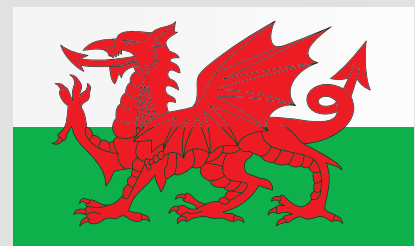




# Standing up for Welsh lungs

Protecting and improving lung health  
beyond COVID-19



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# Welcome



**I am very proud to be introducing our charity manifesto for the Welsh General Election, to protect and improve lung health beyond COVID-19. 2020 and 2021 will be years that we will never forget and have been particularly tough for people with lung conditions, shielding and trying to avoid the most threatening respiratory virus in 100 years.**

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

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

Through several surveys, they told us of the pandemic's impact on their everyday lives, wellbeing and mental health. Their contributions helped to fuel our passion for delivering change to stand up for lung health in Wales.

Many more difficult challenges lay ahead, and this document sets out our goals over the next five years.

Looking beyond COVID-19, we seek to build on our last five years of 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 Wales is calling for new legislation and new regulations to be in place to protect our lungs so that everyone has the right to breathe healthy, clean air.

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 uninvestigated, no wheeze should be ignored, and no one should be misdiagnosed.

When we receive a diagnosis, access to the best treatment should be readily available, whether that is biological drugs for asthma or pulmonary rehabilitation for chronic conditions like COPD. We all have the right to the best care, so we call for support to ensure that these services are available across Wales.

With our calls, we need a new plan. A plan that builds on lessons that we have learned over the last few years and considers recent events. Wales needs a new Respiratory Plan to improve overall lung health and care.

We are the only charity looking after your lungs in Wales. Right now, it might be hard to look beyond COVID-19, but we are focused on protecting health and on ensuring that we all receive the best care that we deserve.

We hope that political parties and candidates can support our manifesto asks and we look forward to working with everyone elected to the next Senedd.

A handwritten signature in black ink, appearing to read 'Sarah Woolnough'.

**Sarah Woolnough**  
Chief Executive

## Who are we?

At some point in our lives, one in five of us will have a lung disease. Across the UK, millions more are at risk. We are the only UK charity looking after the lungs of Wales, and in this manifesto we aim to bring the needs of people with lung conditions to the forefront of policy-making.

As we've seen with the COVID-19 crisis, acute respiratory symptoms can bring countries to a standstill and cause thousands of deaths. The recent pandemic has highlighted the need for clear and robust guidelines and support for people with a lung condition, but has also shone a spotlight on the patchy provision of support and treatment for everyone who has a respiratory disease. This manifesto will highlight 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 diseases.

With support, we provide for people who struggle to breathe the skills, knowledge and confidence to take control of their lives.

Together, we're campaigning for clean air, better services and investment in research and innovation.

One day, everyone will breathe clean air with healthy lungs. Only through your action and commitment to change can we make that happen.

## What are respiratory conditions?

Respiratory conditions are diseases of the airways and other structures of the lungs and are a significant contributor to ill-health, disability and premature mortality. Some of the most common conditions are asthma; chronic obstructive pulmonary disease (COPD); bronchiectasis; interstitial lung disease (in particular IPF); sleep apnoea and recently COVID-19.

Although most long-term respiratory conditions are not curable, various forms of pharmacological and non-pharmacological treatment have been shown to help control symptoms, increase quality of life and reduce premature mortality.

The World Health Organisation has identified chronic respiratory disease as one of the four leading non-communicable diseases worldwide, along with cardiovascular disease, cancer and diabetes.

## Impact of respiratory conditions

Many people struggle with chronic respiratory conditions. These conditions have a significant impact on their lives and the lives of their families. Some experience loss of time from work or school, and difficulty participating in social activities. Anxiety and depression are common, and are associated with worse quality of life, increased medical symptom reporting, more frequent worsening of the condition leading to hospitalisations, staying in hospital longer, and increased mortality.

