

# Focus on Asthma



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**June 2021**

## Context

**One in 12 people have asthma. That means that thousands of people in Medway are dealing with the effects of asthma on a daily basis. In this report you will hear from 13 people about their experience of living with this common condition. They tell us about the impact asthma has on their day to day lives and their experience of services. They wanted to share their story and their ideas for what could be done to help others.**

### Regular asthma reviews

Everyone we spoke to had a different experience of having asthma. Asthma affected people in different ways, but everyone talked about the importance of regular reviews.

Medway Asthma Self-Help (MASH) is mentioned many times in this report and is a Medway-based charity that was set up in 1996 to support people and families affected by asthma and to raise awareness of asthma and asthma-related issues in the community. MASH provides pre-bookable, one-to-one thirty-minute appointments with a specialist asthma and airborne allergy nurse, who can perform lung function testing, airborne allergy testing, discuss symptoms and inhaler technique, annual asthma reviews and personalised asthma action plans.

*"I have had asthma since I was a toddler. I have good days and bad days. I have been hospitalised because of my asthma in the past. For the past couple of days, while it's been raining I have had to use my medication and up the amount I use it, I use a Spiromax inhaler and Salbutamol. I did have an Asthma review towards the beginning of the year which was over the telephone. I was asked how I was feeling with my asthma and the nurse took me at my word. She asked me my weight and I guessed because I didn't know. Reviews really need to take place face to face so that the nurse can see you, otherwise things can be missed, nonverbal cues, body language etc. Even virtual meetings would be better than a telephone consultation."*

*"I have asthma and right now it feels very controlled. Over last year it's been tricky to get hold of an asthma nurse. I am supposed to have an annual asthma review but because of COVID it just didn't happen. I was offered a telephone conversation which I had to miss unfortunately, and another wasn't scheduled."*

*"I started coughing a lot and was given a Salbutamol but then when I was reviewed, I was told I was using far too much so they decided I should see a respiratory consultant. He changed my drugs. I am due for a review but due to recent surgery that I have had it has been delayed."*

*"I wasn't asthmatic till 1988, when I moved to Medway. My asthma is triggered by chest infections and colds. I react badly to air pollution; if you have asthma and live in an area with bad air pollution it can really affect you badly. My last review was cancelled."*

## Difficulties getting diagnosed

*"I have recently found out that I actually have a heart condition, and this is what was causing the breathing problems all the time. I had been saying for years that I didn't think it was asthma. It took my heart condition to get really bad for the past 2 months to make clinicians look at my heart. When diagnosing, clinical staff need to consider all options, it seems that they often make a quick assumption that someone has COPD or asthma. People need to be treated in a holistic way."*

*"I was told that they thought I had Chronic Obstructive Pulmonary Disease (COPD). In 2018 I wasn't making any progress on the COPD drugs. I had an in-house peak flow meter assessment at this time and the nurse asked me when I had stopped smoking – I have never smoked. 'When I saw the respiratory consultant, he said that it couldn't be COPD, which is very concerning as I had been wrongly diagnosed."*

## Asthma and day to day life

**We heard how important it is for asthma sufferers to ensure they take their medication at the right time and in the right way.**

*"It really depends on whether I'm taking my medication properly. If I don't take it as and when I should, I get more breathless. My triggers are animals and pollen. I do exercise most days and I take my inhalers before I exercise. I struggle when its damp and foggy."*

*"I take inhalers before exercise. I definitely need to remember to do it before I exercise. My asthma doesn't have an impact on my day-to-day activities".*

*"I can go on long walks but I tend to sleep a lot afterwards. Anxiety is also a trigger."*

*"Thunderstorms or high pollen count affect me"*

*"I can't exercise without getting out of breath."*

*"Our son's asthma is very well controlled."*

*"It can stop him being able to run around as much as he would like. Some days he struggles to speak and coughs lots so will be very inactive on those days."*

*"I stops me from going outside and exercising"*

*"I have recently retired from the emergency services due to my asthma after 24 years' service. I've had to give up my passion due to the asthma."*

*"Exercise, cold weather, illness, allergies and stress all cause problems which current medication cannot adequately deal with"*

*"Extremes of weather, very hot or cold or windy, affects me"*

*"Exercise is difficult as I get out of breath easily."*

*"I'm unable to go some places in the winter. I can't go to high streets due to all the smoking."*

*"During winter, my son misses lots of nursery and we often must miss work."*

## **COVID & Asthma**

**Covid has clearly affected people who suffer with asthma. Some are positive benefits such as cleaner air which has eased peoples' symptoms.**

*"The roads were much quieter because of the pandemic and the air seemed cleaner. It was the best summer I have experienced in relation to my asthma symptoms being almost negligible. I have noticed a change this year. I have already increased usage of my preventor inhaler".*

*"The main issues is accessing the asthma nurse because there haven't been any face-to-face appointments. I didn't get colds over the winter as isolating so didn't catch colds from others."*

*"I received a letter saying I am extremely clinically vulnerable so have been shielding. This has added to my anxiety, friends have been saying 'oh you can come out and meet up now' but I am going to isolate until I've had my second injection. I am anxious about coming out again and not being able to access the NHS Respiratory Consultant when Medway Hospital has closed the admissions clinic."*

*"We've got damp in the bathroom. We decided not to get it fixed during lockdown but it has triggered my asthma."*



## Prescriptions

**Everyone we spoke to mentioned prescriptions and the need for a larger supply of medication to enable people to manage their symptoms.**

