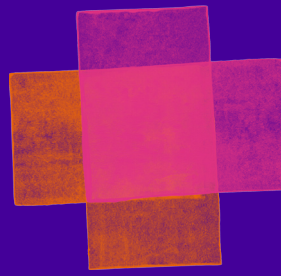


Fighting for lung health
in Northern Ireland



**ASTHMA+
LUNG UK**
NORTHERN IRELAND

THE RIGHT TO BREATHE

2022 Northern Ireland manifesto

Foreword from our Chief Executive

2020, 2021 and 2022 will be years that we never forget and have been particularly tough for people with lung conditions, shielding and trying to avoid the most threatening respiratory virus that we have seen in 100 years. It is so timely, and I am very proud to be introducing Asthma + Lung UK's manifesto for the second Northern Ireland Assembly Election, to protect and improve lung health beyond COVID-19.

Even with the challenge of COVID-19, we have achieved so much as a charity for so many of our beneficiaries. With many firsts such as our Long COVID Hub collecting insight and providing advice when we knew so little. With the shift to virtual working, we continued to keep our beneficiaries connected by holding virtual 'breathe easy' groups. Our helplines and websites saw volumes that went beyond anything that we had ever seen before, as we continued to offer the best advice in an ever-changing environment.

Our team has continued to champion the voice of all our beneficiaries.

Through patient panels and several surveys on topics such as asthma and chronic obstructive pulmonary disease, residents of Northern Ireland told us of the pandemic's impact on their everyday lives, wellbeing, and mental health. These contributions fuelled our passion for delivering change and standing up for lung health in Northern Ireland.

Many more difficult challenges still lie ahead, including the emerging Cost of Living Crisis and how this will impact on those with respiratory disease. This document sets out our goals for lung health in Northern Ireland over the next five years.

Looking beyond COVID-19, we seek to build on our recent work to deliver real changes to people's everyday lives.

Every breath counts. No longer should we be breathing in dirty, polluted air and no longer should we face the possibility of inhaling second-hand smoke on the street. Our team in Northern Ireland is calling for new legislation and new regulations to be in place to protect our lungs so that everyone has the right to breathe clean air with healthy lungs. Northern Ireland also needs an enhanced emission testing programme to identify emerging air quality issues as soon as possible. Early intervention and preventative action is key. With this in mind, delivery on the draft Clean Air Strategy in Northern Ireland is imperative.

We only get one set of lungs, so we all must have the tools available to look after them. That is why we are calling for new diagnostic hubs across the country. No cough should be left unchecked, no wheeze should be ignored, and no one should be left waiting for a diagnosis or be misdiagnosed.

When we receive a diagnosis, access to the best treatment should be readily available, whether that is biologic drugs for severe asthma or pulmonary rehabilitation for lung conditions like Chronic Obstructive Pulmonary Disease (COPD). We all have the right to the best care, so we call for support to ensure that these services are available in every area of Northern Ireland, to everyone who needs them.

Northern Ireland urgently needs a new Lung Health Strategy with funding and clinical leadership to protect and improve lung health beyond COVID-19.

For too long lung conditions have been the third largest killer in Northern Ireland¹. We hope that political parties and candidates can support our manifesto asks to protect and improve lung health and we look forward to working with everyone elected to the next mandate of a fully functioning Northern Ireland Executive and Assembly.



Sarah Woolnough

Chief Executive, Asthma + Lung UK



Who are we?

At some point in our lives, one-in-five people will develop a lung condition. Asthma + Lung UK is the only UK-wide charity looking after the lungs of Northern Ireland and our vision is for a world where we can all breathe with healthy lungs. The pandemic has shone a spotlight on how devastating lung conditions can be, what it is like to struggle to breathe and how it can affect every part of someone's life - their health, relationships, work, and finances. Governments can now see the impact that lung conditions have on individuals and wider society. Northern Ireland has a shortage of specialist respiratory staff which COVID-19 has brought into sharp focus. This manifesto highlights the need for proactive and holistic approaches to help prevent, diagnose, and treat lung conditions so that we can all live better, healthier lives.