We know that respiratory conditions affect people and their families in different ways. We know that for some people, a respiratory condition is a life-changing diagnosis, affecting their ability to live independently, achieve personal ambitions, and sustain their identity or life roles, work or drive. Any of these factors can cause anxiety, stress and depression for the person and their family/carers, and increase their sense of isolation.



# Prevent it

Sadly, there are currently no cures for long-term respiratory illnesses; instead, patients are prescribed treatment and medication to manage their symptoms or slow down the progression of their lung disease, which makes prevention all the more important.

When people think about how best to prevent lung disease, stopping smoking is often seen as the number one measure people can take. However, reducing smoking alone will not prevent all lung disease. The homes we live in, the air we breathe, the jobs we do and our access to exercise all have an essential part to play in preventing poor lung health.

## Outdoor air pollution kills: Welsh lungs shouldn't pay

There is no safe level of air pollution. An air pollutant is any substance in the air that could harm people. Particulate matter, known as PM, and nitrogen dioxide are particularly damaging.

When people are exposed to high pollution levels, for example on a busy road or during a high pollution episode, they breathe in these toxic materials to their lungs. Many people initially experience immediate symptoms such as irritated airways, feeling out of breath and coughing.

People with a lung condition suffer further with high levels of air pollution. Such toxins can exacerbate symptoms, such as an asthma attack or a COPD flare-up. People with asthma may notice that they need to use their reliever inhaler more than usual when pollution is high.

Poor air quality has been linked to several conditions, with growing emerging evidence that highlights the high levels of air pollution impacting every level of society by increasing the chances of lung cancer, childhood asthma, miscarriage, premature birth/low birth weight, heart disease, dementia, mental health issues, obesity and many other conditions.

Air pollution is the most significant environmental threat to public health, second only to smoking. At a cost of £1bn per year to the NHS, air pollution is draining our resources, straining our health system and cutting short over 2000 lives a year in Wales. It is a public health crisis.

## Deliver a Clean Air Act within the first 100 days

Asthma UK and British Lung Foundation Wales are calling for new WHO guidelines to be enshrined in the new legislation as soon as possible. Kings College London found that cutting air pollution by even one-fifth in the UK's most polluted cities would reduce the number of lung cancer cases by 5–7.6%.

### Asthma UK and British Lung Foundation Wales are calling for a new Clean Air Act to:

- Enshrine in law WHO air quality guidelines.
- Mandate the Welsh Government to produce a statutory air-quality strategy every five years.
- Provide a statutory duty on local authorities to appropriately monitor and assess air pollution, and take action against it.
- Introduce a “right to breathe” whereby local authorities are obliged to inform vulnerable groups when certain levels breach recommended guidance.

## Stand up for Welsh lungs by supporting this pledge:

“

I, \_\_\_\_\_, as a candidate for the Senedd for \_\_\_\_\_ will work to deliver a Clean Air Act within 100 days of being elected.

”

## Stop pollution at its source

Tackling air pollution isn't limited to reducing vehicle emissions.

### Top sources of Nitrogen dioxide (NO<sub>2</sub>)



### Top sources of Particulate matter (PM<sub>10</sub>, PM<sub>2.5</sub>)



## Asthma UK and British Lung Foundation Wales are calling for:

- Wales to be the first country in the UK to promote a ban on new sales of diesel cars by at least 2025 and subject the most polluting vehicles in Wales to an emissions charge in all major towns and cities.
- More significant investment in public transport and active travel, including delivering the South Wales Metro project and expanding the cycling network.
- An ambitious plan to be in place to increase the electric car charging network and review alternative methods of fuel such as hydrogen. For Wales to be diesel/petrol free ready by 2030 to support the UK Government's aim for all new cars and vans to be fully zero emission free by 2035.
- A comprehensive scrappage scheme to help people replace polluting diesel and petrol cars with cleaner methods of transport.
- Action to tackle vehicle idling.
- Exclusion zones to be introduced near schools, and major hospitals and health care providers.
- A review of smoke control zones to ban both the sale of inefficient wood burners and the most polluting domestic fuels.
- A Public Health Awareness campaign to help the public make positive choices not only for their health but for the health of others, our planet and future generations.

