

# My Asthma Story

The PCRS Patient Reference Group (PRG) is a small group of people with respiratory conditions who support PCRS to ensure that we always try to embed the patient perspective in our work and consider the holistic management of patients. Our PRG members sit on our regular committees and sub-committees and contribute regularly to our work. We are grateful for their input. We have two representatives who sit on our valuable PRG who suffer from asthma. Here's their story:



### Benedict Greenwood

My asthma story is fairly typical. I've made bad decisions. At times, I've been neglected by healthcare services. But I've also been supported by some brilliant healthcare professionals to learn how to manage my condition better.

I've had asthma since I was a baby. When I was a small child, it was pretty bad, especially in the winter and whenever I had a respiratory tract infection. My parents had many sleepless nights helping me when I woke up coughing and spluttering. Looking back now, they say those nights were pretty scary. No parent wants to see their child struggling to breathe, especially not on a regular basis.

Fortunately, as I grew, my asthma got better and better. I was a very active child, and asthma never got in the way of me playing sports or doing outdoor activities. My inhaler dosing went down to once a day, and at some point in my teens, I stopped taking them completely. I decided that I had "grown out of my asthma". Since I only felt wheezy when I got a respiratory infection and I only had coughing fits on the rare occasion I breathed in strong fumes, I decided I didn't have asthma anymore. I didn't take my inhalers for several years and went unchallenged by healthcare professionals. After all, I wasn't being called for asthma check-ups, and when I went to university, I wasn't contacted by my GP about anything. It was as if I had disappeared from the system.

It took an excellent healthcare professional to take control of the situation when I was 21 and show me that my current habits weren't OK. They explained to me why I still needed to take my inhaler every day even when I felt fine, but they also had a solid, evidence-based put-down for all the excuses and beliefs that I gave for not managing my asthma! They didn't blame me; they just demonstrated to me that I still have asthma and explained why each bit of asthma care was important. It wasn't medications or an exacerbation that made me change my ways; it was the healthcare professional setting aside a good chunk of time to go through the basics of asthma with me.

Nowadays, I consider myself a model of asthma self-management. However, at each asthma appointment or trip to the pharmacy, there's usually something that the healthcare professional can remind me about that will help my asthma, such as taking hay fever tablets in the summer or getting a flu vaccination in the autumn. Even though my self-management is now pretty good, healthcare professionals regularly help me make it just that little bit better.

I have heard people say that patient education doesn't work. I couldn't disagree more.



### Amanda Roberts

Firstly, I would like to say that I have a wonderful life. While my asthma has been lifelong, in recent years medication has kept it on a fairly steady course. I was regularly hospitalised until well after the birth of my second child, but something must have changed. Not really any idea what.

Like many people with asthma, I also have hay fever and eczema. It always puzzled me why I struggled to get healthcare professionals to take my eczema seriously. Somehow, it was always in the shadow of my asthma. And, actually, it was my skin that had the most impact on my quality of life.

My dissatisfaction with the annual asthma reviews I have had is legendary. I long to know more about current medication options and evidence. Long-term use of topical corticosteroids is known to cause skin thinning and other side effects. So now the standard advice seems to be that control for skin conditions should be maintained with five days of treatment and then two days off ("weekend therapy"). I have been using inhaled steroids without any breaks for years and years. What on earth has this done to my lungs?

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