Through research, we can find new ways to prevent, manage (and self-manage), treat, and eventually cure lung conditions. With support, we provide for people who struggle to breathe the skills, knowledge, and confidence to take control of their lives. Together, we are fighting for clean air, better health services and much-needed investment in research and innovation.

What are lung conditions?

Lung conditions are diseases of the airways and other structures of the lungs and are a major contributor to ill-health, disability, and premature mortality. Some of the most common conditions are asthma; chronic obstructive pulmonary disease (COPD); Pneumonia; Bronchiectasis; Interstitial Lung Disease (in particular IPF); and Long COVID-19. Most long-term lung conditions are not curable, but various forms of treatment have been shown to help control symptoms, increase quality of life and reduce premature mortality.

Impact of lung conditions

Many people struggle with chronic lung conditions. These conditions have a major impact on their lives and the lives of their families. Some can't work or lose out on education and find it difficult to participate in everyday social activities. Anxiety and depression are common, and are associated with worse quality of life, increased symptom reporting, more frequent and longer stays in hospital and increased mortality.

Prevent It

Prevention is always a good idea and while there are, as yet, no cures for long-term respiratory illnesses, it is vitally important. When people think about how best to prevent lung conditions, stopping smoking is often seen as the number one measure people can take. However, that alone will not prevent all lung conditions. Our homes, air quality, our jobs and how we exercise all have important parts to play in preventing poor lung health.



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

Outdoor air pollution kills: Northern Ireland's lungs shouldn't pay

There is no safe level of air pollution to breathe in². An air pollutant is any substance in the air that could harm people. Particulate Matter (known as PM), and nitrogen dioxide (NO₂) are particularly damaging.

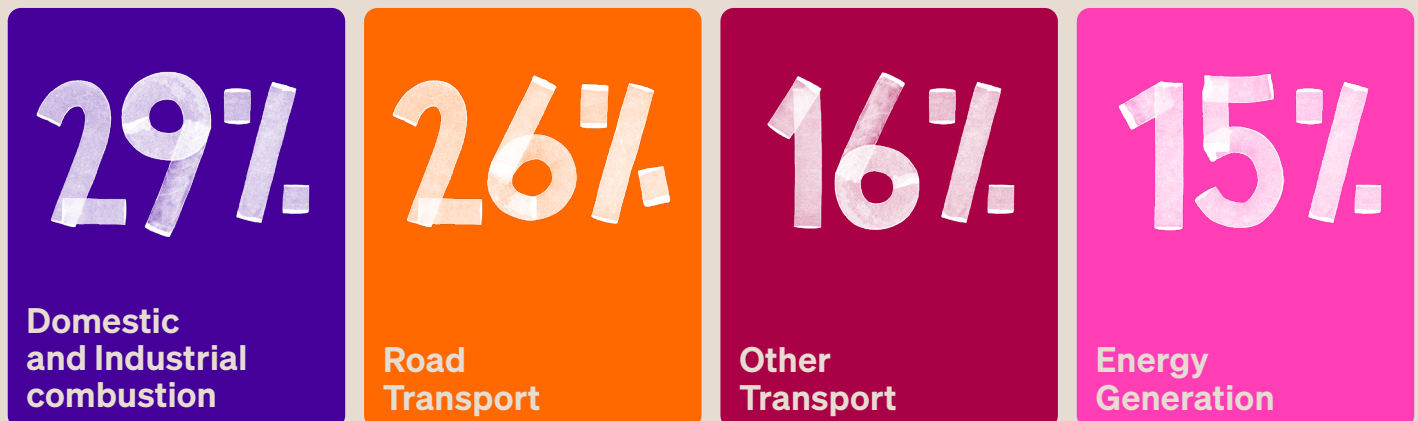
When people are exposed to high pollution levels, for example next to a busy road or during a high pollution episode, they breathe in these toxic materials. Many experience immediate symptoms such as irritated airways, breathlessness, and coughing.

People with a lung condition suffer further with high levels of air pollution. Toxins can exacerbate symptoms, cause an asthma attack or a COPD flare-up.

