

## A patient perspective of living with a diagnosis of asthma

Luke Lawrence

Correspondence: see below

### Abstract

#### Title

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#### Author

Lawrence L.

#### Summary

The challenges associated with having a diagnosis of asthma since childhood and then getting a diagnosis later in life of COPD are explained from the perspective of a patient who wishes to compete at a high level in sport.

The importance of early and correct diagnosis is stressed.

**Keywords:** asthma, COPD, sport, exercise, inhaler

### Introduction

I'm writing this update to help give an understanding of what it's like to have asthma, how the disease can change through your life and how that impacts on someone who leads an athletic life and is looking for sports performance. Through my journey I have also been diagnosed with Exercise Induced Asthma (EIA) and now COPD. However, I'm still pushing to remain fit and keep competing - it's been a long journey. My core point is that each case of asthma/lung problems needs to be reviewed individually, with empathy. COPD for an athlete is a different situation to COPD for an overweight smoker in later life – and yet our treatment course can be the same.

You can read in more detail about what I've been through on my blog

<https://lukelawrenceocr.wordpress.com/2015/05/05/asthma-what-its-like-both-in-life-in-sport/> .

My asthma started as a child. I was one of the only children at my school to have asthma, which was rarer back then. These days it's either more common or the issuing of blue reliever inhalers is more widespread as I see many children with inhalers these days.

### Diagnosis

The diagnosis of asthma or EIA correctly at a young age is something that I'm passionate about. A full asthma attack is an obvious thing to manage/be aware of, however lesser

symptoms of EIA or similar can leave a child simply feeling unfit or struggling in sport, which could in turn lead to them staying clear of athletic activities throughout their life as they always struggled. This, in turn, could lead to obesity. I think it's key to enable children (and anyone getting involved with fitness) to be able to do as much as they can – the wider benefits are clear.

### Treatment

My asthma treatment switched in my teens and became simply reliever inhalers for around 20 years. I had no real reviews - just a repeat prescription for the blue salbutamol. Fast forward to March 2014 and I was at my peak fitness. Training hard to compete in national level and even world championship status athletic events. However, I started to struggle. It made no sense that I was fitter than ever and yet just fatigued so quickly in races. I worked through things, increased my training/running and reviewed my already focused clean diet. I simply felt out of breath - I could not suck enough air in to keep my energy levels up.

I went to the doctor who enquired about my normal day-to-day asthma, which I said was OK and he suggested that perhaps I stop running if that aggravated the asthma. Unreal! Fitness is important to us all however, for me, I had pushed to the front of my sport. It took me out of years of a motivation slump that led me to putting on weight and slight depression. This sport, which I had grown good at, was my focus and reason to eat well and train well. I needed help to continue or be as good as I could be.

Over the next 6-8 months the doctors tried the same basic steps following their set guidelines: corticosteroids - first the brown inhaler through two cycles. I updated the doctor that this wasn't making any difference and, in fact, felt that my day-to-day asthma had worsened but understood we needed to give it time. Then onto combination inhalers; but I felt I was never listened to on what the results were and the difference between 'normal' life and 'athletic performance'. Regardless of what I said, I was on a conveyor belt of care which was taking months. I'm very analytical and came to sessions armed with info about how I had been and yet it didn't seem to help so much.

## Testing

Finally, I went privately to a sport uni to have some testing: spirometry and gas exchange - not just at rest but while exercising. They found my forced expiratory volume (FEV) was low, around 60%, and that I did see some reversal on inhalers (70%). Additionally, whilst in the lab on the bike, they proved I had EIA as well, which was the first time I was made aware of that.

I took the report to the doctors. It was initially dismissed on the basis that private tests were not needed since the NHS has its own tests. I escalated this again and was then asked to see an asthma nurse, who followed the same basic steps. She did, in fact, change my inhaler only to get a call from the GP the next day to say it was wrong and to try another instead. I was becoming frustrated.

## Specialist help

All the inhalers tried only seemed to make my asthma worse, which I was told can't be possible. In the end and over a year into the process I escalated again stating that I was sure something was very wrong. This time, the fear was that I could have any form of lung disease or other issues. Finally, I was referred to a respiratory consultant and at my first meeting it was clear he had spent time to read all my notes, including my private test results which he said were a godsend. This guy listened and used all the data in front of him, including my feedback and combined this with further tests of his own to confirm a further diagnosis of chronic obstructive pulmonary disease (COPD) on top of everything else. Just a shame this was 18 months later.

That year or so was very hard for me motivationally. I'm quite driven and having artificial limitations put on my performance was very hard to handle; it affected me in quite a broad way and actually led to a reduction in training effort over the winter. It felt like, what was the point to keep pushing so hard and not be able to release my potential? Finally, after repeat visits to the Consultant, some of that drive came back and I've continued to fight. However, I'm still no closer to a solution - just slightly improved day-to-day/situational management wise. Maybe that's as good as it can get.

## A final thought

I understand process needs to be followed and that the demand on the NHS is incredibly high. However, the time and cost of misdiagnosis and my repeated chasing, appointments,

phone calls and wrong inhalers would all have been improved with a better initial assessment - or at least an understanding and empathy with my case.

## Further contact/information

Twitter: @LukeLawrenceOCR or  
Blog: [www.lukelawrence.co.uk](http://www.lukelawrence.co.uk)

## Declaration of interests

Luke Lawrence has nothing to disclose.