



My Story

Julie Whitaker, PCC member since 2006

I was diagnosed with progressive pulmonary fibrosis, Non-specific Interstitial Pneumonitis (NSIP) in 2002. I was prescribed immunosuppressants and steroids. I was 42 years old when I was diagnosed and had been suffering from breathlessness on exertion for approximately 2 years. The first time I became aware of being breathless was in July 2000 on a trip to London, but I didn't approach my GP about my symptoms until December 2001. I'd had several chest infections during this period and thought the breathlessness was due to being run down and unfit.

During treatment I began to suffer from severe gastric reflux and in 2008 I had a routine chest CT scan and this showed I had a dilated oesophagus. I had a barium swallow which showed a dilated oesophagus with free reflux and very little peristalsis

I began suffering from stiffness and pain in my hips, knees and shoulders in August 2010 shortly after reducing immunosuppressants. In June 2011 I started having problems in my fingers, ankles and wrists and increased stiffness and pain in my hips and shoulders. I was referred to a rheumatologist in July 2011 and after various tests it was decided I was suffering from a mixed connective tissue disease. It was also thought the problems with my oesophagus were related to the connective tissue disease. My lung condition and reflux continued to deteriorate and I was admitted to hospital in March 2012. I am now on 6 to 8 litres per minute of oxygen on exertion and 1 litre per minute of oxygen overnight and at rest. In January 2015 I was also diagnosed with severe pulmonary hypertension, again caused by the connective tissue disease and lung disease.

I coped reasonably well with the initial diagnosis and remained optimistic, but found problems at work mounting up. I worked as a civil servant in The Benefits Agency and loved the job and the people I worked with. However, I suffered from almost continuous fatigue and recurring chest infections which made working full time very difficult and resulted in my taking frequent sick leave. I tried reducing my hours and even taking my annual leave instead of sick leave, but eventually had to take medical retirement in January 2006 when I was 46 years old. As a result of problems at work and in my family life I'd also suffered from periods of severe depression. After 30 years of working full time I found it very difficult to adjust to being without a career and felt I no longer had a purpose in life. It also had a huge financial impact on my standard of living. I found myself almost mourning for the life I had previously.

When I first started working for the Medical School I was in the process of accepting I could no longer continue my career in the Civil Service because of my health problems. I started initially with the Classroom and Home Visits for first year students, talking about my experiences of healthcare, both good and bad, and the effects my illness has on my life. I then went on to work as a Simulated Patient and a Patient Mentor. It gave my life a focus and helped enormously with my self-esteem, which was at a pretty low ebb at the time. I can now look forward to being a part of a team and working again. I feel more confident and positive about my condition and my life in general. I think my involvement with the PCC has helped me cope with being on oxygen and the reduced mobility I now have, as I can continue working and have the support of my colleagues. Being part of the PCC has given me back a sense of purpose. I also feel it has improved my physical and mental health being able to contribute

and give something back in return for my own healthcare over the past 14 years. It is a rewarding and enjoyable experience working with medical students and has given me opportunities I would not have considered possible when I first started helping out.