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# Impact of COVID-19 on people with Huntington's Disease

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**APRIL 27<sup>TH</sup> 2020**

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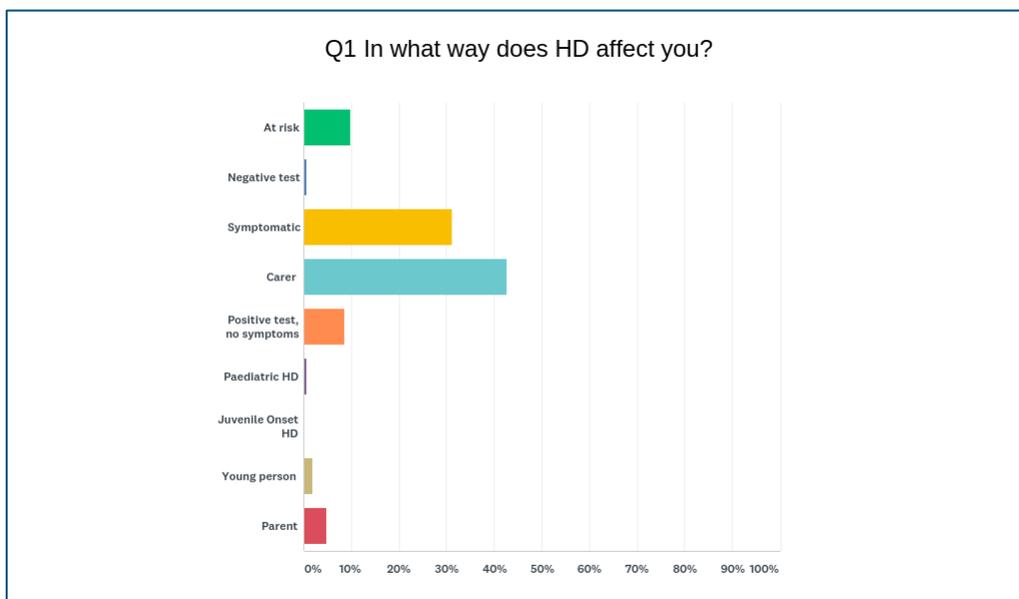
**Scottish Huntington's Association**  
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# Key Findings

## Response rate

We received 171 responses in total for this COVID-19 impact survey. There was an 81% completion rate for the survey with an average completion time of 8 minutes. The largest group who completed the survey were Carers (43%) and then people with symptoms of Huntington’s disease (31%). The graph below shows how people from different groups responded.



## Statistical Analysis

- 62% of people with HD, and their Carers, are worried about becoming more isolated during the pandemic. A clear concern emerged about people with HD who live alone.
- 64% of people with HD and their Carers are worried about the financial impact of COVID-19.
- 22% of respondents had been furloughed or reduced their working hours and pay.
- One in three people with HD are worried about having enough money to pay for essential bills like food and fuel because of the current crisis.

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- 49% are worried or very worried about increasing levels of debt.
  - 48% of family members said the person with HD in their household did not understand the social distancing rules and are worried about the Police taking action.
  - 38% of respondents were worried about their care arrangements.
  - 40% of families report they are having to take on additional caring responsibilities because there is less support available from care agencies right now.
  - 29% of respondents are worried about unpaid Carers having to take on more care.
  - 27% of respondents have had their support levels reduced.
  - 57% of respondents are worried about the increased pressure on family life.
  - 64% of respondents were concerned about the mental health of the person with HD with its consequent impact on other family members due to behaviour changes.
  - 31% of people with HD said they are worried about being unable to get help with their mental health
  - 41% of people were worried about 'practical help with things like banking arrangements', but concern about accessing practical is a recurring theme in the survey.
  - Only 25% of respondents were worried about accessing healthcare in relation to their HD during the crisis.
  - The most common concern was about being able to contact a General practitioner (41%) and 25% were worried about having appointments cancelled with the doctor who provides their specialist HD care.
  - 88% of respondents were **not worried** about getting support from Scottish Huntington's Association.

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# Main Themes

## Isolation

Isolation emerged as a major theme in this research, (62% of respondent being concerned about becoming more isolated) affecting people in quite different ways. One respondent highlights the impact on people living in a long-term care setting and there are around 150 people with HD in this situation in Scotland.

