

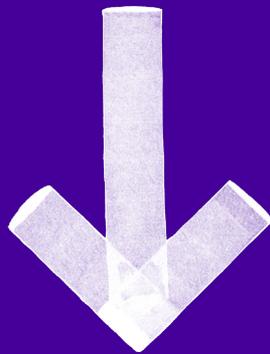
Asthma + Lung UK Strategy to 2027



FIGHTING FOR BREATH

20% FEWER

people to lose their lives or have their
lives affected by lung conditions by 2027



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Foreword

For too long, the nation's lung health has been side-lined, under-treated and under-resourced. This is inexcusable when lung conditions are the third leading cause of death in the UK¹ and millions are affected by breathlessness, which can be terrifying and limit people's ability to get on with their daily lives.

Over the past decade, outcomes for people with lung conditions have not improved to anywhere near the same extent as in other disease areas, including cardiovascular disease and cancer.² The burden from chronic lung conditions, including asthma, chronic obstructive pulmonary disease (COPD), bronchiectasis, interstitial lung disease, long covid and lung cancer, continues to grow.

The poor state of the nation's lung health is partly due to the misconception that lung conditions aren't life-threatening, and that breathlessness is something that people must sadly cope with as part of everyday life. But it is also because many lung conditions are more common in disadvantaged communities, further widening the gap between the lives of rich and poor – and meaning they are less visible to and valued by policy makers.

There has been chronic underinvestment in lung health by governments and health services. It took until 2019 for there to be a national plan to improve lung health services in England, almost 20 years after the first national cancer plan was published. And our opportunities to develop new treatments and cures for lung conditions are hampered by a dismal lack of investment in research and innovation, with lung conditions receiving less than 2% of public funding for medical research.³

The reasons for the poor state of the UK's lung health and current limitations in prevention, diagnosis, care, and research are numerous and complex. But just because they are difficult to solve doesn't mean change isn't possible. What is needed is courage, tenacity and a willingness to think big to find the better ways of doing things.

We're here to take on the challenges. Since the start of 2020, Asthma UK and the British Lung Foundation have been working together to improve the lives of people affected by lung conditions. Now we're going forward as Asthma + Lung UK to drive a transformation in lung health. We're the nation's lung charity and we're here for everyone who's living with a lung condition, regardless of what that condition is.

This starts with shifting perceptions, so people realise that lung health affects us all. Infections like COVID-19, influenza and pneumonia can strike down anyone and leave them fighting for breath. This impacts every aspect of a person's life, way beyond their

health; it can affect relationships, work, finances and interests. And every two minutes in the UK a baby is born in an area with dangerously polluted air, putting them at risk of developing a lung condition from their very first breath.⁴

Transforming lung health means exploring every opportunity in the quest for new treatments, radically improving diagnosis and care for people with lung conditions, and cleaning up the air we breathe so that the poorest in society aren't paying the price.

But we cannot achieve this alone. We will work collaboratively and form broad coalitions that speak with a single, powerful voice. Together, we will work with communities who are most at risk of lung conditions and make their voices heard.

We exist to fight for your right to breathe. We won't stop until lung health is transformed, outcomes for those with lung conditions are improved, and we are all breathing clean air.



Sarah Woolnough
Chief Executive, Asthma + Lung UK



Summary

Everyone has lungs, and every day each of us rely on them for every single breath we take. Yet, despite how fundamental they are, far too many of us take our lungs for granted. And we overlook how difficult life is for people with lung conditions who don't get the help they need or deserve. This is wrong and it must change. That is why we are here, fighting for clean air, early and accurate diagnosis, for best quality care, best quality care and life-changing research, now and for future generations.

Over the next five years we will deliver significant and lasting change. We will be fighting to make sure:

- No one develops a lung condition that could have been prevented.
- No one is left struggling to breathe without a diagnosis or expert care.
- There is no stone left unturned when it comes to finding a treatment, cure or a better way to diagnose and manage lung conditions.
- No one who has difficulty breathing looks back and thinks that, with better care, they could have had a better life.

Specifically, by 2027, we hope to reduce deaths and ill-health caused by lung conditions by 20%, giving thousands of families more precious years with their loved ones. We will do this by working with others to:

- Triple public funding for respiratory research to £150 million each year and increase our own investment in pioneering research.
- Reduce the number of hospital admissions linked to spikes in air pollution and the number of early deaths linked to long-term exposure.
- Increase public awareness of the symptoms of lung conditions and develop methods to diagnose lung conditions with greater accuracy and speed.
- Provide 90% of those who are newly diagnosed with asthma and COPD with support to manage their condition, resulting in 30% fewer unplanned hospital admissions for COPD and 40% fewer visits to A&E for asthma each year.

We also want to push for better ways to do things:

- We will tackle the negative attitudes that have seen lung health neglected and held back progress for so long.
- We will challenge the inequalities that see people from the poorest communities carry the heaviest burden of lung conditions. We will pursue policies that help prevent lung conditions in the poorest parts of the country and better tailor our services to those that need the most support, including by offering information and advice in a wider range of languages.
- We will offer all lung patients information, advice and ongoing support when they are diagnosed, and we will be there during crisis when they need us most.
- We will fund the best science and brightest minds to find new solutions to the biggest challenges in respiratory prevention, diagnosis, treatment and management.
- We will bring together all those affected by lung conditions to make sure their voices are heard by decision-makers, and we won't stop until lung health is given the same priority as other conditions.

