Interstitial lung disease and breathlessness

When was the last time you felt really, truly breathless? You may have asthma, anxiety or an allergy. It may never have happened. In my case it was halfway up a mountain with no clear trigger – I just unexpectedly ran out of breath. I vividly recall my initial surprise, followed by an escalating feeling of panic. My world narrowed and I could only focus on breathing – or not. After a few minutes it passed and has never happened since, but it was an experience which has stayed with me.

As far as I know, my lungs are fine. But respiratory disease is common, affecting one in five people in England [1]. It places a significant burden both on a population level in terms of economics, healthcare and social inequality, as well as impacting on an individual's quality of life; breathing is after all something we do all the time. It can be debilitating, difficult to manage, and can impact psychologically on individuals and their families.

Interstitial lung disease (ILD) refers to a range of conditions which are often progressive with a poor prognosis. The British Lung Foundation recommends that there should be a clear, standardised pathway to palliative care for patients with ILD. However, patients with ILD are less likely to access specialist palliative care compared to those with malignant disease [2]. A strong collaborative link has existed between Marie Curie Hospice and the respiratory team at the Royal Victoria Infirmary (RVI), both in Newcastle upon Tyne, since 2016. At the regional ILD clinic based at the RVI patients can access same-day respiratory and palliative care reviews, and over the past few years an increasing number of patients with ILD have been referred to the hospice both for inpatient admission and to access weekly support from the day therapy unit (DTU) [3].

As specialty doctor at the hospice I provided medical input to DTU patients one day a week, including several patients with ILD. DTU provides regular access to a range of professionals dedicated to improving symptom burden – an occupational therapist expert at aiding patients with pacing techniques and providing equipment, a physiotherapist to improve posture and exercise tolerance, a clinical psychologist, art therapist and complementary therapist to offer support with psychological aspects of respiratory disease and breathlessness. Co-ordinating this is a team of dedicated nursing staff who build an in-depth knowledge of their patients' requirements and wishes over the course of several weeks or months. My offer of opioids, while evidence-based, often worked best when combined with non-pharmacological interventions.

Since March this year things have changed across medicine and beyond. Living with a respiratory disease is challenging at the best of times, and everyone's experiences over the last few months will have been different; but the combination of chronic breathlessness with the added threat of coronavirus must be hugely difficult. Palliative care practitioners have had to find new ways of working, particularly as patients are highly likely to be vulnerable to Covid-19. Patients have been unable to attend DTU in person, and I suspect many have missed this source of advice, camaraderie and reassurance. However, innovative methods including virtual access to healthcare professionals has ensured that this support has been maintained as much as possible.

There is increasing evidence that COVID-19 can lead to long-term sequelae including respiratory problems, and interstitial lung disease and pulmonary vascular disease are likely respiratory complications [5]. Many patients may be experiencing chronic breathlessness for the first time. Palliative care teams are well placed to play a significant role in the ongoing management of these patients, as well as continuing to support patients with life-limiting respiratory diseases. Close collaboration between palliative care and respiratory teams will be hugely beneficial going forward.

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