## Supporting Public Health Wales' vision of a nicotine-free Wales

The single largest cause of preventable ill health and a significant cause of health inequality in Wales is smoking tobacco products. Tobacco dependency is directly or indirectly linked to millions of deaths.

Wales is on course to meet the Welsh Government's target to reduce adult smoking rates to 16% by 2020, but there are no future targets to reduce the numbers further.

E-cigarettes can be a helpful smoking cessation tool, so it's 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-cigs 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.



## Asthma UK and British Lung Foundation Wales are calling for:

- A new smoking and tobacco strategy with a target for a smoke-free nation by 2030 (5% or less smoking population).
- A ban on public smoking in high streets across Wales.
- The minimum legal age to purchase tobacco products in Wales to be raised to 21.
- A review into the compliance and enforcement of current tobacco advertising and prohibiting laws, to seek tougher financial penalties for companies in breach of advertising laws around tobacco products. This is to reduce the impact of selling tobacco products in our most deprived communities.
- A parliamentary inquiry into smoking cessation and tobacco control in Wales.
- Continued support of “Help me Quit” services provided by NHS Wales and funding for promotion of the services and campaigns for quitting.
- Public Health Wales to develop independent guidance in the form of leaflets for smokers who choose to vape as a smoking alternative; stressing it is a short-term use to quit, highlighting “help me quit services” and requiring e-cigarette retailers to display this guidance at all their stores across Wales and online.
- More research into the impact of long-term use of e-cigarettes on the lungs of with people with lung conditions, particularly asthma.





# Diagnose it

People with suspected lung disease have to wait too long to be diagnosed. There is still a lack of accurate, reliable and straightforward diagnostic tests, and too much time passes between appointments. A delayed or inaccurate diagnosis means people don't get the treatment they need and can end up in hospital unnecessarily. For people with aggressive lung disease, a delayed diagnosis means they can't make the most of the time they have left.

The benefits of prompt diagnosis of lung disease are significant, particularly in conditions like asthma, COPD, sleep-disordered breathing, occupational lung diseases and a wide range of interstitial lung diseases. There is a need for greater public awareness of the symptoms of such lung diseases, and of the risks posed by smoking and by any delay in diagnosing smoking-related lung conditions such as lung cancer and COPD.

People with symptoms, abnormal tests or screening results should have these addressed locally and where appropriate, should be referred for further assessment and management when lung disease is suspected or confirmed. Early diagnosis and continuous emotional support are crucial to helping people to live well with lung disease.

To provide the best diagnosis for Wales, we are calling for the Welsh Government to involve people with conditions like asthma and COPD in the development of new diagnostic tools so that future apparatus can be developed for successful real-world adoption.

Expertise should also be localised to diagnostic hubs that share tools, expertise and data to speed up access to and the accuracy of diagnostic tests. Hubs should adopt and test the latest technologies that can rapidly advance our understanding of a person's condition.

## Asthma UK and British Lung Foundation Wales are calling for:

- A nationwide programme of lung screening, including spirometry, to the over-35 age group who smoke, delivered by accredited staff within primary and secondary care.
- A Public Health Wales education campaign on what lung conditions are and when to be concerned about a long-term cough or symptoms that are not going away.
- Increased levels of support for people going through trial treatments for their conditions, especially for parents of children with asthma.

## Stand up for Welsh lungs by supporting this pledge:

“ I, \_\_\_\_\_, as a candidate for the Senedd for \_\_\_\_\_ will champion for a nationwide programme for lung screening to be delivered across Wales. ”





# Treat it

One in five people in Wales live with a lung condition, varying from common conditions such as asthma, COPD and sleep apnoea to rarer conditions such as sarcoidosis. Following a diagnosis, every condition needs prompt, effective treatment often requiring a multi-disciplinary approach.