Lung health in the UK⁵

Lung conditions are the

**3RD BIGGEST
KILLER**

in the UK

1 IN 5 PEOPLE

in the UK will experience a
lung condition

1 person

**EVERY
MINUTE**

is diagnosed with a lung
condition in the UK

1 person

**EVERY
5 MINUTES**

dies from a lung
condition in the UK

We have the

**WORST
DEATH**

rate for lung conditions
in western Europe

Asthma is the

**MOST
COMMON**

long-term condition
for children in the UK

There has been

**LITTLE
PROGRESS**

in lung health over the
last decade

Lung related deaths are

**7 TIMES
HIGHER**

in the poorest parts of
the country

Lung conditions cost the
UK more than

£11 BILLION

every year



Fighting to protect lung health

The challenge

Most lung conditions could be avoided by improving the quality of the air we breathe in our communities, homes, workplaces and schools.⁶ By reducing exposure to tobacco smoke, air pollution, infection, mould and occupational hazards (such as asbestos and other dust, fumes and chemicals) as well as encouraging healthy lung behaviours like exercise, we can greatly reduce the chances of people developing lung conditions at all stages of life.

While lung health problems can affect anyone, there is an unfair burden with the poorest in our society being hit the hardest. Cases of COPD, deaths from lung cancer or pneumonia are all higher among people living and working in more deprived areas.

Where there have been improvements in the risk factors associated with lung conditions, these have not been felt equally. Smoking is the single biggest cause of the gap in early deaths between the richest and poorest.⁷ Air pollution also contributes to this gap, with 85% of people living in areas with illegal levels of air pollution making up the poorest 20% of the UK population.⁸ There is a stark injustice in our society: those who earn and pollute the least are among the most affected by the health impacts of dirty air.⁹

Infectious lung conditions, such as pneumonia and influenza, worsen existing lung conditions and drive-up winter hospital admissions.¹⁰ And respiratory syncytial virus (RSV) in childhood plays a role in increasing rates of childhood asthma.¹¹ COVID-19 has shone a light on how devastating respiratory infections can be. In the UK alone, it has caused over 180,000 deaths since 2020,¹² and there are estimated to be 1.3 million people living with the debilitating effects of long covid.¹³ Access to and uptake of effective vaccinations across all parts of our society is critical to preventing these trends and safeguarding us all from future pandemics.

“Inequalities have long been a striking feature of lung diseases in the UK. Of the many indignities associated with being poor, or relatively so, having increased risk of chronic obstructive pulmonary disease or dying of lung cancer or pneumonia are among the worst. The tragedy of it is that we know quite a bit about what to do to prevent this needless suffering.” – Sir Michael Marmot, Joint President, Asthma + Lung UK and Professor of Epidemiology and Public Health at University College London



“ School is a place where children should be safe. But too many of them are in high air pollution areas, harming the health of children like my daughter Lily. ”

Fidaa and Lily's story

"School is a place where children should be safe. But too many of them are in high air pollution areas, harming the health of children like my daughter Lily.

Lily has had breathing problems since she was a baby. I remember taking her to hospital when she was tiny and being shocked when the doctors said her oxygen levels were very low. Since then, she's had to go to hospital regularly, especially in winter. We've spent so many nights there, I've lost count.

Her attacks were worst between the ages of two and seven. We'd be at the hospital five or six times each winter. I would feel so stressed and frightened seeing her struggle to breathe.

Thankfully, these last two years, she hasn't had an overnight stay. Her asthma has improved since the pandemic started, due to fewer cars on the road. We've also moved to an area with less traffic. But our accommodation is temporary, and the conditions are not ideal for a child with a lung condition. The house is damp, and I had to fight to get a musty old carpet replaced.

Lily's old school was in an area with very high pollution levels, despite being near a park and off the main road. We didn't realise how bad it was until her friend's mum, Ruth, borrowed an air quality monitor from Asthma + Lung UK. The results showed regular spikes of nitrogen dioxide well above legal limits."

Fidaa and Lily, Manchester

The scale of the problem¹⁴

Lung related deaths are

**7 TIMES
HIGHER**

in the poorest parts of
the country

SMOKING

is the single biggest cause
of the gap in early deaths
between the richest and
poorest

**AIR
POLLUTION**

is linked to up to 36,000 early
deaths each year in the UK

15% OF COPD

cases are linked to
occupational causes,
around 450,000 people

400,000 people yearly are
admitted to hospital with

**PNEUMONIA
AND FLU**

Jardine's story

“At 33, I woke from a coma to find my lungs weren't working. People don't realise how dangerous pneumonia can be and that it can be caused by seasonal viruses, like flu.

I remember calling 999 as I gasped for breath; I remember coughing up blood in the back of the ambulance; I remember pleading with the doctors in A&E not to let me die as I hadn't said goodbye to my young boys. Weeks later, I remember waking up. “You're in ICU”, a voice said. I wasn't sure if I was dead or alive. As it transpired, I was somewhere between the two. Alive, but only because ECMO – an artificial breathing machine – was doing the job of my lungs.

