

MY CARE, MY VOICE

A guide to what people with severe asthma should expect from their care



SANOFI 

MAT-GB-2001579(v1.0)
September 2020

My Care, My Voice describes what people with severe asthma should expect from their care, based on the experiences that patients living with the condition have shared with us. If you have any concerns about your care, or you think that you are not receiving the care described here, you can use this document and [Asthma UK's severe asthma guide](#), to discuss this with your medical team. This document has been initiated and wholly funded by Sanofi. Neither Asthma UK nor Samantha Walker received any payment for their contribution.

“Everyone’s experience of asthma is different, but for those with severe asthma the consequences can be devastating. They often have to take long-term, high dose oral steroids which can cause toxic or debilitating side effects including, anxiety, diabetes, cataracts and osteoporosis. Frequent asthma attacks and hospital admissions are a daily reality, which can leave people feeling lonely, isolated and scared, left without hope or the right support. More needs to be done to ensure people with severe asthma can access the care they need. This document seeks to give them the confidence to ask for a referral so that they can have the quality of life they deserve.”

**Dr Samantha Walker, Director of
Research and Policy, Asthma UK**

1

YOUR ASTHMA SHOULD NOT TURN STAIRS INTO AN OBSTACLE

Your severe asthma should not interrupt your day-to-day life or limit your social or work activities. You should feel supported and be given the confidence to live your life without symptoms or being in constant fear of an asthma attack.

If your symptoms are not under control you should speak to your asthma nurse, GP, consultant or other medical professional about what your care options are¹. Your medical professional will listen to you and work with you to help you create a clear asthma action plan² that identifies triggers and asthma attacks, so these can be discussed and escalated, if appropriate, at your next asthma review³. They can also help you recognise when your asthma is deteriorating and take action.

“ *My preventer never worked – my throat felt like it seized up and would automatically trigger asthma attacks... [They] just think you don't know what you're talking about [which, for me,] means spending 20 years of your life without a working preventer inhaler* ”



2

YOU SHOULD NOT HAVE TO GO TO A&E

You should not have asthma attacks so severe that you need to go to A&E. You should be supported to find the right treatments to minimise your symptoms and stop you from having asthma attacks and needing to go to A&E⁴.

You should receive appropriate care and support to manage your asthma attacks⁵. This could mean being referred by your GP or hospital doctor to an expert team in a specialist centre who can undertake further assessments, and who also have additional tools to find the right care for you⁶. If you are frequently in A&E you should ask for a referral to a specialist centre. This could be life-changing in reducing your symptoms⁷.

“ I can try and forget about it day to day but it never truly leaves, I know I’m going to end up in hospital at some point ”



3

YOUR MEDICAL TEAM IS THERE FOR YOU; SPEAK AND THEY WILL LISTEN

You should be offered clear and simple information and support to understand your type of asthma and the options available to you in order to make an informed decision about your care⁴. You should feel comfortable being honest with your medical professional to get the support you really need. This could include explaining that you haven't taken your medication as prescribed because of the unwanted side-effects⁵, or even requesting alternative treatment options if your prescription is not minimising your asthma attacks. Although it might feel uncomfortable at first, this will enable them to adjust your medication and enable you to stick to your treatment goals⁵.

Your medical professional will develop an open, supportive dialogue with you and facilitate a non-judgmental environment, working with you over the long-term, through trial and error, to find the right care for you.

“ *Being put on a different treatment has completely changed my life. I haven't been in hospital for 6 or 7 months now. Being listened to makes a huge difference* ”



4

DON'T SETTLE FOR THE STATUS QUO

While steroid tablets can be an important option at times for most people with severe asthma⁸, you should not have to rely on them, especially due to the long-term risks⁹. If you have been prescribed more than two courses of oral steroids in the past 12 months and have not been referred to a specialist centre for an assessment, you should ask your medical professional to be referred to a specialist for a long-term solution to managing your symptoms¹⁰.

Your medical professional can discuss all treatment options with you – including referral to a specialist centre for further investigations – and they should also be explicit about the adverse short and long-term effects of taking oral steroids⁵.

“ I've had bad side effects with steroids, but I've never been given another option ”



This document was inspired during a Sanofi organised roundtable on Wednesday 8th April chaired by Dr Samantha Walker, Asthma UK Deputy Chief Executive, with five people with difficult to treat or severe asthma who shared their experiences with us. It is intended to stimulate discussions around opportunities to improve care for people living with severe asthma. This document has been initiated and wholly funded by Sanofi.

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