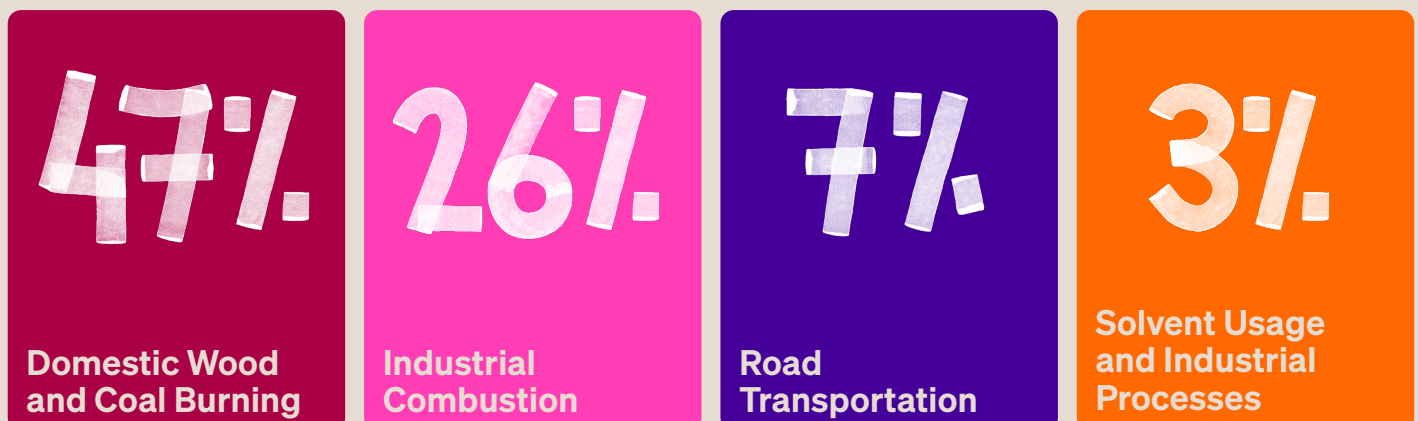
In comparison with other major UK cities, Belfast is the second biggest per head emitter of PM_{2.5} in the UK³. Whilst transport and industrial activity contribute significantly to air pollution, domestic fuel burning produces more emissions than other parts of the UK⁴.

Department of Health project that in the period 2017-2035, the total costs to health and social care are estimated to be in the region of £182m - £635m⁵. Air pollution is draining our resources, straining our health system, cutting short over 500 lives a year here and expected to cause 84,000 new disease cases by 2035⁶. Air pollution is a public health crisis.

Sources of Nitrogen pollution in Northern Ireland (DAERA, 2019)



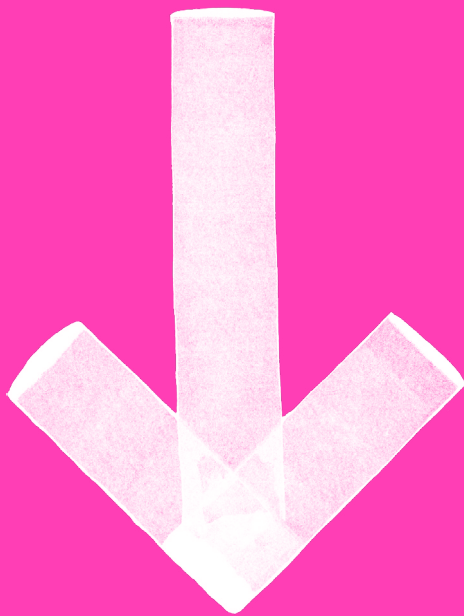
Sources of Particulate Matter (PM_{2.5}) in Northern Ireland (DAERA, 2019)



Asthma + Lung UK Northern Ireland is calling for:

- The development of a **Clean Air Strategy** to provide clear targets and obligations for departments to provide better air quality and lung health for everyone in Northern Ireland.
- A Northern Ireland **Clean Air Act** that would:
 - Enshrine in law the new World Health Organisation air quality guidelines.
 - Mandate the Department of Agriculture, Environment and Rural Affairs to produce a statutory air quality strategy every 10 years.
 - Establish Low Emissions Zones, which cover all aspects of air quality, including Smoke Control and provide a statutory duty on district councils to appropriately monitor, assess and act against air pollution.
 - Ban the sale of most inefficient wood burners and the most polluting domestic fuels such as smoky fuels and wet wood.
 - Introduce a 'right to breathe' whereby local authorities are obliged to inform vulnerable groups when certain levels are breached.
- A **Clean Air Fund** that provides targeted funding for those Local Authorities with consistent exceedances or elevated levels of air pollution.
- Funding to be given to councils to **boost pollution monitoring outside schools and health centres/hospitals**.
- Improved **pollution monitoring, awareness campaigns and public health alerts** so that people living in every part of Northern Ireland are aware of local pollution levels.
- Greater investment in public transport and active travel.
- An ambitious plan to be in place to increase the electric car charging network and review alternative methods of fuel such as hydrogen.
- Implement a ban on idling outside schools to protect Northern Ireland's children while they learn and play.
- **Car-free zones around schools** where significant percentages of journeys are made to school by car.

AS A CANDIDATE



I will support a **Clean Air Strategy** and **Clean Air Bill** to reduce air pollution and improve lung health.

Smoking is the single largest cause of preventable ill health in Northern Ireland, contributing half of the difference in life expectancy between the richest and poorest groups in society⁷ and is directly or indirectly linked to thousands of deaths in Northern Ireland annually.

Asthma + Lung UK Northern Ireland support the Department of Health's goal of a smoke free Northern Ireland. Whilst considerable progress has been made to reduce the number of adults who use tobacco products the COVID-19 pandemic has seen a concerning rise in new smokers aged between 18 to 24. This increase threatens to slow down the reduction of tobacco-linked disease prevalence over the next 25 years unless targeted action is taken to help these new smokers quit soon.

E-cigarettes are thought to be significantly less harmful to health than smoking tobacco⁹. They are an effective smoking cessation tool, so it is essential that people who smoke, as well as health care professionals, have access to evidence-based information about e-cigarettes and how they can be used as a quitting tool. We continue to look at the long-term health effects of e-cigarettes and would recommend that people use them for as short a time as possible to help them give up smoking. However, regulations on how e-cigarettes can be advertised need to be fully enforced, particularly ensuring products cannot appeal to young people.



“

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.

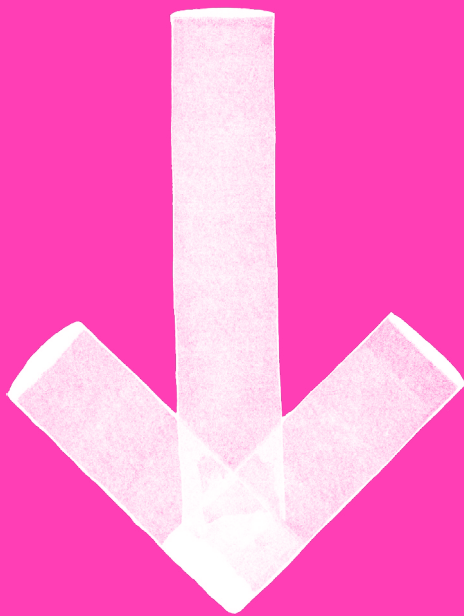
Fidaa and Lily

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Asthma + Lung UK Northern Ireland is calling for:

- A new smoking and tobacco control strategy with a target for a smoke-free region by mid-2030s (5% or less smoking population).
- Greater investment in targeted smoking cessation programmes along with mass-media campaigns to help those who started smoking during the COVID-19 pandemic to stop.
- A ban on smoking around schools, playgrounds and other locations used by children. The minimum legal age to purchase tobacco products in Northern Ireland raised to 21.
- All healthcare professionals to be trained in offering Very Brief Advice on smoking cessation, including all smokers being asked if they want to quit at each GP visit.

AS A CANDIDATE



I will campaign for a **smoke-free**
Northern Ireland by the mid 2030s.

