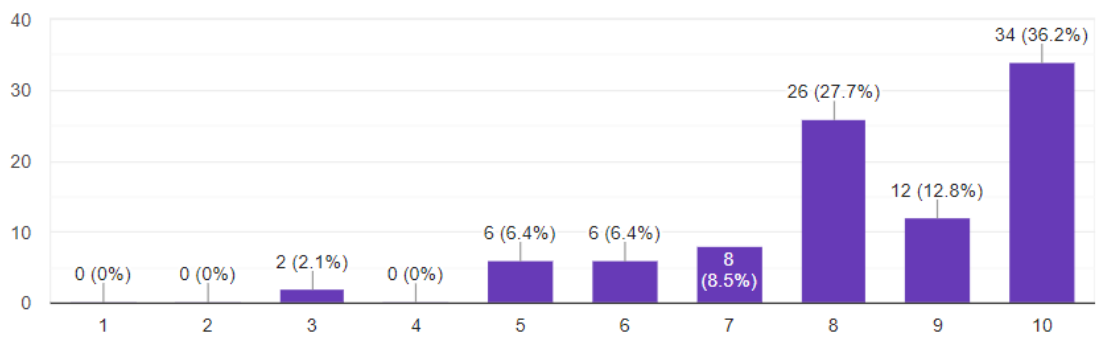


Fig. 1 Parental response rating how worried they are about the Covid-19 Pandemic

Parents were asked to rate how worried they are about the current pandemic with 1 being not at all worried and 10 being very worried. The responses to this question are displayed above, with 72 respondents indicating their current worry levels were 8/10 or higher. This indicates a high level of concern and is representative of general anxieties and uncertainty currently felt.

How would you rate the impact on your well being?

94 responses

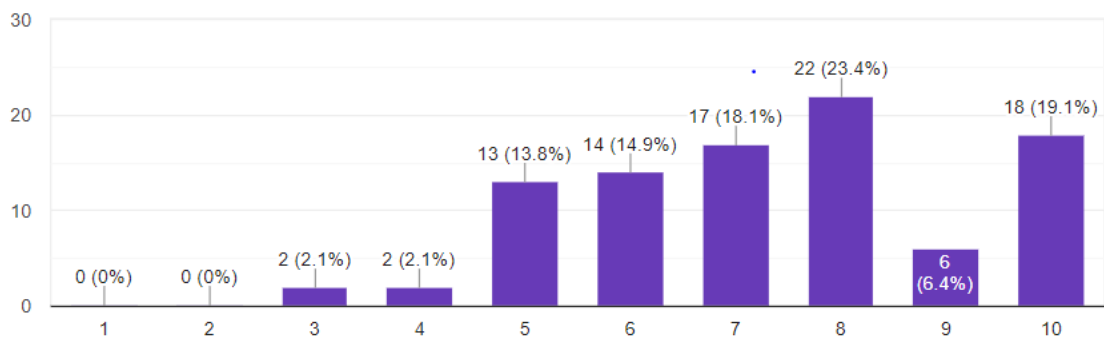


Fig. 2 Covid-19 Pandemic impact on parental well being

Parents were also asked to rate the impact on their wellbeing relating to the current pandemic, with 1 being no impact and 10 being severe impact. As you can see from the chart above, all parent carers have reported that the pandemic is having some impact on their wellbeing, with an overall average rating of 7.36/10.

Parents were asked to give more information on the impact that the pandemic is currently having on their child/young person. The most common responses are:

1. Increased anxieties
2. Struggling to cope with changes in daily routine leading to severe meltdowns/ refusing to leave the house
3. Feelings of increased isolation
4. Fears of death - either for the young person themselves or for others
5. Losses of carer/therapy support, with parents reporting decreases in school support whilst their children are still attending

47% of parent carer respondents report that their child/young person has a special or restricted diet. Of these, there is a constant theme of difficulty buying the right items, specifically pasta, bread and tinned foods. The current buying limit on items (no more than 2-4 per customer) means that many parents need to shop daily in order to keep a stock of the items that their children will actually consume. This is going to become increasingly difficult with more and more schools closing. Parents are also reporting that they are finding it difficult to get supplies relating to their child/young person's continence needs - nappies and pads are difficult to come by.