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

## Asthma

Asthma is a condition that can affect 1 in 10 people in Wales of any age. It is an essential 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 potentially life-threatening 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. Those diagnosed should all be provided with a personalised asthma action plan, including relevant contacts and what to do if their asthma becomes uncontrolled, including training in inhaler technique to support effective self-management strategies for the condition.

## Chronic obstructive pulmonary disease (COPD)

COPD is a chronic progressive disease of the airways associated with high morbidity and mortality. It is primarily managed in primary care, but exacerbations (or sudden worsening) of symptoms often result in acute admission to hospital. Secondary care is involved with providing more complex interventions such as domiciliary ventilation and assessment for a referral to surgery increasingly. Regular inhaler and symptom reviews in primary care, self-management initiatives, long-term oxygen therapy and pulmonary rehabilitation programmes can all improve quality of life and reduce hospital admissions. As the disease progresses, accessing palliative care services can improve the quality of life of patients with advanced disease.

## Bronchiectasis

Bronchiectasis is a condition characterised by chronic sputum production and frequent lung infections, often requiring hospital admission. People with a suspected diagnosis of bronchiectasis should have the diagnosis confirmed by chest computerised tomography (CT). Physiotherapy has a significant role in its management, helping to reduce infections and hospital admissions.

## Interstitial lung diseases (ILDs)

ILDs comprise a large number (over 150) of diverse conditions which primarily affect the lung's smallest airways and alveolar air sacs. While the cause of some ILDs is unknown, there is an overlap with occupational and environmental lung diseases such as coal and slate workers' pneumoconiosis, asbestosis and farmer's lung. 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 diseases such as rheumatoid arthritis.

Idiopathic pulmonary fibrosis (IPF), the commonest ILD, has shown a significantly increased prevalence over the past 20 years, with Wales having one of the highest incidence rates of IPF in the UK. The median survival for IPF is just three years – a prognosis that is worse than many cancers. Lung transplantation is sometimes the only treatment option to improve survival in some forms of ILD.

## Sleep apnoea

Sleep apnoea is a fairly common condition affecting around 4–6% of middle-aged adults. If left untreated, it causes daytime sleepiness, impaired vigilance and cognitive functioning, reduced quality of life and is associated with an increased risk of road traffic accidents. The latter risk is particularly significant for professional drivers of HGVs and public transport vehicles. Early diagnosis and a prudent approach to treatment should form the basis for sleep apnoea interventions, ranging from lifestyle advice to continuous positive airway pressure (CPAP) therapy and home ventilation for moderate to severe cases.

## Vaccinations for our lungs

Far too many people are dying from short-term respiratory illnesses such as flu and pneumonia, which in some cases could have been prevented by better uptake of the flu/pneumococcal vaccination. It is one of the most cost-effective ways of treating someone with a respiratory condition, and it saves lives. In 2018/19, only 47.5% of people with chronic respiratory disease had the flu vaccination, with younger people with asthma being far less likely to have the vaccination than older people with COPD. We believe that innovative solutions need to be found to help more people to access the vaccine.

### Asthma UK and British Lung Foundation Wales are calling for:

- The expansion of flu/pneumococcal vaccination uptake through out-of-hours delivery/delivery in non-healthcare contexts (supermarkets, shopping centres, etc.).
- Better data to be published by Public Health Wales, showing the uptake of the flu/pneumococcal vaccination for each different lung disease.
- The free flu/pneumococcal vaccination to be available to all people with asthma regardless of their treatment plan.
- More investment in research into respiratory viruses and how we develop new treatments or prevention strategies.

## The right medication at the right time

Using medication properly is key to controlling symptoms, so people diagnosed with lung disease 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 recent systematic review suggests that three-quarters of people make errors using their inhaler devices and that this has not changed over 40 years. Adherence to inhaled therapies is also weak.

