



DEFINE *your* ASTHMA

A GUIDE FOR PEOPLE
LIVING WITH SEVERE ASTHMA

*Developed thanks to a global community sharing
their experiences, advice and tips to help others*



*"Although rare, you are not alone"
(Australia, 38)*



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Define Your Asthma is led and coordinated by Global Allergy & Airways Patient Platform (GAAPP). The campaign is supported by GSK, via independent communication agency support and an educational grant.

THE SEVERE ASTHMA COMMUNITY

SEVERE ASTHMA

Severe asthma is a life-threatening condition that can affect your life by forcing you to make unwanted changes to your daily activities. If you have severe asthma, you will experience a frequent and severe worsening of asthma symptoms (asthma attacks/flare-ups). These attacks or flare-ups often occur more than once per year and require steroid tablets or use of emergency services or hospitalisation.

A Patient-Centred Description of Severe Asthma: Patient Understanding Leading to Assessment for a Severe Asthma Referral (PULSAR) developed by GAAPP, GSK and an international team of patients, advocacy groups and asthma experts in 2019.



You likely already know that asthma isn't a 'one size fits all' condition – everyone's experience is as unique as the individual themselves.

Define Your Asthma, supported by GSK, aims to help people living with severe asthma with their own specific challenges.

But what if you could find out how others with severe asthma around the world are doing? What if you could ask an international community for their advice on managing their condition?

That was the inspiration for this guide, the result of a global survey of people living with severe asthma, responding in four languages from 63 countries.

It brings together the thoughts, feelings tips and tricks from this community, and we cannot thank them enough for sharing their experiences.

We hope their advice supports you, and empowers you to start a conversation – whether that's with your family and friends, employer or your doctor.

Most of all, we hope you feel that – while your experience of asthma may be unique – you're certainly not alone.

*Tonya Winders, President and CEO,
Global Allergy & Airways Patient Platform*

PAINTING A PICTURE OF SEVERE HELPING OTHERS TO UNDERSTAND WHAT SEVERE FEELS LIKE

We know life with severe asthma is different for different people, making it hard for others to understand. So what does 'severe' really mean? It has a clinical definition, but we wanted to find out what severe asthma 'feels like' to people living with the condition.

SEVERE MEANS ...



... Knowing I can't do everything I want to – no matter how big or small



... Feeling like my life is controlled by asthma



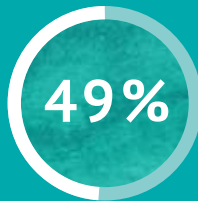
... Not knowing how I'll be affected each day until I wake up

SEVERE ASTHMA MAKES ME FEEL ...

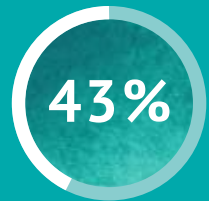
When asked respondents about the feelings experienced in the last month because of severe asthma. This is what they told us:



... feeling anxious or depressed



... feeling that asthma is controlling my life



... feeling afraid of the side effects of my asthma medication

PRACTICAL ADVICE TO HELP

When we asked what helps them to cope with these feelings, the advice was overwhelmingly to:



... Speak with friends
and family



... Seek professional support
– either counselling or
speaking to your doctor



... Speak to others with severe
asthma via online groups and
patient organisations

OTHER ADVICE TO HELP YOU COPE

“Keeping a list of activities I can usually do even on my worst days, celebrating my accomplishments and asthma milestones”

(USA, 40)

“I keep an asthma journal and have a few close asthma friends who I can call when I feel like I need to because they get what it’s like having severe asthma.”

(USA, 38)

“I do keep a journal and write [about] my experiences with asthma. Speaking to people with asthma also helps because you feel not alone – we can relate and laugh at ourselves and offer advice.”

(Fiji, 24)

EXPLAINING TO OTHERS HOW SEVERE ASTHMA IMPACTS YOU

Severe asthma can be unpredictable, and everyone's symptoms are different. This can make it difficult to explain to people around you.