14% of parent carer respondents have declared that they are having difficulty in getting their child/young person's medication. The most common issue is the unavailability of over the counter medications such as paracetamol; however some parents are also reporting difficulties in getting prescribed medication such as Keppra, Melatonin and Midazolam, parents in self isolation are also reporting that they are now totally unable to go into hospitals to collect medication such as Diazoxide from Great Ormond Street.

91% of parent carer respondents declared they are worried about the impact of Covid-19 on their child/young person. The most frequently recurring reasons why include:

1. Fear of the impact on the young persons mental health/anxiety levels
2. Fear of how the illness will impact upon the young persons physical health, or even lead to death - especially for those with underlying health conditions
3. Fear of who will care for the young people if the parents themselves are taken ill
4. The impact of losing loved ones upon the young person
5. Fear of the effects of increased social isolation

Parent carers were asked to detail their current situation, what their personal fears are for the immediate future, and the impact this was having upon their household. The most common themes from these responses are:

1. Concerns around children and adults within high risk groups
2. The negative impact on parental mental health
3. The fear of running out of food and supplies and not being able to get more
4. Financial concerns
5. Unmanageable behaviours, meltdowns and damage caused by young people who are self-isolating

The comments received from parent carers in this particular section are particularly harrowing, and as such some are displayed below:

*“Getting harder to keep a difficult child on an even keel. Not sure what will happen if one of actually gets sick. I'm a single parent with no support in a corona virus risk group, with a child who displays self injurious behaviours when melting down, and suicidal thoughts”*

*“My mental health has taken a nose dive because my daughter is not coping being out of school for her own safety. We feel isolated and lonely.”*

*“Dealing with a Special Needs child at home without the school hours relief is very draining. This impacts my health, job and anxiety levels. It impacts on the atmosphere in the household at a time when my older son too who is studying for his A Levels.”*

*“I am a single mum and the only person supporting my daughter when her activities close. She is violent towards me when anxious and confused and cannot entertain herself beyond short periods. I am fearful of my ability to continue to support her for 12 weeks + on my own without help. I will find this very stressful. I work part time (self employed) from home round my daughter's activities. With these stopping I am currently extracting myself from my work commitments which will have knock ons on my own mental health and some financial implications”*

*“We're a family of 6 all children between 1-13 and the older 3 are finding it hard being kept in when their sister is lashin out so much due to being anxious and stressed without the normal routine”*

*“We are staying home but the whole situation is keeping me up at night I'm having to do sugars more often due to diet change watch her cry over routine changes be sick over anxiety she thinks shes gonna get no food n die she eats upto 10 times a day so having to pay extra for what's left in shops is financially hard on us”*

Taking into consideration all views that have been put forward by parent carers within this survey, FVP have put together a list of ideas in how Peterborough Local Authority can help to support families during this time:

- Enable priority purchasing for parent carers, to enable them to get the specific food types that are so important to their young people
- Arrange a delivery service so that parent carers who are self-isolating are able to get groceries - current online shopping waits are in excess of a week

- Free up professionals to offer telephone/skype consults to parent carers to give advice and support on managing their young people's anxieties and challenging behaviours
- Give clear, disability specific advice to parent carers
- Offer benefit advances to parent carers who may have to buy additional items to ensure they can support their children through the pandemic
- Additional support in paying bills during this time - which works in a similar way to the winter fuel payment
- A council run helpline that parent carers can call for advice and support
- Additional Direct Payments/social care support offered where families are having to self isolate
- Increase respite support where possible
- Coordinate home education support. Provide a comprehensive list of websites which are offering free resources, such as Twinkl, Phonics Play etc
- Ensure attendance at school for children with EHCPs is optional and not enforced
- Additional social care support available for parent carers who become ill whilst being the primary carers for their child/young person