Diagnose It

People with suspected lung conditions wait too long to be diagnosed. There is still a lack of accurate, simple, and reliable diagnostic tests, and too much time between appointments. A delayed or inaccurate diagnosis means people do not get the treatment they need and can end up in hospital unnecessarily.

For people with aggressive lung conditions a delayed diagnosis means they can't access life-prolonging treatments. We are calling for a comprehensive lung health screening programme following the success of bowel and breast cancer screening across the UK.

We urgently need spirometry test rates to improve in Northern Ireland. Spirometry remains a core tool in diagnosing lung conditions early. We know from official statistics that as of June 2022 53% of patients had waited more than 9 weeks for a spirometry test and 27.1% waited more than 26 weeks¹⁰.

Early and accurate diagnosis and continuous emotional support are key to helping people to live well with a lung condition. To ensure the best diagnosis outcomes The Department of Health needs to involve people with conditions like asthma and COPD in the development of new diagnostic tools and in decisions about where diagnostic tests can be accessed.



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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

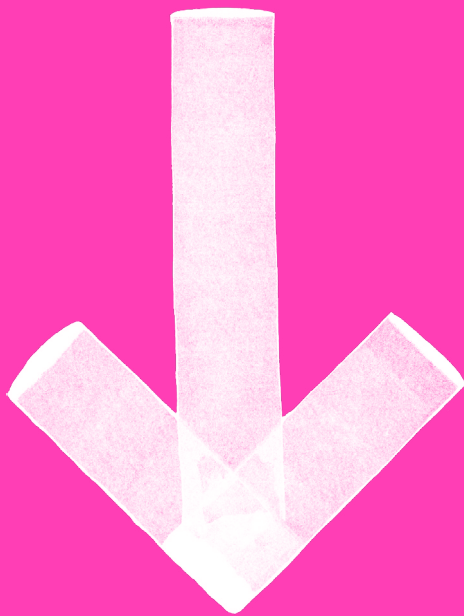
Katy

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Asthma + Lung UK Northern Ireland is calling for:

- A clear patient pathway with services for timely, accurate and complete diagnosis for all people with respiratory symptoms.
- A comprehensive regional lung screening programme, targeting those at high risk of developing lung cancer and other lung conditions.
- A public awareness raising campaign on breathlessness to help healthcare professionals and the public spot the symptoms of the condition and improve earlier diagnosis.
- Targeted case-finding for people who have symptoms suggestive of chronic obstructive pulmonary disease (COPD) in general practice with follow-up care and services.
- Increased funding of Long COVID assessment centres across Northern Ireland

AS A CANDIDATE



I will champion a **regional lung screening programme** to identify undiagnosed lung conditions and get people the treatment they need.

Treat It

In 2015 the Department of Health published the Services Framework for Respiratory Health and Wellbeing, outlining 56 standards to improve respiratory services over a three-year period. The framework was a bold document, but without funding and leadership, services did not improve.

We have identified five lung conditions where improvements in the delivery of care can result in high-impact improvements to people's lung health. These are **asthma; chronic obstructive pulmonary disease (COPD), bronchiectasis, interstitial lung disease (in particular IPF) and Long COVID.**



“

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

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Asthma

Asthma is a condition that affects 1 in 10 people in Northern Ireland of any age¹¹. It is a key factor in repeated respiratory infections in children and causes breathlessness in adults. If undiagnosed or inadequately treated, it can lead in the short-term to asthma attacks and in the long term to irreversible damage to the airways.

Once a diagnosis of asthma has been achieved, information about asthma which is relevant, easy to understand and in an accessible format should be provided. Everyone with asthma should get basic care, which includes an annual review, an inhaler technique check and a written asthma action plan. Unfortunately, we know 53% of people with asthma in Northern Ireland miss the basic level of asthma care¹².

Chronic obstructive pulmonary disease (COPD)

COPD is a chronic progressive disease of the airways associated with high morbidity and mortality. 43,000 people in Northern Ireland are registered as living with COPD, however the total, including those undiagnosed, may be over 55,000¹³. COPD is largely managed in primary care but exacerbations often result in admission to hospital.