Find out how others get that conversation started.

"I would say that it is like having to live life with only half a lung, everything is harder ... you are also afraid that pushing yourself a lot will give you an [asthma] attack."

(Panama, 52)



TOP 10 TIPS TO HELP YOU START A CONVERSATION

01

"Be honest and open but don't 'dump' everything at once. Share little challenges at appropriate times. When you need help, ask for it, and explain why its difficult for you to do 'x' on your own"

(USA, 47)

02

"Don't be afraid to explain every symptom or fear no matter how silly it seems"

(Spain, 42)

03

"Inform everyone in the family and all friends about the disease at an early stage, explain what asthma is – symptoms and the restrictions"

(Austria, 69)

04

"Be clear and factual, never dramatic. Point out the signs when they are present"

(Serbia, 63)

05

"Ask your friend to take a breath and hold, then take a breath again and hold more (without exhaling), then one more time, and they will get an idea how a person with asthma breathes"

(Croatia, 48)

06

"I would encourage family to attend support groups, read up on the condition and don't expect too much from you"

(UK, 68)

07

"Write down your symptoms and what triggers an attack or oncoming symptoms. Let them know if you're scared and when you can't do a task. Write down things they can do to help and in case of emergency. Its a lot to do alone so please tell someone you trust"

(Fiji, 24)

08

"My family has been understanding right from the beginning. If you are facing problems, let your doctor have a talk with your family"

(India, 21)

09

"Have the facts. Tell them what you can and can't do when you're having an attack e.g. not being able to talk. Make sure they know where your rescue medication is"

(South Africa, 29)

10

"I advise people to explain honestly the feeling and the support required at [the] time of [an] asthma attack. This includes my employers so they help me not to stress and worry [...] Having the belief that others can understand my health condition can help severe asthma patients psychologically"

(Ethiopia, 47)

THE DAILY IMPACT OF SEVERE ASTHMA

We know that severe asthma forces you to make unwanted changes to your daily activities.

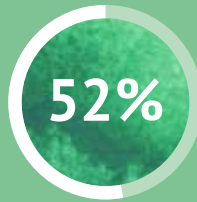
Half of survey respondents told us that during the last month, their normal activities have been disrupted by severe asthma some (27%) or most (23%) days, with 13% disrupted every day.

“When I’m in a flare... I would describe it as trying to get air in and out of the tiniest straw. Not being able to walk or talk. Breathless as if I’m running but I’m just sitting down.”

(Ireland, 47)



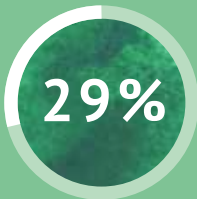
... have not been able to exercise



... have not been able to walk upstairs without becoming short of breath



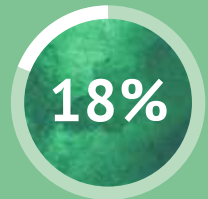
... have not been able to do the household chores, like laundry or cleaning



... had to rely on others to help



... missed a social gathering with friends and/or family



...missed work

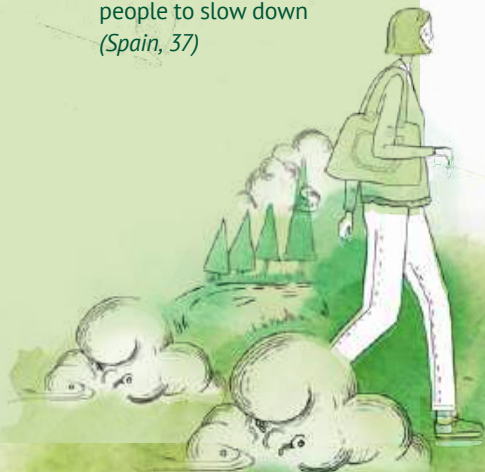
PRACTICAL ADVICE TO HELP



What are people's top tips for managing the physical challenges of their condition? We've pulled together a top 10, with practical advice (that applies wherever in the world you are).