I spent many days awake but unable to move, speak, eat or drink. An army of people had to wash me and a nurse was by my side 24/7. There were tubes, lights, machines and people everywhere. “Your lungs are stiff like a wet sponge left out in the sun to dry,” one consultant told me. The other said I'd be unlikely to get a transplant, so I should prepare for the worst. My rested lungs did eventually recover. I was one of the lucky ones.

It was mostly people in their 20s to 50s on the ward. Not the age group you'd usually associate with pneumonia. These days, we hear a lot about ICU and ventilator capacity due to the pandemic, but we don't think we will ever need that treatment and we don't realise how life-altering it can be. Yet common viruses like flu and covid can lead to severe complications, like pneumonia, sepsis and ARDS – Acute Respiratory Distress Syndrome – in my case.

Once discharged from hospital, I was given the pneumococcal vaccine to protect against further pneumonia. I was advised to renew this every five years, but some people only need a single one-off vaccine. I also get my flu vaccine every year and I make sure my children get their nasal sprays. After all, prevention is better than cure.”

Jardine, West Sussex

What we're fighting for

Our ambition is for no one to develop a lung condition that could have been prevented.

- We will empower people to make change, by listening to them and combining their insights with evidence and analysis to influence decision-makers across the UK.
- We will push for local and national policy changes to drive down smoking rates, reduce air pollution, increase vaccine uptake, and tackle the underlying causes of health inequality.
- We will provide people with the information and support they need to make healthy choices for their lungs and reduce their risks.

By 2027, we will:

- Reduce emergency admissions for lung conditions, for both adults and children, by 20% in the 20 worst affected areas through tackling the underlying causes of ill health.
- Reduce the number of hospital admissions linked to spikes in air pollution and the number of early deaths linked to long-term exposure.
- Halve the adult smoking rate from 14% to 7% and hold the UK Government to account on their target to be smoke-free by 2030.
- Ensure at least 75% of people with a long-term lung condition take up their annual flu jab, and all those eligible for a free flu jab are prioritised in future for any respiratory vaccines.

Babs' story

“Taking up smoking was the worst decision I've ever made. I was 16 and had just started work. I didn't realise how bad it was for my health.

The turning point came when I was about 40. I had run out one day and I spotted a lad drop a half-smoked cigarette on the floor. My first thought was to pick it up and smoke it. It shocked me – it was the first time I truly acknowledged I had an addiction.

After that, I quit. I did it completely on my own, but I was a nightmare to live with. I searched everywhere for a support group, but I couldn't find one. People look down on smokers, there is a lot of judgement. They see it as anti-social, rather than treating it as an addiction.

I was diagnosed with COPD just a few months after I quit smoking. I had pneumonia and then my doctor's surgery gave me a COPD check-up. Before this, no one had even told me I had COPD. When the nurse explained I had a life-long, chronic condition, it was a real shock.

COPD is a hidden disease. People cannot see the signs. Because you look well, they don't understand why you are using the disabled toilet. But I simply cannot walk upstairs – I cannot do what other people do.

Young people today need to be shocked into not taking up smoking like I did. When you smoke, you don't just risk getting cancer – you could get a lung condition that affects you for the rest of your life.”

Babs, Essex



Taking up smoking was the worst decision I've ever made. I was 16 and had just started work. I didn't realise how bad it was for my health.



Fighting for earlier diagnosis

The challenge

People who have difficulty breathing often wait years for a formal diagnosis, or never receive one at all. In part this is because society doesn't always take breathlessness seriously or consider lung problems as worthy of attention as other diseases. Ill-informed public attitudes can mean many people live with debilitating symptoms for years before they seek help.

But even once in contact with healthcare professionals, diagnosis is still too slow. Too much time passes between appointments and people are left waiting months for important tests. What's more, few advances have been made in the way lung conditions are detected and tests are often inaccurate, invasive, unreliable, or costly.

A delayed or inaccurate diagnosis can mean people don't get the care they need, or are put on unnecessary treatments, that may cause them harm and place significant cost on the NHS. Sometimes they may be too ill for treatment to be effective by the time they are finally diagnosed. For people with aggressive lung conditions, a delayed diagnosis means they can't make the most of the little time they have left.

This was the case even before the pandemic placed huge additional strain on respiratory services. Over the past two years, many thousands of people have watched their health deteriorate while they wait for respiratory care, and diagnoses of lung conditions have plummeted due to a halt in testing. For instance, the diagnosis of new COPD cases was down by over 50% in 2020,¹⁵ a decline much higher than for comparable conditions.

“People I see in my COPD clinic have typically been breathless for many years before they got a diagnosis. They have often missed out on treatments that would have improved their symptoms and reduced the burden of chest infections. We need to transform the approach to breathlessness so it is taken seriously and not dismissed as a normal part of ageing. This requires recognition of the problem and rapid access to the diagnostic tests needed.” – Professor Nick Hopkinson, Medical Director, Asthma + Lung UK and Professor of Respiratory Medicine, Imperial College London

The scale of the problem¹⁶

1 in 5 people experience symptoms of a lung condition

OVER A YEAR

before seeking a diagnosis

In the UK, almost half of those with COPD are believed to be undiagnosed – that's