**“Very difficult because although my partner is in a Nursing home she is completely aware of what is going on, so is finding this very difficult to deal with. Her mother and I were used to spending 5-6 hours every day at the home so to have gone from that to zero physical contact.”**

Individuals who were already more isolated are among those most affected by the current social restrictions. Living in a rural part of the country can pose additional challenges.

**“I am used to living alone but I miss not interacting with my neighbours. I live in a very rural part of the Highlands and my neighbours play a big part in daily life, but they are all staying indoors now so I do not see them as much. My nearest family member lives 40 miles away so don't see them too often either.”**

For those already living alone, social distancing has had a significant impact.

**“I live alone and can't see my sister and dad who normally support me, although do speak to them on the phone. I spend a lot of time by myself normally, as I struggle to go out, but now knowing that I can't go out even if I want to, is very difficult. I feel very isolated and alone.”**

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Isolation also increased some people's feelings of vulnerability.

**“Because of HD cannot be in contact with people, worried about falling and no one to help. Had care cancelled but back on Monday. Sad at not seeing people and getting out as much.”**

The additional social restrictions magnified the fear felt by some people with HD about how they are perceived by other people when out in public.

**“Never going out so that I do not upset anyone because of my movements and speech. Scared I fall and nobody to help.”**

As part of the survey members of our team interviewed around 80 of the respondents and in our reflective sessions, we were struck by how isolation had magnified issues around loss.

**“One man I spoke to talked about his relationship coming to an end and now living apart from his wife and children. He has been unable to see them since lockdown started and misses them terribly.”**

For Carers isolation means loss of social contacts that really make a difference to their quality of life.

**“As I have been a Carer for eighteen years, for someone who now has late stage HD, I have few social contacts anyway, so the things I miss are the occasional trip to town for a haircut, etc, and visits from my young granddaughters. As my wife has Carers who come in on four days a week, I can still go out running a couple of times a week (we back onto miles of moor, so I am still thoroughly isolated) but if the Carers can't come for any reason I would no longer be able to get out, and it's the running that helps me the most.”**

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One person with HD captured the impact of isolation and watching the coverage of the COVID-19 crisis.

**“My mood has been low due to being isolated. I feel lonely and forgotten about. Also very bored, and I don't want to watch TV like normal as all there are pictures of morgues, and you can't avoid hearing about the coronavirus. It makes me feel very bored, sometimes I go to bed at 7pm because I'm so bored.”**

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## Concern about the vulnerability of people with HD to COVID-19

Although HD does not necessarily mean individuals are more susceptible to the virus, other underlying conditions, nutritional problems, swallowing difficulties, immobility or other effects of the condition may increase risk. Carers expressed concern for the safety of the person they looked after and, in some cases, this has had a direct impact on care arrangements.

**“I look after my husband who has HD, he has had Carer support for 20 years, but due to the coronavirus I stopped all Carers coming into the household. As a result, my husband is confused and doesn't understand why his Carers are not visiting. I can't take any chances and have asked friends and family to stay away.”**

**“I just need to be extra careful for mum. I couldn't risk her getting it. I just worry.”**

Some people were concerned the person with HD in their family had not received a 'shielding letter', indicating a lack of clarity on this issue.

**“I care for my HD mum who is 86, I'm shielding her even though no letter from CMO. I'm worried about long term how we get food, it's hard going out, local shops very expensive but deliver, supermarkets no good as delivery times are impossible to get!”**

Several respondents were concerned about the lack of PPE provided to care staff.

**“Worried about level of care received in home. I suspected a urinary tract infection, confirmed 5 days later, antibiotics prescribed. Concerned about agency staff in and out and lack of PPE and uniform change.”**

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## Impact on Carers

We know from the survey many families are having to take on additional caring responsibilities to ensure people with HD get the support they need, and it was clear from the feedback Carers are being significantly impacted.

An issue arose where care arrangements were in transition at the time the COVID-19 crisis began. In one case a Carer had agreed to look after a person with HD for a three-month period and with support. This has now become an extended arrangement and the individual has complex support needs.

