

Cystic Fibrosis our focus

Response: Treasury Committee Inquiry into the Economic Impact of Coronavirus

1. Cystic fibrosis is a genetic, life-limiting condition affecting more than 10,500 people in the UK. The wide range of progressive symptoms and co-morbidities affect multiple organs in the body and require a rigorous medicine regime to manage. Living with cystic fibrosis limits, interrupts, and challenges life, making it difficult to live independently, work and socialise. Cystic fibrosis is a severe, progressive, and life-limiting condition. Last year, the median age at death in the UK was only 32, with the primary cause of mortality being respiratory failure. People with cystic fibrosis are identified as one of the most at-risk groups that are susceptible to severe disease from COVID-19. Lung infection, damage, and reduced lung capacity make it difficult to breathe and increases susceptibility to further damage from viral infections.
2. The Cystic Fibrosis Trust is the UK-wide charity dedicated to fighting for a life unlimited by cystic fibrosis for everyone affected by the condition. The Cystic Fibrosis Trust provide a range of direct support to people with cystic fibrosis who are experiencing financial hardship.

Financial support we provide includes:

- Grants for people with cystic fibrosis to help with some of the costs associated with the condition, including emergency, transplant, health and wellbeing, holiday, home care, education and prescription pre-payment certificate grants.
- Support with applying for benefits, such as DLA, PIP or Universal Credit.
- Helen Barrett Bright Ideas Awards to help people with cystic fibrosis start new businesses.

Through the Cystic Fibrosis Trust helpline, we offer practical support and information for people living with CF and their families.

3. Since the outbreak of coronavirus, the Cystic Fibrosis Trust have experienced a dramatic increase in the number of daily queries on the helpline and social media, with a considerable number focussed on concerns about financial hardship and the economic impact of coronavirus. Our emergency grants programme has also been contacted, with the first applications for emergency funds as a result of loss of earnings being received. We have also been contacted by specialist social workers with concern for the most vulnerable people with cystic fibrosis.
4. The most severe social shielding guidance applies to all people with cystic fibrosis, requiring people to not leave their houses for an initial 12 weeks. However, little guidance has been given on managing the financial implications of this guidance. There is uncertainty for households that

include vulnerable persons (such as someone with cystic fibrosis) on how they may immediately access financial support from no longer working. This uncertainty can put people with cystic fibrosis in the impossible situation of continuing to go to work and endangering either themselves or someone in their household. The current measures do not offer the financial support to households with vulnerable individuals who are expected to follow social shielding guidance immediately.

5. Many people with cystic fibrosis and carers are already financially vulnerable due to the additional costs associated with the condition and the impact of cystic fibrosis on their ability to work. Research by the Cystic Fibrosis Trust has found 85% of adults with cystic fibrosis experience at least some concern because of the financial burden caused by cystic fibrosis and of those 32% experience considerable concern or worry.
6. There is an immediate requirement that financial support is provided to individuals and families, whose income has been affected by COVID-19 to support their self-isolation. Removing delays to accessing universal credit is essential, such as ending the 5-week wait so that people can access financial support immediately. Regular payments of benefits, via moving universal credit payments to fortnightly, will support many more families that are now relying on this form of benefit.
7. As more families are now at home full time, more pressure is placed on managing food budgets. We recommend an increase to the child benefit can compensate families for the increased food needs.
8. Further support can be provided for people with a disability such as cystic fibrosis who are experiencing a loss of income due to social shielding measures including additions to the Personal Independence Payment (a mechanism already available to provide Christmas bonuses), as well as provision of free prescriptions for everyone required to self-isolate for 12 weeks. A supplementary carer's allowance (already available in Scotland) can support many carers in managing increased demands to their role.
9. Support is also required for self-employed individuals. An IPSE Report published in 2019 using data from the Labour Force Survey found that the number of self-employed disabled people has risen by 30 per cent in the last five years, with the group now accounting for 14 per cent of the self-employed workforce – this is around 611,000 people.¹
10. Some people with cystic fibrosis may choose to run their own business to give themselves the freedom and flexibility to earn money to live and contribute to the economy whilst juggling daily life with a chronic condition, which carries a heavy treatment burden and for many frequent hospital appointments. Others may just choose this path to follow their ambition in a way that is manageable for them but whatever their reason, they rely heavily on this source of income.
11. It is a worrying time for people with CF who are self-employed and are now following social shielding measures due to being in a highly vulnerable position during the COVID-19 pandemic. It

¹ <https://www.ipse.co.uk/resource/making-self-employment-work-for-disabled-people.html>

is vital that financial support from the government is provided and communicated urgently to ease this additional source of anxiety and ensure people are able to maintain access to a safe living environment and sufficient food and resources whilst being confined to their own homes to protect their health and to compensate for their loss of business.

12. The Cystic Fibrosis Trust welcomes this inquiry into the impact of Coronavirus and can provide links to people with lived experience for oral evidence.