1.5 MILLION people

Almost 60% of people diagnosed with COPD had symptoms for

OVER 5 YEARS

1 in 5 children have to wait

3 OR MORE YEARS

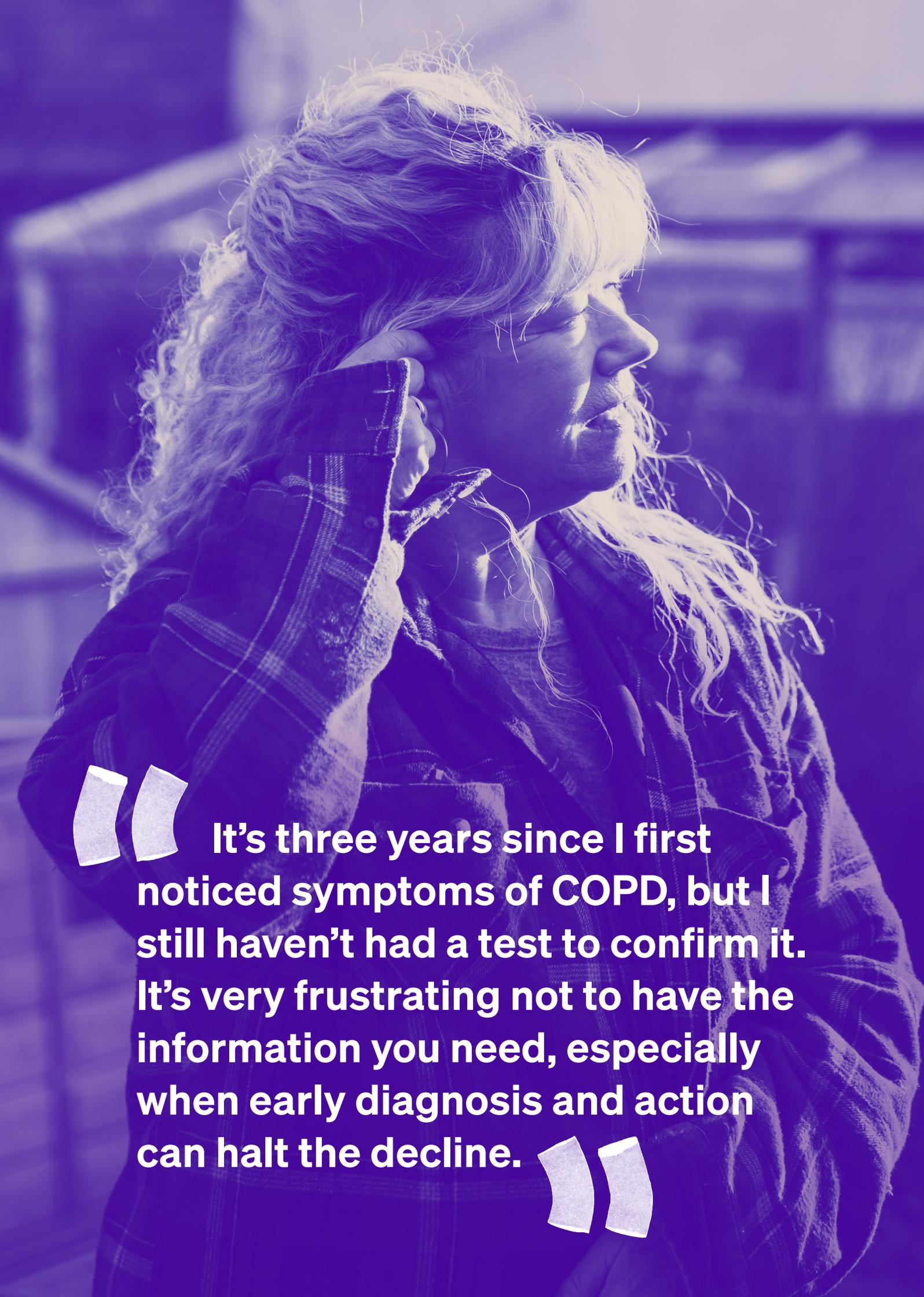
for an asthma diagnosis

It takes, on average

7 MONTHS

to be diagnosed IPF, with many patients waiting 2 years or more every year in the UK'



A woman with curly hair, wearing a plaid jacket, looking thoughtful with her hand to her ear. The image is overlaid with a blue gradient and white text.

“ It’s three years since I first noticed symptoms of COPD, but I still haven’t had a test to confirm it. It’s very frustrating not to have the information you need, especially when early diagnosis and action can halt the decline. ”

Katy's story

"It's three years since I first noticed symptoms of what would turn out to be COPD, but I still haven't had a spirometry test to confirm it or how well my lungs are coping.

It's very frustrating not to have the information you need, especially when early diagnosis and action can halt the decline.

There's been a lot of back and forth with multiple doctors, trying to work out what was causing my breathlessness. I've had to fight for answers every step of the way. That can be exhausting.

I initially saw a nurse in 2019 because I had a persistent chest infection. The first time a doctor mentioned COPD was in September 2020, but it took until February 2021 to speak to a COPD nurse over the phone and that took a lot of chasing.

Finding Asthma + Lung UK through social media has saved me. They have brilliant resources and support groups. It was through them that I found out about pulmonary rehab and how it could help me. Now I'm pushing my doctor for access to it. At their online support group, I'm able to talk about my emotions and my fears.

COPD is a progressive disease with no cure. You can feel the future is out of your control. You have to grieve the life you thought you were going to have. I expected to spend retirement travelling and volunteering with children and animals, not like this. It's hard to accept. But I have to be realistic with what I can manage."

