

Supported self-management – Do it yourself health?



In this article, **Charles Waddicor**, chair of the PCRS-UK Trustees, shares his experience of surviving an asthma attack and his approach to self-management. The article is introduced by **Carol Stonham** guest editor for this issue of *Primary Care Respiratory Update*



When we consult with patients during an annual review, we go through a series of information gathering to confirm that the asthma is well controlled. We do our best to offer education on the disease processes and the effect the prescribed medication has on the disease. Taking this a step further, we co-complete an asthma action plan to help our patients recognise deterioration in their condition and act promptly to prevent further decline. Don't we?

But what about the patients that don't attend for review? Or those that have asthma all their lives and know their disease well? The report from the National Review of Asthma Deaths 'Why Asthma Still Kills' worryingly found that 43% of the patients had not been reviewed by their practice in the year preceding their death and only 23% of patients had personal asthma action plans. Almost half died without seeking medical assistance during their fatal attack.

So what happens to people with asthma for the biggest part of their lives outside of their annual check-up? Is self-management a learnt skill based around knowledge of their condition safely supported by health care professionals or more a case of making it up as they go along?

We are privileged in having a real-life account of how confidence in self managing a long-term condition can teeter from keeping things well under control to failing to recognise when an emergency is arising.

I would suggest you read this account through twice – once from the patient perspective to appreciate how unsettling losing control of a lifelong condition that you had mastered, and once from your perspective as a health care professional. The second time consider how you could do things differently. Self-management isn't just a paper plan given to a patient.

Carol Stonham, Guest Editor, Primary Care Respiratory Update

I am 66 years old. I have had asthma since I was less than 12 months. It was a real problem for me to manage as a child. I was and still am allergic to grass and tree pollens, as well as mould spores. Generally, I am more symptom free in the autumn and winter and more prone to wheezing in the late spring and summer.

The drugs and delivery systems available in the 1950s and 1960s were not very effective and/or had significant side effects. However, once I reached my mid-20s the availability of sodium cromoglicate and salbutamol had transformed my ability to cope.

By the time I had reached my early 30s I had stopped having attacks. I was more active than I had ever been: cycling, running half marathons in my 50s and completing a Triathlon sprint when I was 64. I was becoming over-confident. I felt I knew my asthma. I was in control and could adapt my drug regime to my needs without effort. I rarely had to see my doctor and never about my asthma. I didn't attend asthma clinic appointments. Why should I? I knew more about my asthma than anyone.

The spring of 2017 was a little unusual. It was early, warm and dry. The trees and spring flowers re-

sponded accordingly. Moreover they stayed in bloom for longer. We went to France in April and I strimmed and cut grass for much of the two weeks. By the time we came back at the end of April I began to notice I was wheezing. I upped my dose of beclometasone (100mgs) from 1 puff per day to 3 puffs. When this had no effect I increased it to 4 puffs a day and used my Ventolin 6 or 7 times a day. Rather alarmingly my wheezing got steadily worse. I went to the doctor and he prescribed fluticasone propionate and salmeterol (250mgs) 4 times a day. He tested my peak flow, which was 200. He asked me what it usually was. I had no idea. There was a bit of confusion about the right make of inhaler to fit the large volume spacer, which was eventually resolved by the pharmacist. The day afterwards I was due to go to visit friends in Warwickshire for lunch. I didn't want to disappoint them by cancelling, although I was not feeling well. I was sleeping poorly and was using my salbutamol inhaler every hour. We went to Warwickshire and had lunch outside their house, surrounded by fields and woods. On my way home I realised I was becoming seriously unwell.

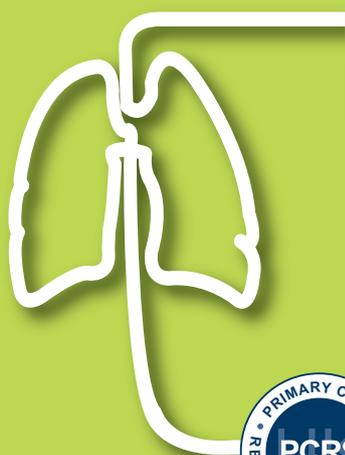
My wife took me to A&E where I was seen promptly. My peak flow by this stage was 140. I had two nebulizers and prednisolone intravenously. After 3 hours I had recovered enough to be discharged.

I have reflected on what these events have taught me and have had lots of helpful advice from Dr. Noel Baxter, Chair of the Executive Committee. I had clearly been over-confident about my ability to manage my asthma. I had been under-medicating myself. I had also increased my drug dosage too late and had waited too long to see my GP. I didn't know what my normal peak flow was and I wasn't using a spacer to take my inhalers. I didn't accept any limitations in my life whilst I was unwell, expecting to carry on as normal.

So what do I do now? I have accepted I must increase my beclometasone dosage to cope with the spring and summer allergens much earlier. I will increase it from 2 to 4 puffs a day at the end of February. I also understand this is not an exact science. In 2017 the pollens arrived earlier than in 2016 and stayed longer. The grass pollens hadn't even started in earnest by the time I had to go to A&E. I now use a large volume spacer each time I take my inhaler, which dramatically increases the effectiveness of each dose. I do check my peak flow regularly. Normal for me on a good day is about 400. Psychologically, I was shaken by the severity of the attack. I felt vulnerable and less confident. Fortunately, these feelings have passed, but I am determined not to underestimate my old advisory again.

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