**“I cannot get visits from services such as my HD Specialist, incontinence nurse, dieticians and GP if required. Respite is not available to us at the moment and the circumstances we are in means that I am providing 24 hour care for the HD patient in my own home whereas I am only contracted for 9 hours per day, 5 days per week (45 hours). This is very difficult as she is not sleeping at night and this has been going on for 3 months since she was told that her partner had passed away which was at the same time that she moved from the nursing home (short term) into my home where I am providing the care.”**

**“I was just starting to get somewhere with my Carer's assessment and organising what was best for my mental health and depression and it is now on hold for an undefined amount of time.”**

Some Carers reported their reluctance to seek medical assistance because they were anxious about ‘wasting’ NHS time.

**“Don't like the fact that I can't see our family at the moment. I don't like the fact that I don't feel confident when my husband is unwell and I need to phone the doctor/nurses and that when I did call, it took longer for someone to come out.”**

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For some Carers work plays an important part in maintaining a sense of identity and in providing a degree of respite in their day-to-day lives and being unable to go to work is having an impact.

**“My escape from HD is my work. It helps keep me sane. Unfortunately, my work has shut down, so it means I don't have that escape anymore.”**

Many Carers worry about what will happen to the support arrangements of the person they look after if they become unwell.

**“I care for my father. We both have HD. If I was to get ill then he's in a lot of trouble”**

Some, having taken the decision to cancel care services because of concern about being infected by COVID-19, were now feeling under pressure.

**“I now have to provide all care to my husband 24/7, I am exhausted but I cannot let anyone into the house as I'm scared he will contract coronavirus. Our daughter lives with us and is able to do the necessary food shopping, but she suffers from asthma and I am also worried about her.”**

**“I cancelled care package as was worried about Carers coming in and infecting us. It's been really hard to manage.”**

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## Care Arrangements

Carers and people with HD had many concerns about the continuity of their current care arrangements.

**“I was told my care was being reduced from two visits per week to one visit per week. Last week no-one came, but they are due tomorrow, so I hope they turn up.”**

As noted for Carers, some people with HD had been ‘caught’ in the middle of a transition to new care arrangements, creating a great deal of uncertainty.

**“I was in the process of setting up self-directed support (waiting to find out how many hours I would be allocated). I assume this won’t start now. I currently have Carers once a day to empty my commode- I received a call from their manager to ask if they were able to withdraw my visit - at the moment it is continuing”**

One Carer captured the concern about whether some key services like respite would be available in the foreseeable future. For some this made their care arrangements feel more precarious.

**“I am very worried that it will take even longer to arrange some respite for us. Under the current circumstances as the HD patient is getting little sleep overnight, I often feel exhausted during the day.”**

**“None of the issues with reduced or terminated care apply yet, but I am concerned that as we rely on only two Carers, who have no one available to replace them, we might find ourselves without Carers with little notice.”**

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## Financial Impact of COVID-19

We know living with HD can cause huge financial stress for families and many reported additional pressures arising out of the current crisis.

Many respondents had been furloughed, had their hours reduced or could no longer work.

**“I work in Oil & Gas, I think it will be a very long time before I work again. My wife and I have witnessed our pension taking a big hit.”**

**“I gave up my job last year, however, my wife has been furloughed and it is unclear how much money she will make. We see our savings dwindling away.”**

For some, it is the practical aspects of managing money that are proving challenging.

**“I cannot access my bank. I wanted to transfer funds from my savings account to my current account and buy a washing machine and a new fridge but have not been able to get through on the telephone line despite numerous attempts where I was on hold for over an hour. I am self-isolating as I am over 70 and my son has HD, and I cannot get to the nearest bank which is many miles away.”**

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## Impact on Family Life

The survey highlighted significant concern about the effect the current crisis is having on the emotional and mental wellbeing of people with HD and their families.

**“I’m worried that there is additional pressure on my family as they are having to look after me and attend to my needs, shopping etc. I am also worried about my mental health and that of my son and daughter.”**

A few respondents highlighted that being bereaved during the current situation made it more difficult for families to grieve.

**“We had a family bereavement two weeks ago (not COVID) and we are all devastated.”**

Difficulties around the person with HD understanding and complying with the current social distancing rules were common.

