

## Patient voice

# Living with allergic bronchopulmonary aspergillosis

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Respiratory difficulties have accompanied me throughout my life, since I was first diagnosed with asthma at the age of 3 years. My asthma was quite severe and even in primary school, I remember having a very early form of inhaler. This was a brown glass inhaler with a rubber bulb at its base. One squeezed the rubber bulb to force air through the glass apparatus and deliver the required medication as the patient inhaled.

At the age of 6 years, I was sent from my home in Cornwall to a hospital school in London. This was a children's hospital where patients could also attend daily school lessons. There I remained until I reached the age of 9 years. When I was discharged and finally returned home, I did not know my mother or my brother and sister as the journey from Cornwall to London was simply too expensive, and I did not see any of my family while I was there.

For the next 2 years I learned how to cope with my asthma, the outside world and built a new circle of friends. I attended a normal school and attempted to catch up on my education. I was frequently hospitalised because of my asthma and it was quickly becoming a serious matter; my life hung in the balance on numerous occasions. So, at the age of 11 years, instead of moving up to secondary school, I was sent to an "Open air" boarding school in Minehead, Somerset. "Open air" schools were all the rage in the 1960s as fresh air, education and medical attention were combined in one. I remained at this boarding school, although

I was allowed home for school holidays, until I reached 16 years of age when I left to begin my working career.

My career soon met a brick wall. No one wanted a worker who was off work and hospitalised for up to 6 weeks at least four times a year. So, after finding jobs, losing jobs and all the time suffering from chronic asthma, I decided to become self-employed. Thus, I worked in several fields until beginning my own landscaping company. However, after a decade or so, my asthma began to worsen so I sold the business and went back to education.

Once I completed my studies, I became a lecturer in science and music at the county college. I was a self-taught musician and played in numerous bands and did many solo shows (figure 1a). I was also a singer and enjoyed the more raucous songs, which helped my breathing substantially. As a lecturer, I taught environmental science in the daytime and music in the evenings, along with gigging live with bands or solo. My breathing at that time was the best it had ever been and I thought my asthma days were behind me.

Then, in 2002, I began to experience breathing difficulties again, building in severity until 2003 when I was hospitalised with a collapsed/blocked lung. I had no idea why my health had suddenly taken a turn for the worse and I hoped it would soon improve, but it didn't. While I was in hospital trying to unblock my lung, I was still being treated for asthma. One consultant suspected a different diagnosis, but as I was not his patient, nothing came



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**A patient shares his experiences of living with respiratory problems, including his diagnosis with allergic bronchopulmonary aspergillosis** <http://ow.ly/AyNI30oc4US>

of his doubts. My lung eventually improved and after 3 weeks in hospital, I was discharged with a home nebuliser, oxygen and a bucket load of steroids and antibiotics.

Over the next year I became extremely poorly, my trips to hospital now took the route of resus, high dependency and finally the respiratory ward (figure 1b). I had never ever been so ill and suffered such difficulties in breathing. My general practitioners and consultants tried everything they knew to help me, but to no avail. I was now very seriously ill and it quickly affected my work. One cannot lecture if one cannot breathe enough to even speak, and I never did learn to wheeze in tune when performing.

Finally, in 2004, I was diagnosed with allergic bronchopulmonary aspergillosis (ABPA). It came to light that the suspicious consultant had ordered tests, but as I was not his patient, the hospital administration took 12 months to notify my own consultant. During one of my frequent visits to my consultant, I was at the end of my tether. I knew I was not suffering from asthma, this was different. The sensation was different, the sputum had a strange texture and the antibiotics simply did not work. I managed to gasp out my suspicions to the consultant, stating whatever was causing my terrible breathlessness, it was not asthma. Then he told me to sit down, he now knew I was not suffering with severe asthma. The tests from the suspicious consultant had finally reached his desk and he informed me I was suffering from ABPA.

At that time, little was known about aspergillosis, but he knew enough to order me to stop any and all of the antibiotics immediately, and prescribed me 6 months of an antifungal, itraconazole. I sought answers about the disease, but little was known at that time. He also informed me that my previous blocked lung was in fact a fungal ball and my immunoglobulin E (IgE) levels were at an extraordinary level of 12 thousand.

By 2008, my breathing difficulties became so severe that I had to give up my job and simply concentrate on staying alive. I existed on



**Figure 1** a) Mike with his guitar. b) Mike in hospital.

antifungals, my itraconazole dose was raised, I was taking prednisolone ranging from 40 mg to 60 mg per day and when in hospital I was prescribed 100 mg of injected hydrocortisone per day for 3 days at a time. I became an outpatient at the University Hospital of South Manchester in Wythenshawe (Manchester, UK), where Professor David Denning had become one of the world's leading experts in fungal diseases.

I remain on itraconazole and steroids. I am no longer able to undertake any of my previous interests and hobbies, or continue with my profession as a college lecturer. My health continues to plague me. Only recently I was again hospitalised with aspergillus-aggravated asthma. I have been prescribed another course of prednisolone and salbutamol nebulisers. I try to remain positive; however, making future plans can be difficult. I cannot say for certain when, or if, I will be well enough to act on said plans.

My life has changed significantly, from an active musical performer, lecturer and martial arts practitioner, into a person constantly battling a debilitating disease and unable to pursue the life I chose.

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ELF was founded by the European Respiratory Society, with the aim of bringing together patients, the public and respiratory professionals to positively influence respiratory medicine. ELF is dedicated to lung health throughout Europe and draws together the leading European medical experts to provide patient information and raise public awareness about lung disease.

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