



# breathe

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## How treatment burden affects the carer: the experiences of three individuals, a mother, a daughter and a husband

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**The burden of treatment extends beyond the patient and can have a dramatic impact on the person in a caring role.** <https://bit.ly/3oekJjo>

This piece will focus on how the burden of treatment can affect not only the person with a condition, but also those who care for them.

These are the experiences of three people who have taken on very different care roles. The first is Lucy Pritchard whose son, Elijah, was born with bronchopulmonary dysplasia (BPD). Pam Carter then discusses her experience of caring for her mother, Eileen, who has bronchiectasis. Finally, Liam Galvin talks about his life with his wife, Phyl, who passed away from idiopathic pulmonary fibrosis (IPF).

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### Lucy Pritchard

Elijah was born on the 9 November 2017 at 24 weeks and 3 days' gestation. He weighed 740 g (1 lb 10 oz). His due date was meant to be 26 February 2018. The extreme prematurity of his birth is the main cause of his current ongoing condition. Elijah has BPD. Elijah is now 3 years old, but for the first 2.5 years of his life, he has been on oxygen.

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Lucy Pritchard, Elijah and family.

Whilst Elijah was in the neonatal intensive care unit (NICU), he was put on a ventilator, oscillating ventilation and nitric oxides as his lungs were so underdeveloped. Elijah needed a course of steroids to help him come off the ventilator and progress on to bilevel positive airway pressure, then to continuous positive airway pressure and then to nasal cannulas.

Elijah left NICU on 1.5 L of oxygen, which for us as parents was very scary, as without the oxygen Elijah was not able to breathe and his saturations dropped rapidly. For our peace of mind and that of his consultants, we left the hospital with a monitor, so that if his nasal cannulas came out at night and his saturations dropped it would alert us that something was wrong.

Leaving the ward on that much oxygen scared us as a family, and we needed to make several adjustments. We had to have a concentrator installed in our home as the large oxygen cylinders would not last long, and when out and

about we always had to take at least two cylinders with us as they would only last 4 h. Every time Elijah passed a sleep study and moved down a point on his oxygen requirements was a huge achievement, when he hit being on a litre that was massive, even though it was still a huge amount of oxygen for someone so tiny to be on.

Winter is a hard time for us as a family, as we are forever conscious that if Elijah gets a cold it can turn in to bronchiolitis and could mean a hospital admission, as he would require more oxygen to help him breathe.

As a family it had a huge impact on us having a premature baby and one with needs. At the time we had a 6-year-old daughter, who spent all her school holidays and weekends at the hospital or spending time with grandparents and missing out on things as a family. Even when Elijah was out of hospital, we planned trips around him, so that we weren't taking him in to an environment that could potentially make him poorly.

Elijah is now 3 years old and has finally come off oxygen and is doing well. We shield him when it comes to winter as we are still worried that if he catches a cold it could lead to something else and, especially now with COVID-19, we are extra careful as a family as to where we go.

Even though Elijah is no longer on oxygen we still have other challenges. Elijah is delayed in his development, learning, speech and understanding, and he does not eat or drink as he has an aversion to food, so he is button fed. A button is a small gastrostomy device, it is held in place with a balloon of water that sits on the inside of the stomach. As parents we have learned to care for the device and to change the water in the balloon on a weekly basis. Every 3 months, we remove the button and insert a new one. Initially this was something that was done by a nurse or trained dietitian. As an integral part of Elijah's treatment, we learned to do this ourselves.

Elijah is bolus fed, so he has three meals a day like us. He eats what we eat it is just blended with his fortini milk (nutritionally complete liquid), so that he still gets his calories with him not snacking in the day. This has also had an impact on wider family members as his grandparents have had to be trained on how to feed him for when I am at work as they care for him.

Life has changed forever for us as a family, we have adapted and learned to navigate the difficulties that have arisen due to Elijah's treatments. When you have already had a healthy baby previously you do not think anything like this will happen to you, my eyes have well and truly been opened to the medical profession, and without them my little boy would not be here at all.