*"The GP surgery did my asthma review over the phone. I did receive a letter saying I needed to shield and my GP has been really good. My repeat prescriptions changed, I was just getting one inhaler each time but this was increased so I got double each time which was great, ensuring I always have enough medication, it also saved me financially as I needed fewer prescriptions due to receiving double the amount."*

*"Prescription charging is frustrating; I only get the one of each medication with each prescription which makes it very expensive. Ideally it would be better to get 3 months' supply each time.*

*"Regarding prescriptions, I have to email the surgery for repeats and they keep missing them, I must follow up with my pharmacy as they don't seem to receive my requests. I'm shielding so volunteers ring me up to deliver the medicine but sometimes they don't come and I am on the cusp of running out. I tried to get in touch with Public Health Medway to get an emergency prescription repeat. You only get a call from a volunteer if your name comes up on the system. If its towards the end of the day and volunteers have been out helping others, you get missed."*

*"My chemist always gives me 3 months' worth, so I have a large stock of medication now. It's frustrating not being able to see someone face to face. If you have a flow meter you can do your own measurements, but you really need a face-to-face consultation, especially for younger people who might not want to admit they have an issue. My daughter often picks up my prescriptions but when was ill, I used the volunteers and found them very good."*

*"Currently I pay full prescription charge for both my salbutamol and qvar. The salbutamol is available much cheaper online. It would be useful to get two for the cost, given that this is a chronic condition, the cost of medication is relatively high."*



## Ideas about how to support people with asthma

People shared their thoughts about what could help them, and other people, living with asthma. Seven people told us they would like better access to asthma health professionals.

*"MASH isn't as well-known as it could be. Getting the word out to the wider community would be great and sharing what MASH does with GPs would also be useful. MCH supports MASH with funding, maybe they could highlight the service in their newsletters so more people hear about MASH and the support they offer?"*

*"MASH is looking to start group activities and clubs for children and families with asthma but it didn't happen because of Covid."*

*"It would be really helpful for Medway to have a directory of services where people can go to look to find their nearest local asthma charity."*

*"It would be good for GPs to be better informed and signpost you better. I was misdiagnosed and a practice nurse made an assumption about my health which was wrong. Everyone needs to be aware of the services available within the community, no one ever mentioned MASH to me. I am only aware of MASH because a member of my family used the services some years ago and I recognised the logo. It would be great to have gatherings, like an open forum where people could come and ask questions that could be answered by people who support asthma sufferers. There could be speakers who would come and discuss different issues and subjects."*

*"It would be great to be able to spread the word of MASH throughout the whole community, minorities within Medway, maybe through organisations who support different parts of our community – advertise in their newsletters. It is easier when you can meet people face to face."*

*"School teachers need to be educated on children having access to their salbutamol inhalers all the time. I think a workshop for them with case studies would be informative. School teachers should also be encouraging the pupils to take their salbutamol if they spot an asthmatic child who is symptomatic during their lessons/break time."*

*"Access to lung function tests at GP surgeries"*

*"The majority of asthma sufferers do not need a support group, but they do need access to medical support when things go a bit wrong, i.e. a chest infection can be near fatal for an asthma sufferer – sadly the 'all seeing' receptionist does not recognise this and more often than not we go without suitable care – a specialist asthma unit who can prescribe in Medway would be a great step forward."*

*"Because I do not constantly purchase my prescription, I am now exempt from getting the flu jab. I would think it is good that I am not using medication all the time."*

*"I think you should be able to buy pumps in any chemist over the counter."*

*"An exercise support group would be fab as you all know how each other struggles to keep going."*

## What are we recommending?

- *Utilise the specialist asthma nurse that MASH (Medway Asthma Self-Help) has available especially for GP surgeries that have long waiting time.*
- *Educate GP practices and other health professionals about the service that MASH provides*
- *NHS services to promote support and information for asthma patients*
- *Look at provision to educate all teachers about supporting children with asthma in the classroom*

## How did we go about it?

We heard from 13 people about their experience of living in Medway with asthma. Huge thanks to Medway Asthma Self-Help (MASH) who helped us to reach people. Thank you to everyone who took the time to share their stories. We really appreciate it.

## What happens now?

All the feedback we have heard will be shared directly with decision makers so that they can understand what it's like for people with asthma. These stories will help the NHS and social care to plan services for people with asthma across Medway.





## **A bit about us!**

Healthwatch Medway is the independent voice for local people in Medway.

We gather and represent people's views about any health and social care service in Medway.

Our role is to understand what matters most to people and to use that information to influence providers and commissioners to change the way services are designed and developed.

Our FREE Information and Signposting service can help you navigate Medway's complicated health and social care system to ensure you can find and access the services that are available for you. Call us on 0800 136 656 or email [enquiries@healthwatchmedway.com](mailto:enquiries@healthwatchmedway.com)

### **Do you have asthma? Do these stories resonate with you?**

Tell us your story and we can make sure your voice is heard by the right people.

Get in touch [HERE](#)

Or call us for free on 0800 136 656 or email [enquiries@healthwatchmedway.com](mailto:enquiries@healthwatchmedway.com)

**All of MASH's services are free and open to all.**

To contact MASH, call 01634 855844, email [medwayasthmaselfhelp@btconnect.com](mailto:medwayasthmaselfhelp@btconnect.com), send a message via their website [www.medwayasthmaselfhelp.co.uk/contact-us/](http://www.medwayasthmaselfhelp.co.uk/contact-us/) or via social media:

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