Department of Health and Social Care
9th February 2023

Dear Minister,

Your Department recently issued a response to a parliamentary petition asking for improved recognition of pulmonary fibrosis. I would like to thank you for this response, and ask whether there might be an opportunity to take the dialogue further.

Pulmonary fibrosis is a terminal disease with a life expectancy worse than most common cancers. The disease is progressive with patients becoming increasingly breathless over time and dying from respiratory failure. Its impact is different from other lung conditions such as asthma and COPD, and commonly involves a sharper and more severe impact on people living with the disease and their family members.

Your Department's response to the petition rightly highlighted that NICE has recently revised its guidance to broaden access to the anti-fibrotic drug nintedanib, which specialist interstitial lung disease (ILD) centres will be able to prescribe to a greater number of patients from March. However, it also suggested that these specialist centres are responsible for the overall care for patients with pulmonary fibrosis. In fact, this is not the case. NICE guidance and NHS England's own service specification make clear that care should be provided by local NHS services, with specialist support and supervision.

The transfer of commissioning responsibilities to Integrated Commissioning Boards (ICBs) this April therefore presents both an opportunity and a risk. Currently, many patients remain under the care of specialist centres, without effective pathways to secure the care they should be getting from their local NHS services. If ICBs do not quickly recognise and respond to this, the markedly higher demand for anti-fibrotic prescriptions risks overwhelming the specialist ILD clinics. Some leading clinicians tell us they are considering closing their clinics to new referrals.

However, the introduction of ICBs also provides an opportunity to improve pulmonary fibrosis pathways and reduce pressure on hospitals caused by unplanned and emergency admissions. These can happen when people experience severe breathlessness, sometimes as a result of poor management of their condition, and cannot access supportive care.

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Effective care for people with pulmonary fibrosis will involve, in addition to the timely prescription of anti-fibrotics: access to appropriate pulmonary rehabilitation (which is different from COPD or asthma rehab); access to oxygen; access to palliative care; and support from a nurse or other professional with appropriate expertise. This will require good provision by local NHS services and cannot be provided by specialist centres on their own.

The Department's response also helpfully highlighted the importance of timely and accurate diagnosis, which enables people to access anti-fibrotics, pulmonary rehabilitation and other services more quickly, and improves their quality of life and survival time. It also avoids people having to make repeated calls on the NHS (normally their GP) due to an incorrect diagnosis, or to deal with a crisis caused by their illness not having been recognised and treated. The response of the Department, in highlighting the QOF indicators for diagnosis of COPD and asthma, serves to emphasise that there is no equivalent for pulmonary fibrosis. Slow diagnosis and delayed treatment remains an common experience for most patients.

Action for Pulmonary Fibrosis plans to work with specialist clinicians and others to develop a consensus pathway for pulmonary fibrosis. It will set out what effective care looks like provide guidance to ICBs on how to improve their pathways and reduce pressures arising from unplanned admissions. Following the changes in commissioning responsibilities and prescription eligibility this spring, we hope the new consensus pathway will raise the profile of pulmonary fibrosis with planners and commissioners and avoid problems arising from poorly functioning care services.

I would welcome an opportunity to discuss with you how we might be able to work with your Department and NHS England to promote this pathway, and get services working as they should for patients with pulmonary fibrosis.

Yours faithfully,

Louise Wright
CEO

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