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### **Pam Carter**

I am not my mum's main carer. She has been married to my dad for 61 years and they live in the same house I grew up in, which is about a 10 min drive from my house. Mum had a lobectomy when she was 9 years old and has lived with bronchiectasis all her adult life. However, for many years, there was no real treatment burden as mum's only treatment was to take antibiotics when she got a chest infection. She had always been advised that she would not be a candidate for surgery. She was stoical and often sceptical towards the medical profession, some of whom did

not seem to know a lot about her condition and most of whom repeated the endless question “have you ever smoked”?



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Pam Carter.

Over the past 5 years or more she has become more frail, her bronchiectasis is now advanced, she has atrial fibrillation, right-sided heart failure and has had episodes of cellulitis, cataracts and skin cancer. This impacts on her quality of life and mum has been very proactive in setting up an end-of-life care plan. Creating the plan together was, in itself, an emotionally challenging process for me, but one I wholeheartedly support.

For a while, mum attended a Breatheasy group, but while resources were available to set up the group, the expectation seemed to be that patient group members would be able to take over the running over the group and sustain it. This proved unrealistic, especially as the members all had health problems and voluntary sector finance and support is not necessarily easy to access. Mum and I were both sorry when the group folded.

I worked full time, but requested flexible work and reduced my hours to care for mum. My employer was sympathetic so sometimes I could juggle my work when mum needed to go to hospital appointments. In 2017 my contract came to an end, so I took early retirement. It was a relief on the one hand to have more time to spend with mum and dad, but on the other I needed time to adjust and missed work. A bonus is having time to spend with grandchildren, but that can bring further competing demands between the different generations.

As mum's condition has worsened, she has been introduced to puffers, inhalers and nebulisers. She takes diuretics for heart failure, and she and dad have to have a strict regime of administering daily medication and ensuring they have supplies in. Sometimes, understandably, there are frustrations in dealing with systems for appointments *etc.*, especially with the move to digital systems, and I try my best to provide reassurance and hope to avoid mum sinking into depression. I was with her when a bossy physiotherapist tried to teach her to use an Acapella device that did not make much difference to mum's breathing. A respiratory consultant spoke about the possibility of mum entering a clinical trial, but at the time neither she nor I could face the idea of regular visits to the hospital with the stress of finding a car park space and the unknown issue of what the trial was about or the practical implications for mum, so we declined.

I am well aware of advice on self-care and have coping strategies for when I need some "me" time and I try very hard not to feel guilty about the fact that mum is suffering while I have been relatively fit and well. Our local hospice was offering 1 day a week therapy for mum, but since the COVID-19 lockdown this now takes the form of a weekly phone call, which we are still grateful for. Sometimes our relationship has felt like a rollercoaster of me being too protective or even patronising mum then at other times being acutely aware of just how great my parents' needs are as they age. I am very conscious that people with chronic illness do not usually get "Get Well" cards and can be expected to put on a brave face. We have an agreement about what housework I help with, what they can manage and when we all sometimes just want to forget about health or illness, enjoy each other's company and have an outing. Unfortunately, recently I have had to have treatment for a lung problem and so we are back to our strategy of "muddling through".

To sum up, any "treatment burden" is greatly eased when clinicians and health professionals are respectful and caring towards patients as well as carers. Ultimately, we all need to feel that our health matters, that our individual experiences are listened to and that we can achieve a good quality of life.

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## Liam Galvin

Liam Galvin met his future wife Phyl Troy in at a music festival in Thurles, Ireland in the early 1990s. They had their son together in 1997 and married the following year. After several years of marriage, Phyl's older brother and one of her older sister's got IPF; sadly, they both passed away after 3 years and 4 months, respectively. It was at Phyl's brother DJ's funeral that she started to feel breathless herself. With their knowledge of her sibling's conditions, Phyl and Liam went to see a specialist, and it was confirmed that Phyl also had IPF.

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Liam Galvin.

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Liam was interviewed for this article and the following is a summation of our discussion, which he has read and approved.

There is a huge impact on the partner and family generally. Fighting the disease, but we also had issues with health systems and the financial impact of trying to get Phyl the treatments that she needed. This meant that I was working more and had less time to spend with her.