TOP 10 TIPS TO HELP YOU MANAGE PHYSICAL CHALLENGES

- 01** Exercising on a treadmill instead of outdoors [...] having others cook meals, resting more (*USA, 40*)
- 02** Rest and breathing exercises (*Venezuela, 57*)
- 03** Diminishing some activities, spacing out and delegating others (*Serbia, 63*)
- 04** Exercise is great it really helps. Also steaming helps. A few times I'll ask my family to do whatever they can to help (*Fiji, 24*)
- 05** Yoga and chest physio (*China, 32*)
- 06** Take short breaks while exercising (*India, 21*)
- 07** Rest and reflexology (*Greece, 63*)
- 08** I sit while I prepare meals and I have exercises I can do sitting (*USA, 47*)
- 09** Just take [things] step by step (*Namibia, 43*)
- 10** Rest when I feel I can't breathe, tell other people to slow down (*Spain, 37*)



TOP TIPS FROM THE SEVERE ASTHMA COMMUNITY WHEN SPEAKING TO YOUR EMPLOYER

Work is a big part of life for many of us, and you may have some concerns about whether you'll be treated differently or how your condition will be perceived.

But it's important that someone in your workplace knows what to do should you experience an attack.

Speaking to someone about severe asthma may also mean they can better support you on a daily basis.

Your health is private and unless your workplace policies make it a requirement, telling your employers that you have severe asthma should be done on your terms.

ADVICE FROM OUR RESPONDENTS:

More than half (58%) of our survey respondents who are employed, have told their employer they have severe asthma. Here are their tips to others who want to do the same.

64% ... would suggest giving your employer some information about severe asthma from your doctor or patient support organisations such as GAAPP

42% ... would suggest thinking about three ways that you would like your employer to support you

28% ... would suggest writing down what you would like to say

"Be upfront. There is absolutely no shame in having asthma."

(South Africa, 29)

"[Develop an] action plan [with] emergency contact details."

(Australia, 35)



NOTES AND THOUGHTS

Use this page to capture anything that will be helpful to you – any questions you have, tips you want to use or changes you plan to make to help you live better with severe asthma.



A large, empty rectangular area with a light blue background, intended for writing notes and thoughts.

GIVING YOUR LOVED ONES THE INFORMATION THEY NEED

Lots of people we surveyed recommended putting family and friends in touch with your healthcare team. This helps them better understand the condition and provides an opportunity to ask the questions they may not want to ask you!

We asked severe asthma specialist **Professor Wolfgang Pohl** from the Sigmund Freud University in Vienna for his take.



What are the most important things family or friends of those living with severe asthma should know?

"That their loved one is living with a very serious condition that will affect the smallest things and the biggest things in their lives. It's a completely different type of asthma to milder forms that others may have. It's important that they understand the condition is unpredictable and asthma attacks can happen at any time, often without much warning and even when their loved one is doing everything right and taking their medication correctly."

Asthma attacks can be scary, what should family and friends do to help during an attack?

"Asthma attacks are not only scary – they can be life threatening and need to be controlled as quickly as possible. It's important that you're prepared before an attack happens. It's likely your loved one won't be able to talk to you when they're experiencing an attack, so make sure you know where their medication is. Discuss how you will know if they need to go to hospital. It is also important that you help to support your loved one, keeping you both as calm as possible – not always easy but panicking will make the situation worse."

How can friends and family support their loved ones day to day? It can often be difficult to know how best to help while allowing them independence.

"Sit down and ask them. Everyone is different. Some people will need help with lots of things – for others, helping them carry the shopping may be enough. The key is remembering the help they need may change. Symptoms can change on a weekly or even daily basis, so make sure you check in regularly. You shouldn't worry that you're stealing their independence, by helping them now, you may actually be helping them to stay independent for longer. Let them know you want to help and not to be afraid to ask!"

Should family and friends stop their loved one from doing certain things?