Over-reliance on short-acting reliever inhalers is responsible for a high proportion of avoidable asthma deaths. Likely, fewer than half of people with COPD using inhaler therapy and nearly 1 in 5 with asthma received an inhaler technique check in the last 12 months. All relevant healthcare professionals must be trained and upskilled in inhaler use and technique to do this effectively.

In addition, connected devices for asthma have been developed – particularly smart inhalers which can objectively track, monitor and prompt medication use. Smart inhalers could revolutionise care by managing long-term conditions at scale; enhancing supported self-management; supporting risk stratification; personalising care; reducing avoidable emergency admissions and improving patients' safety and quality of life.

Biologic treatments for severe asthma can be used as an alternative to oral steroids. They work by blocking the activity of some of the immune system chemicals that trigger inflammation in the airways. NICE and AWMSG have approved some of these drugs for severe asthma treatment, but referral rates for these new treatments are low.

Two anti-fibrotic drugs 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 a lung function of between 50% and 80%, which means that patients in the early stages of the disease and more advanced stages are not eligible.

Wales could be the lead in developing better treatments for those with long-term lung conditions. Through collaboration with scientists across the UK to evidence the clinical utility, clinical validity, cost-effectiveness and care-pathway benefits of innovative diagnostic devices, the Welsh Government can help to make sure that if you have a lung condition in Wales, you are not left behind the curve.

## Asthma UK and British Lung Foundation Wales are calling for:

- A dedicated respiratory funding stream for scientific research into lung conditions via Health and Care Research Wales.
- A new Respiratory Health Delivery Plan for Wales to succeed in the 2018–20 plan.
- A review of the GP contract to reverse the fall in the number of annual reviews and spirometry for people with asthma and COPD since the ending of QOF.
- Investment in community-based respiratory specialist nurses and allied healthcare professionals to support people in the community and prevent readmission to hospital.
- Health Boards to improve asthma care that is supported by digital innovation, ensuring data sharing across the NHS to improve asthma care, enabled by the latest digital innovations, including smart inhalers.
- Investment in a tertiary service to support people living with severe asthma based on the hub and spoke model available for IPF. Severe asthma currently affects nearly 3.6% of people with asthma (roughly 11,304 adults in Wales), and we want everyone eligible to have access to biologic drugs through reduced variation in severe asthma care for equitable access to this life-changing medication.

## Stand up for Welsh lungs by supporting this pledge:

“ I, \_\_\_\_\_, as a candidate for the Senedd  
for \_\_\_\_\_ will call on the Welsh  
Government to deliver a new Respiratory Health Delivery plan. ”



# Live better with it

We want people with lung disease to live full and active lives and continue to do the things that are important to them and their families. Unfortunately, at the moment the NHS is set up to help when things go wrong, rather than to help people stay well. While we look for a cure to lung disease in Wales, the evidence supporting self-management interventions for asthma is robust. It should be seen as an exemplar condition to trial connected technologies, such as smart inhalers to help people better self-manage their condition.

Education is key to improving understanding of lung diseases, helping achieve earlier diagnosis and improved self-management. Having confident and informed people with lung conditions at the centre of the decision-making processes will allow them to take ownership of their conditions, leading to fewer unplanned primary care consultations, reductions in visits to outpatient departments, reduced hospital admissions and reduced length of stays in hospital.



People with chronic lung disease benefit significantly from a multi-disciplinary approach to care and gain the most benefit from this care when it is delivered in the community, closer to home. This ensures that individuals have two critical elements of care: physical and psychological support. These are important, when living with such chronic disease, to help the individual cope with distressing symptoms such as breathlessness, as well as ensuring that respiratory infections are treated earlier to prevent worsening structural damage to the lungs.

In Wales, 61% of people are not receiving the basic care they need to manage their asthma well, contributing to over 3,319 emergency hospital admissions in Wales a year and around 74 asthma-related deaths. We have the lowest uptake of asthma action plans in the UK, and this cost-effective intervention has been shown to improve quality of life and keep people well.

