

26 March 2020

Dear Sir / Madam

Cystic fibrosis (CF) is a life-shortening, progressive, genetic condition. It causes a build-up of thick sticky mucus that causes severe, irreversible damage to the lungs and digestive system, making it hard to breathe and to digest food.

Over 10,500 people in the UK have cystic fibrosis; the average age of death is just 32. The condition requires a rigorous treatment regime often comprising dozens of tablets and hours of physiotherapy each day, to keep the lungs clear of mucus and ward off lung infections.

Due to difficulties digesting food, people with cystic fibrosis 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 stay as healthy as possible and help fight the infections that can damage their lungs and shorten their lives.

The impact of cystic fibrosis on the digestive system and the need to regularly clear mucus from the lungs also means that people affected by CF often need greater quantities of toilet paper and tissues.

Due to their increased risk of respiratory complications, people with cystic fibrosis have been categorised as one of the groups most at risk from coronavirus, and therefore must socially shield for at least 12 weeks.

We are extremely concerned to learn via our helpline and social media channels, that many people with cystic fibrosis are experiencing significant difficulties in obtaining the food and provisions they require to stay well, and would like to highlight the following in particular:

- Lack of online delivery slots for most major supermarkets
- Unable to register as a new customer for some supermarkets
- Unable to register / not being recognised as a vulnerable group by some supermarkets
- Item rationing, meaning people with CF cannot purchase sufficient food to meet their additional nutritional requirements and stay well
- Item rationing, meaning people with CF cannot purchase sufficient quantities of toilet paper and tissues to manage the effects of their condition

Due to the need to social shield, people with cystic fibrosis **cannot** leave their homes to shop for food or for any other purpose. For others living in the same household, to leave their homes to shop for food increases the risk of them catching coronavirus and potentially passing it on to the person with cystic fibrosis they live with, which could have devastating consequences.

This situation is causing untold amounts of stress and anxiety to people with cystic fibrosis and their families at what is already a hugely concerning time, given their increased vulnerability to coronavirus. Those affected by cystic fibrosis may also be financially disadvantaged due to their condition, and therefore being able to shop at a supermarket, rather than relying on more expensive local grocery delivery options that may be available, is essential.

We urge you therefore to take immediate action to ensure people with cystic fibrosis can shop online for food and other essential provisions as soon as possible and with priority ordering status, including:

- Being able to register as a vulnerable group for online grocery orders
- Being able to purchase additional quantities of essential groceries in order to meet their additional nutritional requirements
- Being able to purchase additional quantities of toilet paper and tissues to manage the effects of their condition

This will ensure people with cystic fibrosis can avoid any potential damaging impact on their lung health that could arise if they fail to maintain adequate nutrition during this crisis.

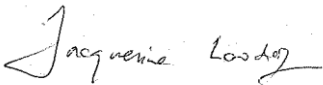
Yours sincerely,



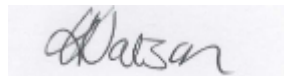
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