

The impact of a late diagnosis of bronchiectasis



Francesca Robinson talks to **Barbara Preston**, a member of the PCRS-UK Lay Patient and Carer Reference Group, about how a missed diagnosis of bronchiectasis has affected her



Barbara Preston, aged 73, was diagnosed with bronchiectasis in her early twenties but believes she developed the condition when she was three years old as a result of a bout of double pneumonia.

Throughout her childhood she suffered from a persistent cough, particularly in the winter, endured frequent respiratory infections and was generally regarded as 'delicate'. "My mother hardly ever took me to the doctor because I don't think she saw much point. In retrospect I think she was probably right, because all they did was give me cough medicine and told me I would grow out of it," says Barbara.

At the age of 17, on the third visit to her GP because of a persistent respiratory infection, she was referred for a chest X-ray. She was told she had 'congestion of the lungs' and was given antibiotics for the first time and told to go to bed. She was taught postural drainage, which she says provided some relief, but she remembers coughing for weeks afterwards.

During her second year at university Barbara had an ongoing respiratory infection with haemoptysis and visited the GP several times. Eventually he sent her for a TB test which came back negative. She was given antibiotics but still did not improve.

In 1964 when Barbara, now aged 20, went home for the summer, and still struggling with a respiratory infection, went to see her local GP who referred her to King's College Hospital, recommending an operation 'to cut out the bad bits'. While in hospital she had a bronchoscopy and a bronchogram and was finally given a diagnosis of bronchiectasis. She was told it was not advisable to operate because too much of her lungs were damaged. In those days the treatment was postural drainage and occasional antibiotics, although there was no sputum testing.

Although some GPs were supportive, it was really self-management by default and it was only from the 1990s onwards that Barbara says she began to gain more control over her disease when she met a GP who treated her as a partner in her care. She was given a rescue pack of antibiotics for the first time and a sputum testing kit.

Barbara says it did help to eventually receive a diagnosis, but feels that 50 years ago they did not really know how to diagnose and treat bronchiectasis. She says care can still be patchy: "As late as 2006, on changing practices, I found they didn't want to give me antibiotics unless I had a temperature but I can have an infection without a temperature – that's quite normal for people with bronchiectasis. They would only give me seven days' worth of antibiotics whereas now they give me 14 and you had to wait to see a doctor to prove you were ill enough to need them."

The main impact of the late diagnosis of bronchiectasis on Barbara was a childhood blighted by regular illness. She now has severe osteoporosis in her spine and was told by a consultant that this could be a result of her bones not developing strongly during childhood because she was ill so frequently.

The lack of a correct diagnosis resulted in Barbara having many GP and hospital appointments at an additional cost to the NHS. Poor understanding of how to treat bronchiectasis in the past has led to Barbara taking many courses of antibiotics, not only an unnecessary cost but also an issue for antimicrobial resistance.

Barbara is sanguine: "I'm sure that I could have had better health throughout my life if I had had an earlier diagnosis, but possibly that was due to a poor understanding of this disease in the past."

"Currently I'm fitter than I have ever been. Now the medication they give you is much more effective, whilst gradually gaining the knowledge to self-manage makes an enormous difference to my quality of life. I take one antibiotic three times a week, have been doing so for three years and now have very few infections. For many years I used to take eight or nine courses of antibiotics but more recently I have managed nearly a year without a full course, which is an all-time record. I am colonised by Pseudomonas, but it's under control."

Could anything have been done differently? "I would like to give the doctors the benefit of the doubt because I think 70 years ago they didn't understand bronchiectasis as well as they do now," says Barbara.

She adds: "Now there is no excuse; the British Thoracic Society has developed a pathway of support and we are beginning to get consultants who specialise in bronchiectasis. However, healthcare practitioners must work in partnership with their patients as, in the end, living with bronchiectasis is all about self-management. Modern medication is extremely helpful, but it's down to the patient to learn when and how to take it, keep up their chest clearance exercises and live as active and healthy a life as they can manage."

Jane Scullion, PCRS-UK Trustee and Respiratory Nurse Consultant, comments: "Missed diagnosis remains problematic both for patients and healthcare professionals, and this article is a timely reminder that we should always consider alternative diagnoses and responses to our treatments."

Noel Baxter, GP and PCRS-UK Chair comments: "Differentiating between COPD and bronchiectasis or recognising that a difficult to control asthma now has a bronchiectasis component is still a challenge today. National and international guidelines in respiratory disease can often provide the directness and focus for interventions, but when it comes to a diagnosis, there is less clarity and clinical suspicion and weighing up the evidence provided by the individual is still the greater part of getting it right. A patient with greater 'activation' and knowledge and a diagnostician who gives time to and listens out for their ideas and concerns is the partnership that is most likely to help us get earlier diagnosis."

Lay Reference Group Member Profile

Name: Barbara Preston
Barbara, aged 73, lives in Nottingham

What condition do you suffer from?
Bronchiectasis

When were you diagnosed?
I wasn't officially diagnosed with a bronchogram until I was 20 but I had probably had the condition since I was three. Nobody recognised it in those days; I was just told to go away, take cough medicine and I would grow out of it.

What has made most difference to you in terms of your care?

Being able to self-manage. GPs (and now my consultant) gradually began to trust me and provide a rescue pack and sputum testing kit so I don't have to waste time getting an appointment. This makes me feel as though I am in control and can keep on top of things. I'm very active in my local Breathe Easy group and I work hard to look after myself through exercise, diet, etc.

Why were you interested in joining the lay reference group?

Because lung disease is a bit of a Cinderella – and particularly bronchiectasis – in the public's eye, and yet so many people's lives are affected by it. There needs to be greater awareness that more could be done not just amongst the public but also among the medical profession. The quality of care is very patchy across the country, so I think it's really important to give the patient perspective and try to support PCRS-UK's important work. Plus it's all very interesting.

What messages would you like health professionals to hear?

I would like them to really understand the importance of supporting patients in achieving self-management. Most patients are capable and want to have control over their health and have a better quality of life. But it isn't necessarily a quick fix. I see newly diagnosed patients come along to our Breathe Easy group feeling angry, depressed and helpless. But gradually, as they become better educated, they learn to take control so they both save the NHS money and achieve a better quality of life, becoming much happier at the same time. I believe it's really important that patients and healthcare professionals work together.