

When my husband Murray was diagnosed with PF on New Year's Eve 2008 he was only 54 years of age, running his own plumbing, heating and gas installation business, our sons were both still living at home and we had a large mortgage. He only sought medical attention because his irritating cough following a cold was getting on my nerves!

Within only two years Murray was unable to continue to work due to the physical demands of his job and the breathlessness and exhaustion that it caused, so retired on medical grounds. Having been self-employed he was not entitled to any government benefit other than £1.42 per week, which was an insult rather than a help. Our mortgage critical illness policy did not recognise PF as one of the qualifying illnesses, despite a report from our consultant stating that it is more critical and untreatable than some of the cancers that did qualify for payment. The insurers would only pay out if and when he was put on an official transplant waiting list. This had not yet happened.

The PF was proved to have been due to an industrial injury many years previously but the pursuit of compensation was incredibly difficult and expensive, involving a great deal of travelling all over the country for examinations and reports from experts in London, Norwich, Cambridge and Sheffield, as well as travelling to and from the solicitor in Chelmsford, all at our own expense.

Needless to say, life was incredibly difficult and stressful and we both agreed that the lack of finances and the resulting debt and mortgage arrears were far more of a worry than the illness itself. We really did not know what the future would hold.

In 2012 Murray was finally put on the transplant waiting list and most of the mortgage was cleared, but we still had a lot of debt and decided the best thing would be to move house, downsize to a much smaller home that would be easier for him to manage, clear our debts and get rid of the stress. We managed to do this the week before Christmas 2013 and bought our new house with hardly any money to spare, but at least we were debt-free and had just enough income from the industrial injury pension on which to manage but with very little left over for anything extra.

In February 2014 after just two months in our new house the call came for the transplant. This was wonderful news after a two-year wait and two previous false alarms. The transplant went ahead but sadly that night, due to complications following surgery, he had two cardiac arrests leading to a massive stroke and was put into an induced coma and on total life support to allow his body to heal. This was a very cruel blow after we had been through so much already.

After a rollercoaster three weeks he was finally woken up and it looked as though he would pull through although it would be a long and difficult journey and would be in Papworth for at least three months, probably longer, depending upon his progress. I was devastated. We live 85 miles from Papworth and the journey there and back every day was costing me £150 a week, which I just did not have. I really didn't know what to do. I knew that I had to be there every day because he was so very ill and looked forward to my visits. It was at this point that I contacted Malcolm Weallans at the PF Trust as I knew they were able to help in certain circumstances. This was not easy for me to do as we have always tried to be independent and to manage on our own, but I was desperate. To my absolute relief and delight Malcolm kindly said that of course they would help, and I was very quickly given enough money to cover my travelling expenses for the next 12 weeks. Murray spent a total of five months in hospital, three months at Papworth and two months at our local hospital. The new lungs are doing brilliantly well and he is recovering steadily from the stroke. We are very happy.

I cannot express how much the generosity of the PF Trust meant to me, and Murray, at that time. It meant that I could comfortably travel every day to see him, which I know helped his recovery and was so important for both of us as it brought a small amount of normality to a very abnormal situation and enabled us to be together. Without the PF Trust this would not have been possible and I shall never be able to thank them enough for their kindness and help when we needed it most.

Elizabeth