Regular inhaler and symptom reviews in primary care, smoking cessation support, self-management initiatives, long-term oxygen therapy and pulmonary rehabilitation programmes can all improve quality of life and reduce hospital admissions. As the condition progresses, accessing palliative care services can improve the quality of life of patients.

The 2021 Annual COPD survey showed that only 13.5% of those diagnosed with COPD in Northern Ireland receive the NICE-recommended five fundamentals of COPD care that they need and only 62% were confident of what to do if their COPD flared up¹⁴.

Bronchiectasis

Bronchiectasis is a condition characterised by chronic sputum production and frequent lung infections, often requiring hospital admission affecting 1 in every 1000 people in Northern Ireland.

Physiotherapy has a significant role in Bronchiectasis management, helping to reduce infections and hospital admissions.

Interstitial Lung Diseases

ILDs comprise over 150 diverse conditions which primarily affect the lung's smallest airways and alveolar air sacs. Whilst the cause of some ILDs is unknown, there is an overlap with occupational and environmental lung conditions such as coal and slate workers' pneumoconiosis, asbestosis, and farmer's lung¹⁵. It is known that some ILDs are caused by cigarette smoke and others may occur as a reaction to medication. Yet others occur in association with conditions such as rheumatoid arthritis.

Idiopathic pulmonary fibrosis (IPF), the most common ILD, has increased in prevalence over the past 20 years¹⁶ affecting over 1,200 people in Northern Ireland, the highest IPF prevalence rate in the UK¹⁷. The median survival for IPF is just three years, a prognosis that is worse than many cancers¹⁸.

Long COVID

Long COVID describes signs and symptoms that last for longer than 4 weeks after getting COVID-19. It is estimated to affect 10% of people who have had COVID and can affect your whole body. Common Long COVID symptoms include extreme tiredness (fatigue), shortness of breath (which is the second most reported symptom), chest pain or tightness and problems with memory and concentration (“brain fog”)¹⁹. Symptoms can change and come and go over time.

It is important that people who present with Long COVID symptoms in primary care are supported in receiving timely referrals to specialist support.

Seasonal Flu and Pneumonia

Too many people die from short-term respiratory illnesses such as flu and pneumonia. Over 25 died in Northern Ireland due to influenza in 2019 and over 620 with pneumonia²⁰. Some cases could be prevented by better uptake of the flu/pneumococcal vaccination, one of the most cost-effective ways of treating someone with a pre-existing lung condition and it saves lives²¹.

The right treatment at the right time

Using medication properly is key to controlling symptoms so people diagnosed with a lung condition can live their lives as they wish. Inhalers are a vital part of treating COPD and asthma but there are significant problems with their use. A systematic review in errors of inhaler use suggests that three-quarters of people make errors using their inhaler devices and that this has not changed in over 40 years²².

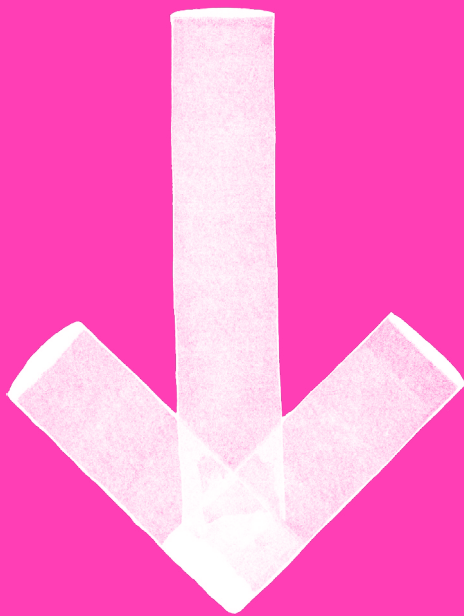
Overuse of reliever inhalers in asthma care has been linked to increased risk of hospital admission and even death²³. It is vital that all relevant healthcare professionals are trained in inhaler use and technique to do this effectively. Biologic treatments can improve symptoms and reduce attacks in people with severe asthma by helping to stop the body processes that cause lung inflammation. NICE and Department of Health have approved some of these drugs for severe asthma treatment but just 26% of people with severe asthma in Northern Ireland are currently eligible for treatment, and of those, two-thirds have not yet received access²⁴. This means many people are still reliant on toxic oral steroids, which can cause diabetes, cataracts, and osteoporosis.

