# The COVID-19 Pandemic and Carers

A Parent Carer's experience during the COVID-19 Pandemic

"I'm a single parent (sole Carer, no shared care) living in a small flat caring for my son with complex disabilities alone. During the pandemic our respite package collapsed and for the first lockdown his SEN school closed completely, to all pupils, even vulnerable pupils. My son and I lost all support overnight and it was a very dark time. He has a social worker, though at one time she was also off sick and wasn't replaced. I felt completely abandoned. I don't have a support bubble. My son has very high care needs (day and night) and is usually cared for in other settings on a 2:1 basis. I'm very tired and haven't had a full night's sleep in months. He's back at school now, which is the only thing that's kept us going— it allows me to do all the things in those 5 hours so I can safely care for him the other 19 hours. However he still isn't receiving the full range of therapies and interventions that his EHCP states he needs. He hasn't had most therapies for over one year and I'm worried this will have had a permanent affect for his development. Now, a year later, we are finally in the early stages of setting up a replacement respite package. It's been one of the hardest years of my life."

COVID-19 is still a huge issue and worry for Carers

A day in the life of a Young Carer during the COVID-19 Pandemic
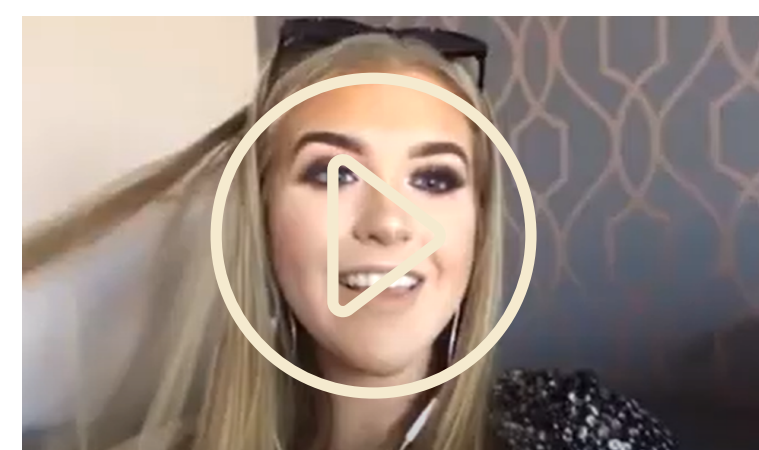
"Being a Carer and highly vulnerable is difficult"

How did COVID-19 impact Carers?

- There are more unpaid Carers in 2022 than before the pandemic, with one in five of the UK's adults (approximately 10.6 million people) now supporting a relative, close friend or neighbour because of chronic illness, including mental ill-health, dementia, disability, or older age.
- 42% increase in unpaid Carers providing significant care (20+ hours) Carers UK, 2022
- 81% of Carers took on increasing hours of care
- 78% reported that the needs of the person they care for have increased
- 69% reported that their mental health has worsened
- 64% have not been able to take any breaks
- 64% also said their physical health has got worse as a result of caring
  Caring Behind Closed Doors, Carers UK (October 2020)

"Being vulnerable has made the people I care for very anxious"

What did this mean for Carers?

- Day service provision stopped
- Constantly changing routines and rules
- 'Routine' procedures being cancelled
- Care packages being suspended because of rising COVID-19 cases
- Not being able to visit loved ones in care homes
- Young Carers often saw the true extent of situation at home
- Trying to juggle working from home with caring (and sometimes home-schooling)
- Digital isolation

Carers shared that there has been a decline in their physical and mental health

Support services and centres shut down

What about different groups of Carers?

- 91% of adult siblings said COVID-19 had made their situation more challenging (Sibs, April 2021)
- "It's been hard to help my sister understand what is happening. She doesn't know why I can't see her"
- "Day services and activities closing have left my brother with nothing to do."
- 81% of parents said their sibling child's mental health had worsened
- 43% of young siblings were providing more care
- 40% were feeling isolated & missing support from family and friends

Lonely Lockdown – Life for siblings of disabled children in the UK, Sibs (April 2021)

**James' Story,
Young Adult Carer**

**Charlotte's story,
Sibling Carer**
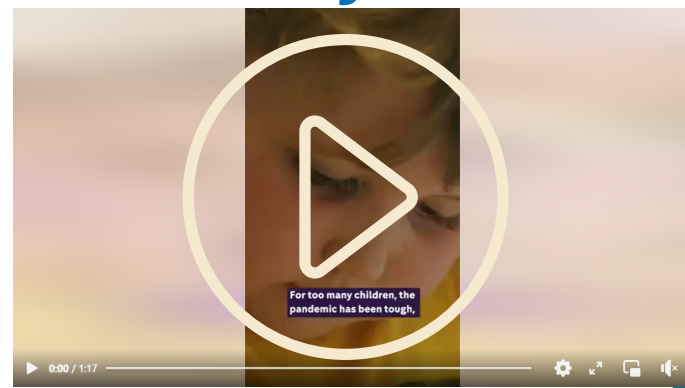
Young Carers Covid-19, One Year On

- 74% said their ability to cope with their caring role had deteriorated
- 60% felt their education had been negatively impacted
- 59% said their family has been negatively financially impacted
- 53% had not had any respite or break from their caring role
- Only 1 in 3 felt the needs of Young Carers had enough recognition during the pandemic
- Only 1 in 10 felt that Young Adult Carers had enough recognition
- "It's like the clap for Carers – it wasn't actually a clap for Carers, it was a clap for health and care workers – don't get me wrong, they have a really difficult job and I'm glad they are being appreciated – but when they finish, they can go home, switch off and relax – I don't get an off-switch from my caring role"

Caring Together, March 2021

Positives outcomes:

- Virtual support removing barriers
- Not having to leave person they care for
- The increased use of flexible working
- More volunteers providing support

Carers shared their positive feedback about the Carers Matter Norfolk Virtual Cuppas:

Carers Matter Norfolk
0800 083 1148

- Being able to connect with Carers across Norfolk
- Great help to fight the thought of being on your own, and identifying some places for help. Supportive seeing people in the same boat
- It has saved my mental health
- Has been a godsend, particularly throughout the pandemic but also now as things have not gone back to normal and we would not be able to meet everyone face to face

"Living with COVID-19"

- Many health settings still having enhanced provision in place
- Many Carers are still worried
- Access to testing and the associated cost of living crisis
- What is the long-term impact – health? Education? Employment? Isolation?

Not everyone has online access. People need to be supported with technology

Difficulties sharing issues Carers want to talk about because the person they care for can overhear

Next Steps/Recommendations:

- Consistency and clear communication
- Have we identified all of the 'new' Carers during the pandemic?
- Ensure Carers are able to access their own health appointments/check-ups
- Make proper use of the GP Carer registers and new carer codes for GP surgeries
- Continue with hybrid support for Carers and focus on mental health of Carers (not just within Carer organisations)
- Impact of Long COVID
- Ensure we take forward learning across the Integrated Care System
- Carers Lead within Integrated Care System

"Never had an annual health check"

Carers Conference 2022