



November 2023

Dear Constituent,

Thank you for contacting me about Cystic Fibrosis. In recent years, there has been great progress in improving access to precision medicines that can tackle the root causes of Cystic Fibrosis (CF).

Since 2019, thousands of people with CF have been able to benefit from licensed treatments being made available through the NHS in England. As a result, I fully recognise the disappointment that many people with CF and their families will have felt at the initial decision by NICE not to recommend Orkambi, Symkevi and Kaftrio for use in the NHS.

Over the next month, NICE will be consulting on the recommendation, and I know that patient groups like the Cystic Fibrosis Trust intend to share the views and experiences of people with CF and their families. My understanding is that this recent decision does not apply to anyone with CF who is currently taking a modulator therapy.

I also understand that the Cystic Fibrosis Trust has been highlighting the issues faced by people with cystic fibrosis around PIP assessments. Landmark reforms to the benefits system set out in the Health and Disability White Paper, “Transforming Support”, will change the emphasis from what people cannot do to what they can by legislating to abolish the Work Capability Assessment (WCA) so that in future years there is only one functional health and disability assessment – the Personal Independence Payment (PIP) assessment. PIP helps with the extra costs of a disability or long-term health condition.

The PIP assessment will also be improved by changes announced in the White Paper, including by continuing to test the introduction of a Severe Disability Group for those with the most severe health conditions, so they do not need to complete a detailed application form or go through an assessment.

Good data on health outcomes is vital to understanding the effectiveness of treatments for cystic fibrosis. That is why I applaud the work of the Cystic Fibrosis Trust and their Registry which collects data on demographics, treatment and health outcomes of consenting people with cystic fibrosis.

An annual report is commissioned by NHS England which provides NHS clinicians and commissioners information to inform decision making on cystic fibrosis services in England. The latest report from December 2022 can be accessed here:

<https://www.cysticfibrosis.org.uk/sites/default/files/2022-11/CC8-10%20Registry%20At-a-glance%20report%202021.pdf>



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There is an extensive list of conditions exempted from prescription charges in addition to exemptions for people on certain benefits or through the NHS Low Income Scheme.

Some people with cystic fibrosis may meet the eligibility criteria for prescription charge exemptions and may therefore be in receipt of free prescriptions.

The system of exemptions as a whole means that 89% of prescriptions are dispensed without charge. Additionally, patients who need more than one prescription each month can save a minimum of £20 every three months by purchasing a pre-payment certificate (PPC) from the NHS Business Authority. This covers an unlimited number of prescriptions for the length of the certificate, regardless of whether they specifically relate to the condition.

Income from prescription charges is put back into our NHS and generates a valuable source of funding for the NHS. Between 2015/16 and 2019/20, prescription charges generated over £2.8 billion for the NHS, which contributes to patient care and essential running costs for frontline services. This money would have to be found elsewhere if charges were abolished entirely.

Thank you again for taking the time to contact me.

Yours faithfully,

CHRIS HEATON-HARRIS MP
MEMBER OF PARLIAMENT FOR DAVENTRY