Katy, Bristol

What we're fighting for

We want no one left fighting for breath without knowing what's happening to them, waiting to be seen or heard.

This starts with shaking up beliefs about lung conditions. No one should delay getting a diagnosis because they think their symptoms are trivial or just another part of ageing. No one should avoid seeing their doctor because they worry there is no treatment and nothing can be done to help them. And no one should leave a medical appointment feeling that their breathlessness hasn't been taken seriously.

- We will confront false beliefs about lung conditions and improve public and healthcare awareness of the symptoms of lung conditions, to make sure all breathlessness is taken seriously.
- We will work with governments and health systems across the UK to make sure there is a diagnostic pathway, that uses the best available diagnostic tests, delivered by sufficient numbers of well-trained professionals.
- We will push for better collection, recording and linkage of lung health data so we can track waiting times for diagnosis and treatment, monitor progress and understand barriers to improving the outcomes and experiences of patients.
- We will encourage the testing and uptake of new, cutting-edge technologies to transform the diagnosis of lung conditions, making it faster, more accessible, and more accurate.

By 2027, we will:

- Ensure everyone who presents with breathlessness receives the diagnosis and treatment they need within six months of presentation, with ambitions to reduce this time to bring it more closely in line with other major conditions.
- Have at least three new biomarkers that can accurately diagnose lung conditions.
- Have health systems across the UK gathering data on the time to diagnosis and time to start treatment for all major lung conditions, regularly reporting on this and tracking success in line with other major conditions.



“ Lung disease is a hidden disability – I look perfectly well until I struggle to breathe. People don’t understand the reality of lung conditions until it happens to a loved one. ”

Diven's story

"It's ironic that I was probably the fittest I'd ever been when I first noticed the symptoms of my lung condition.

I was climbing the stairs to the train platform on my way to work, but I was completely out of breath. I'd run a half marathon earlier that year – I knew this wasn't right.

It took an incredibly long time to get a diagnosis, despite how debilitating my breathing problems became. My doctor sent me for tests to rule out asthma, but then I had to go private to get a CT scan. It took 18 months after I first noticed symptoms to diagnose interstitial lung disease with diffuse systemic sclerosis, which is an incurable autoimmune condition.

The news was a massive shock. I worried about how I could carry on living a life that I loved, and if my wife and I could start a family. There's nothing worse than the unknown – having a speedier diagnosis would have taken away much of my worry.

Having to give up sports had a massive impact on me. I felt isolated, as sport was the focus of my social life. Going onto steroids and immunosuppressants stabilised my lung function and recently I've been able to return to the gym. I've got a personal trainer who understands my condition and I use an oxygen machine when I exercise.

My condition isn't common, and it can be hard to know where to turn for support. Lung disease is a hidden disability – I look perfectly well until I struggle to breathe. People don't understand the reality of lung conditions until it happens to a loved one.

Losing control over your future is hard, but I'm hoping to run the London Marathon this year and am working with the oxygen team to help me get through it. I won't let lung disease beat me."

Diven, London

Fighting for everyone to live well with a lung condition

The challenge

Too many people living with lung conditions have too few treatment options and are left to navigate the health system on their own, missing out on support they desperately need. It is wrong that people lose years of their life battling with lung conditions when they could have been living well.

Without access to the best care at the right time, many people end up being seen as an emergency or being admitted to hospital, when they often could have been treated earlier and more effectively before they became acutely unwell. For some people it tragically and unnecessarily reduces their years of life.

Hospital admissions for lung conditions have doubled in 20 years,¹⁷ and are a key driver of winter pressures – with 80% more admissions during winter.¹⁸ This was the stark case even before the outbreak of COVID-19, and admissions will only keep growing with an ageing population and more people with multiple long-term health conditions.

We are trapped in a vicious circle of late diagnosis, limited treatments, poor support for people to take the best care of themselves, and emergency hospital admissions. Not only does this cause untold pain for patients and their families, but it puts avoidable strain on our health services.

“Most people with lung conditions spend very little time each year in contact with healthcare professionals. With the NHS stretched like never before this is only going to get worse. For the rest of the time they are monitoring, treating, and trying to understand their health and their lungs on their own. Asthma + Lung UK bridge this gap and equip people to better manage their condition and maximise their lung health. Our collection of services gives people a platform to stay well. They combine the lived experience of people with lung conditions with the latest research, evidence and guidelines all distilled by the UK’s respiratory experts.” – Dr Andy Whittamore, Clinical Lead, Asthma + Lung UK and practising GP

The scale of the problem¹⁹

Lung conditions are a leading

CAUSE OF DEATH

in UK children

Over

60% OF ASTHMA DEATHS

could be prevented with better routine care

An estimated

25% OF COPD DEATHS

could be prevented with better routine care

As many as

25% OF PEOPLE

with COPD do not receive the very basics of care

Over 30,000 people in the UK have IPF. The average life expectancy is

3 YEARS

a poorer prognosis than for many cancers





“ My life has been turned upside down by long covid. The most debilitating symptoms are breathlessness and fatigue. Even hanging up my washing can leave me out of breath on a bad day. ”

Rakhee's story

"I contracted COVID-19 in May 2020 while working as a clinical pharmacist during the first lockdown.

