The challenges of living with severe asthma

The patient and healthcare professional perspective

Patient perspective

A 59-year-old female from France, who was first diagnosed with severe asthma 10 years ago.

When I was first diagnosed with asthma, the symptoms were very severe. I had daily problems and often visited the emergency room and experienced absences from work.

My doctor tried a number of different high-dose treatments, but my asthma remained uncontrolled. I was referred to a specialist clinic and my asthma was defined as eosinophilic severe asthma. This meant that I could be enrolled in the DREAM trial, which was testing the effectiveness of anti-interleukin-5 therapy. During this trial, my symptoms improved and my asthma was well controlled, but after the trial, I returned to oral steroids and experienced an exacerbation every month.

Taking the steroids resulted in me gaining weight, which left me feeling depressed. My asthma has had a serious impact on my life and I am now afraid of doing things that I used to perform without any fear in the past. I have always competed in tennis tournaments since I was a child; however, I had to stop this and found that I couldn't even play for fun with my partner.

When I was first diagnosed with asthma, I remember asking the question, "Why has this happened so late in life?" I did not understand why asthma was commencing at 40. It was an enigma and the physicians were unable to answer this question.

I also asked about the origin of my asthma and what would trigger it. I wasn't a smoker and had always lived a healthy life and been active in sport. I felt bad because I did not respond to the usual treatment despite my willingness to adhere to the medication and my aim to be cured.

I have had to make some changes to my daily routine to help improve my symptoms. I learn to anticipate the exacerbations by paying more attention to subtle changes in my daily symptoms. Reporting my symptoms was a considerable help as I learned to notice the changes that affected them. At present, I am just adapting my daily activities to my potential and to the day-to-day control of my asthma.

There are a number of factors I notice that affect my asthma control. Passive tobacco smoke at work or in other places leaves me feeling short of breath and I usually need to take my rescue medication at this time. Variations in climate such as windy weather or dry weather can also make my asthma control worse. It is usually difficult to anticipate these situations, so I need to rely on my inhaler or my nebuliser.

Asthma medication is very important for me. I never forgot them and obviously I

comply with the action plan I received; as a physician myself I understand the benefit that should come from my treatment and I learnt how to adapt my treatment to my condition. I do not like taking oral steroids, so I was happy to take part in a clinical trial; however, trying new drugs is not easy. A research clinical trial is always a challenge and being on a placebo was obviously a concern. Fortunately I received the active drug and now, after a gap, I am receiving the drug in the extension phase.

New guidelines on severe asthma are crucial but they need to be widely disseminated, easy to read and clear for professionals to understand which patients should be referred to specialist clinics as these people will be the most difficult to treat.

The healthcare professional's perspective: Pascal Chanez

Pascal Chanez is head of the Asthma & Allergic Rhinitis Section in the Respiratory Disorders Faculty at Aix-Marseille University, France and member of the European Respiratory Society/American Thoracic Society Task Force on severe asthma.

If a patient is uncontrolled despite the best available therapies, it is crucial to conduct a 6-month follow-up with them to investigate what could be causing this. During this time, physicians should assess the diagnosis of asthma, the role of persistent environmental triggers and any comorbid conditions interfering with the potential control of asthma. At the end of this period of time, if the patient has their triggers under control and is compliant with their medicine, yet exacerbations still exist, they would receive a diagnosis of severe asthma.

When I begin working with a patient, we have to establish a good partnership. There is work to be done with considering triggers and treatment of comorbid conditions so it is essential that the physician and patient can work well together to investigate these different areas that could be preventing asthma control. We should simplify the management of the condition by using existing drugs and establish action plans for different acute situations.

We must anticipate a follow-up based on achievable objectives including reducing daily symptoms, avoiding any exacerbations and maintaining the best achievable lung function with an optimal balance between efficacy and side-effects of the drugs.

After following the usual steps of assessing comorbidities and triggers with the patient who has given her experience here, her asthma remained uncontrolled. She required 5–10 oral systemic steroids courses, top doses of treatment with inhaled corticosteroids and long-acting β agonist (ICS/LABA) combination. She had no other comorbid conditions, except a body mass index >30 $kg \cdot m^{-2}$ and no allergy or rhino sinusitis polyps, and no aspirin or stress intolerance. After our follow-up, we confirmed that she had severe asthma.

We worked on chronic and acute action plans, which are paramount. We differentiated action plans from prescriptions for medication from the pharmacy. The action plans should be specific for a patient including information on the chronic treatments and the way to cope with increase of daily symptoms. In the patient's experience, the action plan included a specific schedule of regular outpatient visits including a role for their general practitioner, specialist and physicians from a specialist centre.

At each visit, we reviewed the last period. We investigated the control of asthma based on daily symptoms and composite scores of control such as the Asthma Control TEST (ACT) or Asthma Control Questionnaire (ACQ). The daily activities and the use of rescue medications are valuable items in reflecting good or bad control. The occurrence of exacerbations should be reported along with the potential triggers, including lack of correct compliance or lack of "reactivity" from the patient side or from the healthcare system.

The new European Respiratory Society/American Thoracic Society guidelines on severe asthma are important because they aim to define severe asthma for the first time and provide steps for the clinical management of this condition. They used the best available evidence and advocate for a step-by-step approach in the diagnosis, management and treatment of severe asthma which can be used in most cases.

We all consider that this is a fast moving area of medicine considering the knowledge on the pathophysiology and the treatments. We hope that the new guidelines will contribute to better dialogue between patients and physicians. They take us a step forward in understanding this heterogeneous condition and should lead to patients being referred to specific centres at an early stage to access the best possible treatment.