The most cost-effective treatment for lung disease such as COPD is access to pulmonary rehabilitation (PR) which is a programme of exercise and education for people with a long-term lung condition. Sadly, too few patients have easy access to PR and often must wait until their condition worsens before they can benefit. We believe that more must be done to improve access to PR.

Following on from pulmonary rehabilitation, the National Exercise Referral Scheme (NERS) operates in every part of Wales to allow people to remain active and stay healthy in a local leisure centre. The scheme supports people with a wide variety of health conditions. Still, there has been an ongoing Welsh Government review, and funding has not increased for several years, restricting the number of people who can access these services.

Another way of staying active is through Singing for Lung Health, a programme that the British Lung Foundation has been rolling out across Wales. Evidence shows that singing can reduce shortness of breath, improve symptom management, improve quality of life and reduce loneliness and isolation. While Singing for Lung Health groups exist across Wales, only Betsi Cadwaladr UHB funds the singing instructors.

Currently we have a reactive approach to self-management, with many people with asthma only interacting with healthcare services and engaging with their asthma during and soon after an attack. The NHS needs to take a more proactive approach where patient data is used to monitor and predict when someone is at risk of



an asthma attack or is required to make changes to their asthma management. To make this a reality, improved data sharing between healthcare services and the incorporation of technologies into pathways is vital.

COVID-19 brought its own challenges and problems for the nation to address. What the condition highlighted was lack of support there was for those with COVID-19 and those self-isolating in the vulnerable shielded groups. The use of digital self-management helped to provide assistance during this critical period. We are calling for services like NERS and PR to be delivered digitally more often, especially during the peak of the flu season, where at-risk groups choose to socialise less and minimise contact. Providing funding for such digital innovation can help those who self-isolate during such periods to continue to stay active and well.

Finally, as the long-term effects of COVID-19 are still unknown, we are calling for continued monitoring and support for those who have experienced the virus. Through continued research into the symptoms and the effects of COVID-19 (like our “Post COVID Hub”) we can deliver a commitment to protect groups now vulnerable from the virus.

## Asthma UK and British Lung Foundation Wales are calling for:

- Every person living with asthma to have a personalised asthma action plan.
- Every person living with COPD to be taught how to manage their condition when they are newly diagnosed and issued a self-management pack.
- Regional education days to be provided for people with less prevalent conditions such as severe asthma, bronchiectasis and IPF, to help manage their conditions.
- Pulmonary rehabilitation programmes to be expanded, so they are not only available to people with moderate to severe COPD.
- NERS to be expanded so that it can support more people living with chronic lung conditions to stay active and keep well.
- Singing for Lung Health to be funded in every health board.
- Better data sharing between primary and secondary care in Wales.
- Digital self-management tools to be rolled out across Wales.

## Stand up for Welsh lungs by supporting this pledge:

“ I, \_\_\_\_\_, as a candidate for the Senedd for \_\_\_\_\_ will fight for access to pulmonary rehabilitation to be expanded to all people with mild COPD, Bronchiectasis and IPF. ”

# Stand up for Welsh lungs by supporting these pledges



Deliver a Clean Air Act within 100 days of being elected.



Champion for a nationwide programme for lung screening to be delivered across Wales.



Call on the Welsh Government to deliver a new Respiratory Health Delivery plan.



Fight for access to pulmonary rehabilitation to be expanded to all people with mild COPD, Bronchiectasis and IPF.



**We're working to change the lives of everyone affected by asthma, bronchiectasis, COPD, ILD, mesothelioma, pulmonary fibrosis and all other lung conditions.**

**Our support helps people who struggle to breathe manage their lung condition and live well.**

**Our world-leading research finds new ways to prevent, treat and cure lung disease.**


**Our campaigns help make vital, lasting change.**

## **Asthma UK and British Lung Foundation Wales**

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