I didn't have the classic symptoms – I felt run down, nauseous and had swollen glands but my symptoms did not warrant hospital admission. A week later, I developed breathing problems which was very frightening. Although I have asthma, I was previously very fit and healthy.

More than a year and a half later, and my life has been turned upside down by long covid. The most debilitating symptoms are breathlessness and fatigue. Even hanging up my washing can leave me out of breath on a bad day.

I rely heavily on family and friends for support, and I've had to adapt my role at work because I can't manage the walk between the pharmacy department and the ward more than once a day. My colleagues are understanding, but I feel guilty given how much pressure the NHS is under. I used to take classes in tap, Irish and Bollywood dancing but now I can't even contemplate the walk from the car park to the venue, let alone completing a class.

Long covid is such a new condition and I felt like I was going round in circles with doctors for a long time. Nobody knew how to manage the evolving symptoms and it was difficult to access specialist help.

One of the most helpful tools has been pulmonary rehabilitation, which a respiratory consultant suggested. The physiotherapist diagnosed a breathing pattern disorder and she taught me techniques for diaphragmatic breathing. Over the course of a few appointments, I saw a huge improvement. I wish I'd had access to this service three or four months earlier as it would have made a big difference."

Rakhee, Edinburgh

What we're fighting for

We want no one who has difficulty breathing to look back and think that with better care they could have had a better life.

- We will connect with lung patients at the point of diagnosis. We will offer information and reassurance and ensure they can access ongoing support, particularly in moments of crisis when they need it most.
- We will urge health systems across all UK nations to make high-quality care a reality for everyone who has difficulty breathing.
- We will offer patients and their families the best possible advice and information through our website, online chat and nurse helpline, to include provision in a wider range of languages such as Urdu, Polish, Cantonese and Punjabi.
- We will drive the creation and adoption of data-driven digital tools that enable people with lung conditions to monitor their health and make informed choices.
- We will provide exercise programmes with trained instructors, specifically designed for those who have difficulty breathing.
- We will expand our volunteer-led Breathe Easy groups to provide peer-support networks for people with lung conditions, and make sure they reach into disadvantaged communities.

By 2027, we will:

- Give 80% of people with lung conditions the opportunity to access our network of Breathe Easy support groups.
- Ensure 90% of those who are newly diagnosed with asthma and COPD receive information and support on the care and management of their condition.
- Reduce unplanned hospital admissions for COPD by 30% and visits to A&E for asthma by 40% each year.
- Increase access to life-changing drugs for people with severe asthma or interstitial lung disease by 30%.

Gabbie's story

"All my sister Dominique wanted in life was to be a mum. But she only got five precious months with her baby, Kayden-James, after suffering a fatal asthma attack aged just 19."

One minute I was chatting to her on the phone, the next she was gone. It's still hard to accept. Asthma runs in our family, so we know how scary it feels when you struggle to catch your breath. But I don't think we ever believed an attack could kill her.

Dominique's asthma was particularly severe during her pregnancy, and she was hospitalised quite a few times. The whole family told her off because we felt she was overusing her inhaler and needed to see a doctor, but she didn't appreciate the danger of her condition. It had become a way of life for her, to reach for a pump.

There were no warning signs on the day she died. She was making up Kayden-James's bottle before bed when she collapsed. My grandmother tried to give her CPR but her heart was too weak after years of poorly controlled asthma and it shut down.

I miss my sister every day. Dominique was unique – bubbly, outgoing and always the centre of attention. She had so much to look forward to.

Kayden-James is five now and every birthday is bittersweet. He gets more like his mum every day and keeps her memory alive for us, but it's devastating that she's missed so many of his milestones.

He also has asthma like his mum. He was in and out of hospital regularly when he was a baby, but now he is under a specialist and receiving good care. I wish Dominique had received the same level of treatment and better medication – she might still be here today.

Even though I have asthma myself, there was so much I didn't know about it until she died. Asthma kills – it is time we take it seriously so no more children are left to grow up without a mum."

Gabbie, Neath, South Wales



All my sister wanted in life was to be a mum. But she only got five precious months with her baby, after suffering a fatal asthma attack aged just 19. One minute I was chatting to her on the phone, the next she was gone.



Fighting for life-changing research and innovation

The challenge

There has been little improvement in how we diagnose, treat, and manage lung conditions in the last 20 years. This poor progress is both a tragedy and a disgrace, and the UK falls way behind most other European countries.²⁰ Research and innovation hold a vital key to changing and saving lives. But there has been insufficient attention or investment in delivering the step change that is now urgently overdue.

Our poor understanding of lung conditions means that diagnosis remains slow and often inaccurate, and people can go undiagnosed for years. There have been few advances to help people manage their condition through more effective use of existing techniques and drugs. This is despite the many digital technologies that could help with this. There have been a handful of new drugs developed over the past decade, but they can only be accessed by a small number of people. Very few new classes of drug – of the kind that can radically improve lives – have been developed.²¹

Respiratory research and innovation does not receive its fair share of funding given the impact of lung conditions on the nation's health. The £47m of public funding spent on respiratory research in the UK amounts to less than 2% of the £2.56 billion invested in health research each year.²² The level of under-investment is significant, especially given we have the highest respiratory death rate in western Europe.²³

The UK has led the way in achieving ground-breaking milestones in lung health, and yet we've underexploited our know-how in many areas of respiratory science. The iconic blue inhaler was created here in the 1950s, and we led the world with our rapid development of COVID-19 vaccines. But limited funding has resulted in too few scientists and innovators choosing to build a career in respiratory research, which further restricts opportunities to attract public and private investment.

