

## Response: Environment, Food and Rural Affairs Committee Inquiry into food supply during the Coronavirus pandemic

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. 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. Due to difficulties digesting food, people with cystic fibrosis also have significant additional nutritional requirements. They must take digestive enzymes whenever they eat to help them get the nutrients they need from food. They also require a high-fat, high-calorie diet in order to maintain a healthy weight and help fight the infections that can damage their lungs and shorten their lives.
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 and emotional hardship.
3. All people with cystic fibrosis have been told to socially shield for an initial 12 weeks, which requires people to not leave their homes within this time. In response to this new guidance, the Cystic Fibrosis Trust have experienced a dramatic increase in the number of daily queries on the helpline and social media. Many people with cystic fibrosis are experiencing significant difficulties in obtaining food and provisions they require to stay well, with a considerable number focussed on concerns about getting access to food from online deliveries and getting on the supermarket's vulnerable list to get priority delivery slots. Other concerns have centred around item rationing meaning people with cystic fibrosis are unable to purchase enough quantities of food and other supplies to manage the effects of their condition.
4. When people grouped as extremely vulnerable in the UK were told to start socially shielding, there was little guidance given on managing the wider implications. There was confusion around whether you need to receive your NHS letter before registering for food on the UK Government website. This led to delays and further issues around securing a delivery slots with supermarkets and requiring people within the household to go to the supermarket. We go into further explanation into these points below.
  - a. There was confusion about whether a person shielding needed to wait for an NHS letter before they could register for food deliveries or if they needed to register anyway. This confusion caused mass delays for food parcel deliveries due to the roll out of NHS letters taking much longer than anticipated. This left many people with CF unsure with what to do and causing unnecessary panic about whether they would get access to food. The Cystic Fibrosis Trust tried to reduce this anxiety by disseminating the information available and encouraged our community to register for food on the Government website regardless of whether they had received their letter. However, there was limited information publicly available which further delayed any actions to address these concerns.
  - b. We also encouraged people with cystic fibrosis to order food delivery online. With 1.5 million people and possibly their households socially shielding, many people with cystic struggled to get a food delivery slot. Supermarkets appeared unprepared to manage the increased number of food deliveries to the those socially shielding. The Cystic Fibrosis Trust sent letters to leading UK supermarkets and DEFRA for clarity on access to food for vulnerable people. The responses we received were vague and often contradictory advice and reinforced the notion that supermarkets were unprepared. It was unclear whether supermarkets would receive a copy of the vulnerable list data from the Government or whether the person asked to shield had to register. We suggest going forward increasing communication with UK supermarket chains to better prepare for any further increase in demand, particularly if the UK goes back into lockdown again due to another wave.

- c. Even now, most supermarkets are only allocating 25% of their delivery slots to the vulnerable and many are waiting weeks to get a delivery slot. Some supermarkets have additionally stated they will prioritise existing customers and not take on new customers. It would be helpful if supermarkets were clearer on why this is and how they are prioritising food delivery slots. We would suggest the Government clarify with supermarkets on how vulnerable people are being prioritised to ensure that all vulnerable people manage to get access to a delivery slot to avoid any further unnecessary delays. This is a particular problem for single parent households, who cannot take a child with cystic fibrosis shopping as they are being shielded and are therefore reliant on deliveries. We are now starting to hear from parents via our helpline that children are losing weight due to the difficulties obtaining food, which in cystic fibrosis is particularly concerning due to the implications on lung health.
  - d. Without access to a delivery slot, someone from each household needed to go to the supermarket for the family as many households decided to socially shield together to minimise risk. Even then, it has been difficult to shop at the times allocated for the more vulnerable as either someone with cystic fibrosis did not 'appear to be vulnerable' or the person shopping on their behalf could not prove they were shopping for a vulnerable person. The Cystic Fibrosis Trust published a letter to help clarify the situation and explain the dietary needs to a person with cystic fibrosis to show to supermarket chains but the concern about leaving the household remained.
5. The inability to purchase food at budget supermarkets and the need to shop differently is also causing significant financial hardship for some who are having to resort to more expensive shops and suppliers. For some, even the additional cost of delivery from online supermarket shopping is pushing them beyond their budgets. In just 5 weeks, we have processed almost 100 emergency grants towards extra food costs for people with cystic fibrosis. Without our financial support, they have told us they would be unable to afford the food and essentials they need to protect their health.
6. We commend the Government for the dissemination of the food boxes. This helped alleviate a lot of anxiety in the community. However, there was slight confusion about how items of food were chosen. People with cystic fibrosis need to consume a higher than average amount of daily calories and so require fattier items such as full-fat milk or yoghurt rather than skimmed. Additionally, people with cystic fibrosis on modulators need to have 10 grams of fat with each dose. There have been some hindrances in clarifying a person's dietary requirement. We appreciate this system has been put in place urgently to help implement such large changes very quickly but feedback from the community has highlighted that, when registering on the Government website, there is no opportunity to explain this requirement. We would recommend amending the form to implement a free text box function to allow for clarification especially as people with cystic fibrosis are probably not the only vulnerable people to need this.
7. There has been inconsistency between England and the other devolved nations and how to register and access for these food boxes. When registering on the UK Government website, those on the devolved nations were referred to their own countries' website without any signposting on where to go. The process in the devolved nations was also announced later than in England causing further anxiety in the population as it gave the impression that those in the devolved nations were being overlooked. Improved communication between the UK Government and the devolved nations is essential to avoid such delays and ensure better preparedness for any changes going forward.
8. The anxiety and panic could have possibly been mitigated by increased communication between the different stakeholders in the Government and the Cystic Fibrosis Trust. The Trust did not receive any information on the process and have been signposting the community to public available information. The Trust is in a great position to be a conduit to communicate with people with cystic fibrosis and it would have given us the opportunity to get ahead of the range of concerns that have been raised. This would have also helped alleviate pressure on GP's and Cystic Fibrosis Clinical Teams who got an influx of questions regarding access to food, when they are already inundated with medical queries.
9. The Cystic Fibrosis Trust welcomes this inquiry into the impact of Coronavirus and can provide links to people with experience for oral evidence. Please contact [policy@cysticfibrosis.org.uk](mailto:policy@cysticfibrosis.org.uk)