There is this roller coaster of emotions, Phyl tried to keep everything as normal as possible for me but also our young son, Niall, who was still in school at the time. There was this conflict between how Phyl and I dealt with the situation; she was more concerned with how I was going to be affected and how I would cope with her not being there. I was more concerned about her, how she was feeling and making sure she had what she needed. We were united though, in our concern for Niall.

You want to make sure that the time you have left, you spend together; because of this, you feel a sense of isolation. You cut off ties with immediate family and friends. Everything becomes focused on spending time as a family, and that was fine, it was what we needed.

Despite feeling somewhat isolated from family and friends, we got involved in IPF support groups, this was important for Phyl, but it was a huge support for me too. I got a lot from being able to talk to and empathise with the other family members at the back of the room. That support was really important for me and I would recommend it to anyone else going through the same thing. Phyl was facing into the disease, but I was facing into losing her – I couldn't imagine life without her.

Physically it was exhausting, ordinarily we would share the household responsibilities, I cook, she cleans. But the responsibility started to fall exclusively on me. This was compounded by the fact the I was working, sometimes an 80-h week, to raise enough funds for Phyl's treatment.

Ireland has a tiered healthcare system, there are certain conditions that are on a list which are treated free of charge. IPF is not on this list. Also, in order to be seen as quickly as possible, we needed to use private health services. As such, there was a huge financial outlay for the costs for treatment. This was a huge burden, as I was working every hour I could to pay for the treatments which Phyl needed. This added emotional stress also as, of course, when I was working, I was not with Phyl and we were losing that time together.

We worked very hard to navigate the logistics of treatment, we live in a small town, 1.5–2 h away from a consultant, and we had to physically get there each month. The travel along with the exhaustive tests at the consultation would deplete Phyl's energy and add to my exhaustion. This greatly affected the quality time we could spend together and added additional strains. The same went for her pulmonary rehabilitation sessions with the physio, these were far away and physically depleting for Phyl although they did help her immensely. Even the small things like having to drive and the challenges of finding a parking space at the hospital added to the stress we felt and added to the difficulties of managing my time over those years.

Another obstacle was navigating her oxygen treatment. Her prescription was not reliable as different suppliers would interpret it differently. In some regions, they would only prescribe six cylinders in a month and she could get through that in 1 day! At the time there was no oxygen plant in Ireland and it all had to be imported. We had 2 weeks of very severe weather and there were shortages of oxygen in Ireland, this was particularly scary. We had a lot of situations where we really had to fight to get Phyl what she needed. This was exhausting and very troubling as you do not want the person you love to suffer, especially for avoidable reasons. Along with this, just the logistics of using oxygen were burdensome, where do you store it? The only space we had was in the hallway, we needed more sockets and getting an electrician can be difficult. It sounds small, but these extra things really take up room in your mind when you just want to focus on your wife.

It was hard going outside with Phyl, with her oxygen, she was self-conscious of other people looking at her. I was proud as punch to be out with Phyl, but I did get protective when I saw people stare at her.

Treatments did add to the strain of caring for Phyl, the main things that were hard about her treatments were logistical or financial. So much of this could be avoided if they were more considered by policy makers and doctors, but the support available from patient support groups cannot be underestimated.

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## Summary

These accounts have talked about the burden that treatments can have on those caring for other people. What is evident is that, from the carer perspective, the burden to the patient is inextricable from the burden that they experience as a carer. Some key themes emerged about common difficulties, these included logistics, especially when relating to travel and hospital parking, and constraints on both time and financial situations, the later contributing further burden to the former. Oxygen has been another key contributor to the burden of treatment; the concerns about shortages, of device failure and of storage have all lead to increased difficulty from the perspective of the carers. In all three accounts, the support of the medical professionals who have worked with the families has contributed significantly to easing the burden that carers experience. This highlights the importance of the role of healthcare professionals in working with patients and carers to ease treatment burden and improve quality of life for all involved.

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Sadly, shortly after writing this article, Pam's mum Eileen Dale passed away. She will be sadly missed by her husband Geoff, their children, grandchildren and great grandchildren. With many thanks to Eileen and Pam for their valued contribution to this edition of *Breathe*.

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## Footnotes

- **Conflict of interest:** J. Denning is an employee of the European Lung Foundation.

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