But when breakthroughs have happened, they have been transformative. For example, new biologic treatments have given hope to thousands of people with severe asthma that they can have a good quality of life without constantly being admitted to hospital or suffering the side effects caused by oral steroids.

“Over the last 50 years the UK has produced world-leading respiratory research. However, being able to undertake the best research requires adequate investment, and historically this research has been underfunded. While we should be proud of what has been achieved, there is so much more to do. The time has come for a national step change in respiratory research.” – Professor Ian Hall, Director of the Centre for Biomolecular Sciences at the University of Nottingham, Vice Chair of Trustees for Asthma + Lung UK



“ The doctors asked if I had been to intensive care before and I thought: ‘What do you mean? It’s only asthma’. But after that terrifying experience, I learned that asthma can kill. ”

The scale of the problem²⁴

Lung condition research receives

LESS THAN 2%

of public funding for health research

Jo's story

"The first time I had an asthma attack was petrifying. I was at my work Christmas party when I started coughing and couldn't catch my breath. Someone called an ambulance, and I was hurried to hospital. I felt very panicked. The doctors asked if I had been to intensive care before and I thought: 'What do you mean? It's only asthma.' But after that terrifying experience, I quickly learned that asthma can kill.

After that, my life turned on its head. My asthma became severe and uncontrolled, with frequent attacks. I no longer went out without a backpack filled with inhalers, information on my medical history, and spare underwear and toiletries in case of a trip to hospital.

I had to turn down invites to some events because they were too risky and developed social anxiety. I was rushed to hospital from a friend's wedding, and missed many major life events due to illness. Some colleagues wouldn't understand why I needed so much time off for 'just asthma' and jokingly called me 'sick note'.

I relied on steroids to stabilise my condition, but the side effects were unbearable. I would be on steroids for less than a week and put on half a stone in weight. The changes in my mood were so intense and horrible I'm surprised my husband stuck by me. I'd wake up each morning and not know who I would be that day – irritable, teary, angry, moody.

That's all changed since I started on biologic drugs. I noticed a huge improvement almost immediately and have only needed two courses of steroids since starting on biologics. It's not an exaggeration to say this medication has been life-changing. Asthma no longer dominates my life. I can go out and not really think about it, instead of it being my main priority.

I find it so upsetting that there are many people who are still in the same boat I was in several years ago. I know I'm very fortunate to live near a centre of excellence for asthma and to have a consultant who is advocating for me. Every person with asthma deserves this."

Jo, Bristol

What we're fighting for

We want there to be no stone unturned when it comes to finding a treatment, cure or a better way to diagnose and manage lung conditions.

- We will continue to fund the best science and brightest minds to find new solutions to the biggest challenges in respiratory prevention, diagnosis, treatment and management.
- We will accelerate progress in respiratory research and innovation to address the greatest unmet needs. We will use our funding and overall knowledge of the lung health landscape to drive activity in priority areas.
- We will develop and expand the capacity and collaboration of the respiratory research community of government, academia, pharmaceutical and medical technology companies.
- We will bring together scientists, clinicians and innovators to ensure that their work tackles the issues that matter most to patients and make sure that the results are likely to improve the lives of people with lung conditions.
- We will expand our own research and innovation programme so we're investing £5 million in research every year.

We also need other funders to lean in. We're asking governments, academia, pharmaceutical and medical technology companies to all play their part. We want to see the UK Government triple their annual investment in respiratory research and innovation to £150 million. This would encourage private investment and bring funding in line with the proportionate impact of lung conditions on the nation's health.

With the right focus and resources, by 2027, we could:

- Identify and develop at least three new biomarkers that can accurately diagnose lung conditions.
- Identify at least three novel drug targets for new treatments to reduce death and ill-health for the most fatal and life-limiting lung conditions.
- Develop at least three new self-management tools and deliver them into the hands of over 2 million people with lung conditions to transform lives and minimise healthcare use.

James' story

“During my training days, I met many people with bronchiectasis who were frustrated by the lack of effective treatments. Despite the devastating impact of bronchiectasis, there's very little research into it. That's why I decided to focus my career on bronchiectasis research – I felt like I could make a big impact.

I got started thanks to a PhD grant from the Medical Research Council. What's crazy is that it was the first grant for a bronchiectasis project in 50 years!

In bronchiectasis, there's a common cycle of inflammation and infection, where the body's own defences damage the lungs instead of killing the bacteria. This leads to flare-ups and worsening symptoms. I think we can fix this cycle by finding better ways to use antibiotics, and by developing treatments that improve the way the lungs' defences work.

One major problem is that no two people with bronchiectasis are alike. A drug that's worked for one person may not work for someone else. Thanks to a grant from Asthma + Lung UK, I've been researching how to create 'lungprints' – like a unique fingerprint, but of your lungs. By doing this, we hope we can eventually match the right treatment to the right person, at the right time.

In the short term, it'd mean we could guide doctors to use drugs more effectively. And in the long term, we could help develop better drugs that target the root cause of every individual's bronchiectasis. This is the largest and most detailed study of bronchiectasis ever undertaken. It could transform the way we treat the disease.