"Trust your loved one to listen to their own body and decide what they can and can't do. But keep them in mind when making plans and try to put yourselves in their shoes. If you're planning a holiday, where is the nearest hospital? If you're going on a day out, how much walking will be involved? Could factors such as people smoking or cooking nearby trigger an attack? Thinking about these things will help them."

One question that people may be too scared to ask is, will their loved one die?

"Severe asthma is a serious condition and asthma attacks can be life threatening. Remember that for many people living with severe asthma, fear of dying is something that already worries them. Over a third of survey respondents (38%) said they had worried about it during the last month. The best thing you can do is support them and be well prepared for when an attack happens, so they feel reassured that you are there for them."



MYTH BUSTING



There are plenty of myths and misconceptions about severe asthma. Here we've brought together some of the most common misunderstandings with those our respondents told us about.

Myth 01

"I don't like to share with people because they feel [severe asthma] is transmitted." (Kenya, 36)

Severe asthma is *not* a condition that can be passed from person to person.

Myth 02

The symptoms are the same for everyone with severe asthma

Although severe asthma has a list of identified symptoms, those living with the condition won't all be affected in the same way. Severe asthma is very unpredictable and it's important that people identify their own triggers.

Myth 03

"So many people hear asthma and say, 'oh I have that - I had to use an inhaler in gym class as a kid'." (USA, 40)

Severe asthma is a different condition to asthma. There are also different types of severe asthma, including severe eosinophilic asthma which can be diagnosed with a blood test.

Myth 04

Severe asthma just means your asthma is uncontrolled

Uncontrolled asthma is where your symptoms are not controlled with your current treatment, but they improve with treatment changes.

Severe asthma is a specific type of asthma that does not respond well to standard asthma treatments.

Myth 05

There is no hope of improving

Treatments for severe asthma have improved greatly in recent years with the introduction of biologics and the condition is better understood than it used to be. If you feel that your current treatment isn't working, speak to your doctor and ask to be referred to a specialist. A specialist will be able to check if you have a different type of severe asthma.

HOW TO SPOT WHEN YOU'RE LOSING CONTROL

Receiving a diagnosis of severe asthma isn't where the story ends, in many ways, it's just the beginning. Balancing the side effects of treatment with asthma symptoms is a challenge faced by most people living with severe asthma. Oral corticosteroids (OCS) are important medicines to treat asthma attacks as they quickly reduce inflammation. However, using them frequently can lead to serious health risks and repeated use may be a sign that your treatment plan should be reviewed.

So, it's important to know when it's time to speak to your healthcare team about your options for better control. Luckily, there are four simple rules to help you spot if your asthma is uncontrolled.

RULES OF TWO

- 01** Do you have asthma symptoms/attacks more than twice a week?
- 02** Do you wake up due to asthma symptoms more than twice a month?
- 03** Do you need to take oral corticosteroids twice a year?
- 04** Do you refill your reliever inhaler more than twice a year?

If you have answered yes to any of these questions, you should speak to your healthcare team about reviewing your treatment plan.



THERE IS FINALLY HOPE

Dr Neil Martin has treated severe asthma for over 15 years. Here, he explains why the community finally has hope.

Asthma affects 339 million people around the globe. However, a small yet significant amount of that number (around 5 – 10%) are affected by severe asthma, which is defined by relative resistance to usual treatments.

Severe asthma patients are on high doses of inhaled steroids and are often dependent on other treatments, such as oral corticosteroids, either requiring frequent courses or using these as maintenance medications. While these treatments help to control the symptoms, the side effects can have a huge impact on quality of life.

43% of people surveyed in the development of this guide said that in the last month, they'd felt afraid of the side effects of their asthma medication. We have to do everything we can to reduce this statistic.

It's so important that we make sure that healthcare professionals understand why and how severe asthma is different to asthma, are able to recognise it and know how to get their patients the right help.