Two anti-fibrotic drugs, pirfenidone and nintedanib, are available for IPF, which can slow down disease progression, helping to improve quality of life. But under NICE guidelines they are only available to patients with lung function between 50% and 80%, meaning patients in the early stages of their condition and more advanced stages are not eligible.

Asthma + Lung UK Northern Ireland is calling for:

- The urgent development of a new **Lung Health Strategy**, to restart, rebuild and transform respiratory services in primary and secondary care.
- A dedicated **Centre of Excellence for Respiratory Medicine** for Northern Ireland bringing together health care professionals, academia, and researchers to treat rarer lung conditions and improve standards
- Investment in an **integrated respiratory service** as recommended in the Bengoa Report, increasing numbers of community-based respiratory specialist nurses and allied healthcare professionals. Additional funding to expand Long COVID care centres and hubs in Northern Ireland to ensure people get the right treatment for their different symptoms.
- A review of GP services contract to reverse the fall in the number of annual reviews and spirometry tests for people with asthma and COPD.
- The development of regional databases of those living ILDs, whose treatment would largely be secondary care focussed.
- The inclusion of a dedicated respiratory chapter in all future Northern Ireland Health Surveys to build a more complete picture of lung conditions.
- All eligible patients to have equitable access to biologic and anti-fibrotic medications.
- The expansion of flu/pneumococcal vaccination uptake through out-of-hours delivery/delivery in non-healthcare venues (leisure centres, sports clubs, supermarkets, shopping centres, etc.).

AS A CANDIDATE



I will call for a **Lung Health Strategy** that will ensure the best care for all living with a lung condition.

Live Better With It

We want people with lung conditions to live full and active lives and continue to do the things that are important to them and to their families. Unfortunately, currently our healthcare system is set up to help when things go wrong, rather than to help people stay well.

At an estimated cost of £250million per year²⁵ to the health budget just for treating lung conditions, there are significant sums to be saved by being proactive with healthcare. Whilst we look for cures for lung conditions, the evidence supporting self-management interventions is strong and they should be regarded as exemplar conditions to trial connected technologies to help people better self-manage their condition.

Education is key to improving understanding of lung conditions, helping deliver early diagnosis and good self-management. Having confident and informed people living with lung conditions at the centre of the decision-making allows them to take ownership of their conditions, leading to reduced unplanned visits to GPs, visits to outpatient departments, hospital admissions and length of stays.

In Northern Ireland 53% of people are not receiving the basic care they need to manage their asthma well, contributing to over 2,000 emergency hospital admissions annually and over 30 asthma-related deaths²⁶. People who can self-manage and have an asthma action plan are better equipped to manage their symptoms and less likely to be admitted to hospital for their asthma²⁷.

Thousands of people across Northern Ireland have been affected by COVID-19 and a number of these will be impacted by Long COVID, requiring ongoing support. Northern Ireland needs long-term funding and staffing-level commitments for Long-COVID assessment centres, providing the respiratory, rehabilitation, physiotherapy, and emotional support for those living with this group of conditions.

The most cost-effective treatment for lung conditions, such as COPD, is pulmonary rehabilitation (PR), a programme of exercise and education for people with a long-term lung condition. Sadly, even before the pandemic too few patients had access to PR and often had to wait until their condition worsened before they could benefit. PR had to stop at the start of the pandemic and has been slow to restart.

We are calling for services like PR to be delivered digitally more often, especially during flu season, when at-risk groups choose to socialise less and minimise contact. Providing funding for digital innovation can help those who self-isolate during these periods to stay active and well.

