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# Impact of COVID-19 on Young People living with Huntington's Disease

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Scottish Huntington's Association  
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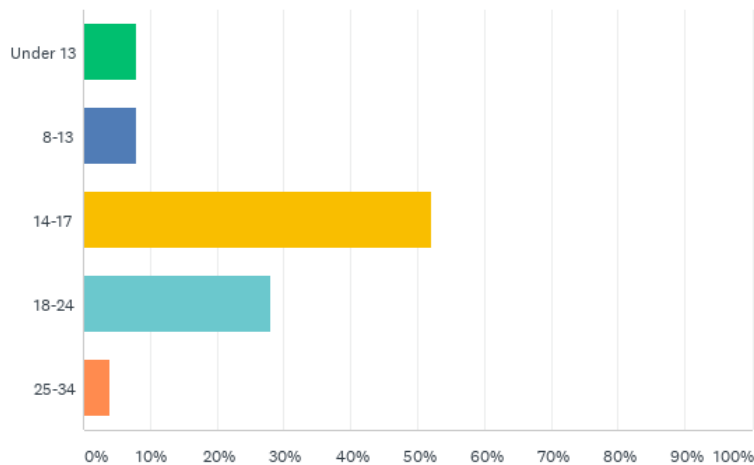
scottish  
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# Key Findings

## Response rate

We received 25 responses in total for this COVID-19 impact survey. There was an 88% completion rate for the survey with an average completion time of 8 minutes. The largest age group to respond to the survey was 14-17 with 18-25 year-olds coming next.

Q1 What age group are you in?



## Statistical Analysis

- 72% of young people are worried about becoming more isolated during the pandemic.
- 42% of young people are worried about the financial impact of COVID-19 on their family.
- 67% of the young people who responded or someone in their family had been furloughed or had their pay reduced.
- 50% of young are worried about having enough money to pay for essential bills like food and fuel because of the current crisis.
- 62.5% are worried or very worried about increasing levels of debt.

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- 29% of young people said the person with HD in their household did not understand the social distancing rules and are worried about the Police acting.
  - 52% 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.
  - 30% of respondents are worried about unpaid Carers having to take on more care.
  - 20% of respondents have had their support levels reduced.
  - 81% of respondents are worried about the increased pressure on family life.
  - 61% 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.
  - 72% of young people are worried about how COVID-19 will impact on their schooling or college/university studies.
  - 65% of young people said their mood was more variable than usual.
  - 29% of young people said that an existing mental health problem has been made worse because of COVID-19.
  - 100% 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, (72% of respondent being concerned about becoming more isolated) affecting people in quite different ways. Separation from family was having a significant impact.

**“I’m not able to see my gran and grandad I can’t watch my sister’s baby boy grow up. I can’t see my family”**

For many, distance from friends and from the activities they enjoy is having an impact.

**“I miss seeing my friends at school and through my clubs. I keep in touch with them through Skype, but it's not the same.”**

For some young people there was a palpable sense of loss; loss of expected opportunities and important milestones being one.

**“I have just finished school and was due to start University in September. I haven't been able to finish school, take my exams or have my prom. I had lots of plans for the summer and end of school which have all been postponed. I'm isolating at home alone with my parent.”**

**“I've missed out on school trips which were once in a lifetime, and it might impact on the subjects I wanted to take next year.”**

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## Impact on education is a significant concern

Some young people are worried they are at a critical stage in their education and how this will impact them.

**“...stressing out as they would be starting working for next year and there isn't the same enough support as there would be in school”**

For some young people, it has been difficult to adapt to studying at home.

**“...it will impact it a lot, struggle to focus at home. worried about getting work in on time”**

**“We're getting work home, but it's hard to get motivated to do it and the teachers are sending things through at lots of different times so it's very frustrating.”**

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## Impact on Young Carers

Having caring responsibilities is a common experience for young people in HD affected families. In this survey 65% said they provided support to someone with HD in their family. Of those, 52% said they were worried about the impact of COVID-19 on the care arrangements for that person.

The lockdown of nursing homes as well as the risk of transmitting the virus was raised as a concern. This was an issue for 40% of the young people who responded.

**“I cant help my Grandad anymore as I don't live with him and he cant go to his respite. I am worried he will catch it and die.”**

30% of young people reported, a family member who provided care, also worried as a key worker and were less able to provide support because of concerns about transmitting the virus to someone with HD.

## Impact on family life

81% of Young People in the survey were concerned about the impact of COVID-19 on family life.

39% reported an increase in the frequency of irritability or temper control in the person with HD.

30% said the person with HD in their family did not understand the social distancing rules.

50% said they thought the situation caused by COVID-19 had impacted the person with HD in their family's mental health. 44% thought it has impacted on the mental health of other family members.

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## Impact on health

29% of young people said they were worried an existing mental health condition had worsened during the COVID-19 crisis.

**“My anxiety is worse due to not being able to get out and about as much”**

Increased stress and anxiety was a significant issue for 65% of Young People who responded.

One young person highlighted that access to genetic testing had been halted because of the crisis.

**“I am awaiting genetic testing and can’t go through with it because of the changes to testing at present time. This is causing me stress although I understand why it has been postponed.”**

53% of Young People reported they are eating less healthily.

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## Impact on money

42% of Young People had concerns about how COVID-19 is impacting their own or their family's financial situation.

50% of Young People were worried their family might not be able to pay essential bills like food, fuel or broadband.

63% worried about increasing levels of debt and 67% were concerned because their household had less income because of reductions to hours worked or someone being furloughed.

## Getting help from SHA

100% of the Young People who responded to the survey were confident they would get the help they needed from SHA.