Since I began working in bronchiectasis, I've done everything I possibly can to raise the profile of the disease and to bring new investigators and scientists into the field. It's so exciting to see the progress we're achieving and it's only thanks to the generous donations of Asthma + Lung UK supporters.”

Professor James Chalmers, Dundee



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Being an outstanding organisation

The challenge

The scale and pace of change required across prevention, diagnosis, the delivery of care and research is substantial and urgent. To fight for the improvements we want to see, we also need to transform as an organisation.

Crucially, we want people who have difficulty breathing to be at the very core of everything we do, sharing their experiences and challenging us to strive for more. We need people living with lung conditions to lead our support groups, to campaign for better lung health and help us amplify their voices and demand change. We need to expand our network of supporters to raise increased funds through challenges, activities and personal donations.

The task is too large for any single organisation to deliver alone. Alongside our work supporting people with lung conditions, we will encourage governments, health services, the scientific community, pharmaceutical and technology companies to think big, share and cooperate, and push for better. Together, we can achieve more and faster.

Derek's story

"The best way I can describe COPD is that your lungs are like paper. I was 39 when I was diagnosed, after a concerning shortness of breath when I walked. But there was very little information. I was given an inhaler and sent on my way.

Now I run COPD help sites, a local Breathe Easy group, and I sit on the Wales Patient Panel for Asthma + Lung UK. I joined the panel so I could make sure the voices of people like me were heard by Welsh Government and I could shape the charity's campaigns. It is so important that people living with lung conditions are listened to and services built around our needs."

Derek, Treorchy, South Wales

Caroline's story

I'm a Respiratory Nurse Specialist in Asthma + Lung UK's clinical helpline team. Every week we speak to hundreds of people affected by lung disease. We do our best to provide a listening ear and empower each caller with support, advice and information to help them manage their condition better and give them the confidence to seek help when they need it.

We speak to a variety of callers – those who are waiting for a diagnosis, or who are newly diagnosed and unable to access care; relatives and carers of people with advanced lung disease; parents of young children; even school staff and healthcare professionals. Many of our callers are anxious and feel alone, so our aim is to always provide hope and practical steps for what they can do next.

Caroline, London

We're ready for the challenge

To transform lung health, we need to transform as an organisation too. Our new strategy and look is one part of this – but just as important is the way we behave, think and work together to achieve our ambitions. That's why we've thought long and hard about what kind of organisation we are and will need to become to be the best we can be for people with lung conditions. Our new values are an important first step on that journey:

- **We have courage:** We are tenacious, making things happen and removing barriers to success. When things are difficult, we keep pushing. Sometimes we fail, but we try again, and learn from our mistakes. This will be vital to driving the transformation in lung health.
- **We always push for better:** We think big and always look for better ways to do things. And better never stops! We encourage innovation and new ideas. We challenge things that are not right and celebrate great work. We're not content to stand still and will always push for the best for people's lung health.
- **We empower our people to be their best:** We support each other to be our best and to do great things to transform lung health. We value diversity and inclusivity and are always true to ourselves and fair to others. We think this will be vital to overcoming the health inequalities experienced by people with lung conditions.
- **We work as one:** We work as one team towards one goal. We collaborate with each other and with our partners to achieve it. We hold each other to account, and we support each other to deliver the very best.
- **We listen and understand:** We listen to people affected by lung conditions to understand their views and needs, informing everything we do. We listen to other experts to continually add to our knowledge. We take the time to see things from other people's perspectives.

By living these values, we believe that we can unite the lung health community and achieve real change for those who struggle to breathe. It is important to us that we are held accountable to them and are challenged to live them every day.

1

We have
courage

2

We always
push for
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3

We **empower**
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4

We work as
one

5

We listen and
understand

Orla and Ellie's story

"Ellie has really struggled with her asthma over the past couple of years and missed out on precious time at school because she was in and out of hospital. As a parent, seeing your child having difficulty breathing is terrifying and you feel so helpless. Thankfully, she is now feeling much better. She is under the care of an asthma clinic and has a new asthma action plan, which gives advice on what to do if she has a flare-up and when to seek help.

Ellie's dad, sister and brother also have asthma, so she was really keen to take part in the Take Steps Challenge last year to raise awareness of the seriousness of asthma and show that having a lung condition doesn't need to hold you back. Ellie, along with friends and family, walked 64 miles in 30 days and raised over £500 for the charity."

Orla and Ellie, Belfast

We need your help

To meet the needs of those affected by lung conditions, we also need to grow as an organisation – both in terms of the work that delivers life-changing impacts, and the income that supports this. We want to be the first charity people think of when they choose to support people with lung conditions, and over the next five years we plan to raise at least £90 million to deliver our work to help all those who struggle to breathe.

Of course, we know that all donations are extremely precious so we will run our operations and processes as effectively and cost-efficiently as possible so that maximum investment goes towards this work.

Thanks to our supporters and volunteers, we've already helped millions of people living with a lung condition. We hope you, and many others, will continue to support us as we fight for a world where we can all breathe with healthy lungs. This is only possible with your help.

Help us transform lung health by joining the conversation by joining the conversation today at **[AsthmaAndLung.org.uk](https://www.AsthmaAndLung.org.uk)**

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FIGHTING FOR BREATH

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