

# Cystic Fibrosis our focus

## Key findings from Southampton University's SHARE study into experiences of shielding

The study captured children and young adults with CF's experiences of shielding. The survey was open between May and July 2020.

The results showed that shielding caused significant disruption to people's lives and had an impact on their wellbeing. Most people surveyed had used information provided by the Trust about the virus. We've continued to keep this information up to date throughout the pandemic to help the CF community stay informed.

**73%** of parents  
**50%** of children and young people with CF  
reported that they were worried about the virus



**59%** of parents  
**61%** of children and young people with CF  
no longer felt the hospital was a safe place during the virus



**95%** of parents  
**92%** of children and young people with CF  
received information from the Cystic Fibrosis Trust



**73%** of parents worried about their child feeling more isolated



"I understand this is for my health and wellbeing, but I feel if [shielding] lasts any longer, I'll have wasted nearly half a year inside, time I simply don't have spare to waste."

"As the virus has led to lockdown and shielding our concerns have stretched beyond that of the virus and the impact upon his future health and wellbeing."

"I'm petrified of catching it. My dad works away and hasn't been allowed to come home so no new germs are brought into the house."

43%

of children and young people with CF reported that shielding guidance was clear and easy to understand



**Lives were disrupted:**

Education, work, relationships and friendships were all disrupted by shielding. Needing to isolate from other people in the same household posed an extra challenge for some.



**Emotional wellbeing was affected:**

As well as worrying about catching the virus, many people worried about feeling more isolated. Parents also worried about the impact on their child's development.



**Exercise levels were reduced:**

Most people had lower levels of exercise, likely due to guidance to avoid contact with others and the closure of gyms and classes.



**Worries about the end of shielding:**

Many were anxious that the general public may not follow the guidelines and have less understanding of how to avoid infection than the CF community.

“My isolation has impacted my ability to find work and cut me off from my family.”

“Psychologically overwhelming. Fearful of all contact outside the house.”

“As parents of children with CF we are well used to weighing up risks against quality of life - there is risk for them everywhere, even in our own homes!”

“My son shielded extremely well and as a teenager enjoyed being off school and still does!”