The current Cost of Living crisis in Northern Ireland will disproportionately affect those who are living with lung conditions. More needs to be done to support households in NI. There is no price cap in place which means the cost of electricity, home heating oil and gas is subject to volatile price hikes. According to the Department of Finance, previously announced funding through Barnett Consequential contributions are now under threat, due to a lack of a functioning Stormont Assembly. NI's lowest income households have on average £29 per week disposable income. We call on the Political Party's in Northern Ireland to get back around the table and form a functioning Executive to allow local decision making and interventions to be reintroduced.

Those in need of rehabilitation should be able to access rehabilitation services where and when they need them. The Department of Health here needs to develop new strategy for rehabilitation care in Northern Ireland. Rehabilitation is essential in enabling people to live their lives to the full. Rehabilitation must be recognised as an unmissable part of rebuilding services and of Covid-19 recovery.

In addition, community rehabilitation reduces demand on the most expensive parts of the health service. Most emergency admissions are of people with long-term health conditions. Making community rehabilitation available to people before they are in crisis cuts demands on emergency care.

We are therefore calling on leaders and policy makers across government to take urgent action to ensure that community rehabilitation is given the support needed. A comprehensive strategic approach to meeting rehabilitation needs is required. We are asking political representatives to commit to the right to rehabilitation as a fundamental element of our health and care system and support it to develop so that everyone can access high quality rehabilitation.

“ 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. ”

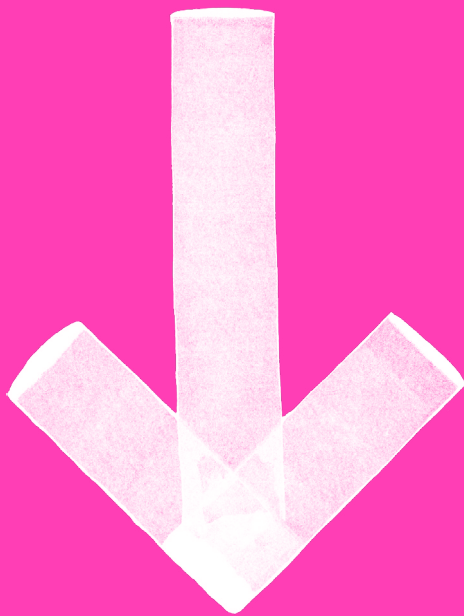
Jo



Asthma + Lung UK Northern Ireland is calling for:

- Department of Health to establish the 'Right to Rehab' so everyone living with a lung condition can access appropriate rehabilitation depending on their needs
- The elimination of referral and criteria-based routes to rehabilitation moving towards "request for assistance" models that ensure no one is excluded from accessing support.
- Every person living with asthma to have a written asthma action plan, annual review, and inhaler technique check.
- Five Fundamentals of COPD Care, as recommended by NICE, to be delivered to every person in Northern Ireland living with COPD.
- Digital self-management tools to be rolled out across Northern Ireland.
- Re-establishment of a functioning Executive and Assembly to help mitigate the impact of the cost of living crisis
- People living with terminal lung conditions to get the palliative care support they need.

AS A CANDIDATE



I will support the **Right to Rehab**, so that everyone with a lung condition gets the rehabilitation they need.

Stand up for Northern Ireland's lungs

By Supporting These Pledges:

1

Support a **Clean Air Strategy** and **Clean Air Bill** to reduce air pollution and improve lung health.

2

Campaign for a **smoke-free Northern Ireland** by the mid-2030s.

3

Champion a **regional lung screening programme** to identify undiagnosed lung conditions and get people the treatment they need.

4

Call for a **Lung Health Strategy** that will ensure the best care for all living with a lung condition.

5

Support the **Right to Rehab**, so that everyone with a lung condition gets the rehabilitation they need.

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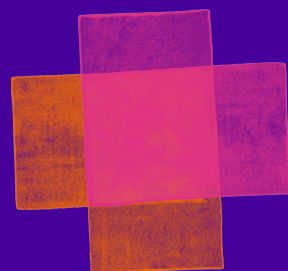
FIGHTING FOR BREATH

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LUNG UK**
NORTHERN IRELAND

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