**“My husband is finding it difficult to understand social distancing and when we are out. I am constantly having to remind him to keep to the 2-meter rule. Also, he is struggling to understand why we are not allowed to see family. Also, we are having issues with our son's attitude, which although has been ongoing since before Coronavirus, has been exacerbated during lockdown.”**

**“The person I care for is very stressed about the situation. I am trying to ensure he complies with social distancing, but he is saying it's ridiculous and implying that I am being 'difficult'”**

**“I am finding it stressful and difficult to cope with sons care needs and he is not able to comply easily with the restrictions.”**

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For some people with HD, it is difficult to understand or retain knowledge of why their routine has changed or they are unable to go out.

**“My husband who has HD, doesn't understand why his Carers are not coming every day, he has had them for nearly 20 years and is very upset that he doesn't see them. I have to comfort him and try to distract him when he becomes upset over the lack of visitors and Carers.”**

A common concern was an increase in the person with HD's level of irritability and this is sometimes happening while family members are dealing with other pressures.

**“My wife who has HD at times can be irritable, during this covid19 crisis this has become worse. I am self-employed, due to Covid 19 I am not working. I am worried about my company. I have to say I feel very stressed.”**

**“There is a marked difference in the behaviour of my HD symptomatic son and feel his symptoms are worsening.”**

Some respondents felt they were coping now, but are concerned about the future, if the lockdown continues.

**“Nicer weather and having garden helps our MH during this time. Am on anti-depressants so have to keep an eye on my own MH during this time. Being at home 24/7 - with my community groups cancelled - not known how long we will be in lockdown is concerning.”**

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## Accessing healthcare

In general, although access to healthcare has shifted to more remote methods, respondents were getting access to support when needed.

There were some concerns about getting prescriptions.

**“I was very worried about getting my prescription as I had nearly run out of diazepam and I called the doctor, they posted to me but said it would take a week, although actually it came sooner, so that was fine.”**

The lack of face to face visits was highlighted as a concern.

**“The Carers are doing a great job and flagging up any issues to the relevant health professional but it is more difficult when those health professionals cannot visit and see my son in person.”**

In some situations, the lack of face to face clinical assessment had negatively impacted the healthcare of the person with HD.

**“My husband had leg tremors but I did not know what it was. Reported this on this on the Wednesday to the nurse and she said that if he had not had a bowel movement then this might be the cause and was advised to keep drinking water and give Laxido drinks. By the Sunday, had to call the nurses again as he was shaking all over, they advised me to call 111. 111 said to phone the nurses back out and had to do this. They then sent out nurse to check and she found that the catheter was blocked and this was what the problem was. After the catheter was changed, he was fine.”**

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Some concern was expressed about whether people with Huntington's disease would be given access to a ventilator if they needed it. (NB There is absolutely no policy in place in Scotland that would deny someone with HD access to a ventilator if they required it).

**“There would be a real worry that having Huntington's would mean you are not given ventilation due to your illness despite leading a good quality of life.”**

**“I have not received a shielding letter which gives access to government support. I worry about getting the illness and not being treated aggressively because of the Huntington's.”**

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## Resilience

While there is no doubt the COVID-19 crisis has confronted people with HD and their families with a range of new challenges and concerns, there was also clear evidence that many are resilient and coping well.

**“I have no concerns but would like to add that just got PIP through and awaiting call from FWO, I am working from home. I get amazing support from my local HDS and want to thank everyone at SHA for doing a fantastic job, especially during this period.”**

**“For me, I am actually enjoying the isolation and spending more quality time with my family which we don’t normally do. This is not a negative experience for me. My only worry is money running out, although my benefits are covering most items. My family say that I am more chilled out/less irritable due to less pressure on having to do things.”**

**“Concerns being 'at risk' and having to go out to bank and essential shopping. I am taking advantage of the community volunteers to help deliver shopping sometimes. Neighbours are supportive too.”**

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## Things SHA could do to help

Overwhelmingly, respondents felt well supported by SHA (88% said they were not worried about obtaining support from SHA during the crisis). There were a few ideas in the survey responses for way.

1. Some additional information on the website to cover:
  - a. What Carers should do in an emergency.
  - b. Clarification of access to ventilation if someone with HD required it.
  - c. Clarification of 'Shielding arrangements' for people with HD.
2. Help to get practical support with things like shopping or banking.
3. More opportunities for Carers to interact with one another that would mitigate not being able to attend local Carer support groups.
4. Additional support for people with HD and Carers around their mental health and wellbeing.