One of the challenges in severe asthma is recognising and assessing the impact the condition is having. People living with severe asthma often adapt their lifestyles to help them cope with the condition and reduce symptoms, so unless you ask about this you're not getting the full picture of what they can and can't do. I've been treating severe asthma for over 15 years and I've seen many examples of people who have simply withdrawn from life to the point they no longer recognise themselves. We have to do better.

Everyone deserves to have their asthma reviewed by a specialist when they're struggling with the disease and its impact. We want to treat people at the earliest opportunity for the greatest benefit and get them back living the life they want to live.





Of those survey respondents who take oral steroids, 46% have reduced their dose in the last seven years. That is encouraging but we must do more.

Treatment choice is evolving and with that comes greater optimism. There is a real chance to help people living with severe asthma to transform their lives. However, we need to make sure those people are seen by the right specialists in the right clinics. We need to empower people to understand their disease, to ask the right questions of the right people, to ask for more.

At GSK, a big part of our mission is to advocate for patients. That's why we work with GAAPP, helping to support the incredible work they do.

There is a new wave of treatment possibilities for severe asthma and that offers a new opportunity where there hasn't always been one. Quite simply, as a respiratory consultant, I can finally offer more hope for those with this condition, something I had not been able to do before, and allow them to get back living their best lives.

Dr Neil Martin,
*Consultant Chest Physician and
GSK Global Medical Affairs Leader*

REGAINING CONTROL

"It took 20 years to receive a severe asthma diagnosis, meaning I've been on high dose oral corticosteroids for almost 30 years. I'm 53 now and incredibly lucky to be a wife, mother and grandmother, but the asthma and the steroid side effects have meant I've missed many events in my life. Sadly, it's not always allowed me to be the wife, mother or grandmother I wanted to be.

Thanks to new treatments, I've finally been able to reduce the steroids. I can now play with my beautiful grandchildren and be much more active in my church.

Please, if you need help, ask for it. Reaching out is a sign of strength, not weakness."

(Brenda Young, USA)

ONE THING

Severe asthma is a chronic condition, meaning it is persistent and people will live with it for a long time. Treatment is focused on trying to control the symptom rather than curing the condition. Living with a chronic condition can feel overwhelming,

but living with something for a long time also means that people find the best ways to live with it. Everyone reading this guide will be at a different stage in their diagnosis and management of severe asthma, the same as those who responded to our survey.

SO WE ASKED OUR SURVEY RESPONDENTS: THINKING BACK TO THE START OF LIVING WITH SEVERE ASTHMA, WHAT ONE THING DO YOU WISH YOU HAD KNOWN?

"There are many different medications and treatments to try to get things under control – be patient while figuring it all out"

(USA, 38)

"Although rare, you are not alone"

(Australia, 38)

"To get help earlier"

(Gozo, 46)

"There are multiple patient associations that can help us"

(Spain, 27)

"Get the right diagnosis"

(Austria, 53)

"Use respiratory physiotherapy exercises"

(Spain, 41)

"It [asthma] doesn't define me"

(South Africa, 59)

"I wish I'd asked to be referred to a good pulmonary specialist"

(Ireland, 56)

"That there is a lot of medication and that it is better to be informed and that not everyone is treated with the same medication."

(Uruguay, 58)

This guide has been translated into Arabic, German, Italian, Portuguese (Brazilian), Spanish (European) and Spanish (Latin American).

Please contact your local patient organisation, or GAAPP, for a copy in your preferred language.

Find your local patient organisation by visiting:
<https://gaapp.org/member-organizations/>

For more information about Define Your Asthma and to download more resources, please visit:
<https://gaapp.org/define-your-asthma/>

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This guide was developed using insights obtained from an online survey of adults (aged 18+) who said at least one sign from the PULSAR checklist applied to them. Fielded June – August 2020 by Pegasus on behalf of GAAPP.

Base size of respondents for quantitative data (in all but the 2 instances detailed below): n=128.

Base size of respondents who are employed: n=86.

Base size of respondents who take oral steroids for their severe asthma: n=102.



*Define Your Asthma is led and coordinated by
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