

# LET ME BREATHE

PRE-BUDGET SUBMISSION

2019

#MyAsthmaStory

asthma.ie

### WHAT IS ASTHMA?

Asthma is an inflammatory disease of varying severity that affects the airways – the small tubes that carry the air in and out of the lungs. People with asthma have airways that are extra sensitive to substances (or triggers), which irritate them.

When the airways come into contact with an asthma trigger, the muscles around the walls of the airways tighten so that the airways become narrower. The lining of the airways swell and produce sticky mucus. As the airways narrow, it becomes difficult for the air to move in and out. That is why people with asthma wheeze and find breathing difficult.

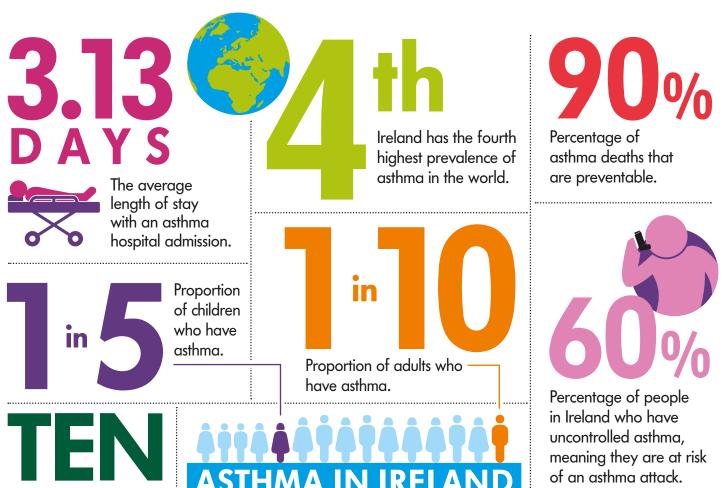
Common triggers include cold and flu, cigarette smoke, exercise and allergic responses to pollen, furry or feathery animals or house-dust mites.

Whilst there is no cure, asthma can be controlled by avoiding triggers and by the use of 'reliever' and 'controller' medication.

When a person's asthma is out of control, they are in danger of having an asthma attack. An asthma attack is a serious medical emergency and can be fatal.

#### WHAT DO PEOPLE WITH ASTHMA NEED:

- 1. Substantially Reduce the Cost of Asthma Medication
- 2. A Free Annual Asthma Review with their GP
- 3. Specialised Hospital Doctors, Nurses and Diagnostics For Children
- 4. End the Post-Code Lottery for People with Severe Asthma
- 5. Re-visit the National Clinical Programme for Asthma (NCPA)
- 6. An Inhaler Can Save a Life
- 7. Eradicate Outdoor Air Pollution
- 8. Protect Indoor Air Quality
- 9. Reduce The Tobacco Threat
- 10. Fund The Asthma Society's Essential Programmes



Average number of days of work adults miss each year due to asthma.

Average number of days

of school children miss

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each year due to asthma. The number of people in Ireland who have asthma, including one in five children.



people who dies every week as a result of their asthma.



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How often someone in Ireland visits an Emergency Department with asthma.



The number of asthma admissions to hospital every year.



### ANN

Ann is from Cork, lives with her husband and is 67 years old. She had childhood asthma and, in the last year, she has been experiencing a lot of shortness of breath. She has always had regular chest infections every Winter but this year she has taken four rounds of antibiotics and she has also been taking oral steroids when these chest infections were hard to shift.

She is currently being treated by her GP but it's not clear to Ann if the diagnosis is for asthma or for COPD as both of these conditions have been mentioned to her. She stopped smoking ten years ago.

### TOM

Tom is 40 years old and lives in Dublin. Tom is Aoife's Dad – she is 4 years old. Aoife has newly been diagnosed with asthma by her GP. Tom had asthma himself as a child but he is unsure if treatment has changed since then.

Tom's really worried about Aoife, about what the diagnosis means for her. He wants to be able to take part in activities, to be able to go to school, to feel well. He's worried about her being at the crèche, at his ex-partner's house, at his parents' house, at parties, in case anything goes wrong.

She had an asthma attack last month and he was there and got it under control. It scared the life out of him. The worry is affecting him at work.

His ex-partner doesn't want Aoife to be dependent on medication so she doesn't see the condition in the same way Tom does and She's not sure about taking all the medication she's been prescribed. It seems like a lot and maybe it's not all necessary, she's always had chest trouble. There are two things she's really worried about in the future: lung cancer and needing to be on oxygen.

#### WHAT DOES ANN NEED?

- To reduce shortness of breath and infections
- A definite diagnosis
- Access to spirometry and chest x-ray
- A referral to respiratory consultant
- Support and sensitivity

Aoife doesn't take the medication consistently across the week as a result.

He has been reading up about asthma to better understand it but he wants support and guidance.

#### WHAT DOES TOM NEED?

- An asthma management plan for Aoife that everyone can follow
- Access to the Asthma Adviceline and website
- Materials on asthma that Aoife can understand
- An early childhood programme from ASI to help with both parents, the crèche, and other relevant people – including asthma attack information
- Reassurance so he doesn't pass on any possible anxiety to Aoife



### CLAIRE

Claire is from Waterford but now lives in Dublin with her partner David and their two children, Grace (who is six) and Daniel (who is three). She has been told by her GP that it looks like Grace has asthma but that they won't be able to get a proper diagnosis for a while.

Grace wheezes in Winter months, particularly on cold mornings and coughs persistently by night. She get sick easily and has often been sick upon her return to crèche or school in September/October. She has had two asthma attacks in the last year. One was in school and one was while she was at her grandparents house in Waterford. The asthma attacks terrified Grace and her parents. Grace is a real worrier. She worries about the asthma and also about making a fuss at school and is anxious about taking her inhaler in front of the other kids.

Daniel is three and is a happy-go-lucky kid. He has been having recurrent chest infections since he was a year old and had to be treated in hospital when one of these became serious quite quickly. He seems to have a runny nose all the time.

Claire is really worried about how to manage their money with the costs of having two children with asthma. Now that Grace is six, they no longer get free GP visits for her. The monthly medical costs really take a toll for them as a family. Even with the Drugs Payment Scheme, the cost is so high that everyone feels the burden of getting sick. The only relief is that Daniel is still able to see his GP with the under-6 programme. Claire and David also find it confusing about why neither of the children are actually diagnosed with asthma. It makes it hard for them to tell the school, family and friends how to manage with Grace and Daniel's medication. Claire's parents smoke and she finds it hard to talk to them about not smoking around the children. Claire worries every single day during Winter about Grace having another asthma attack at school.

#### WHAT DOES CLAIRE NEED?

- Help with the cost of medication and devices
- Help to speak to her family/ the school
- Take-up of ASI Schools/ Early Childhood Programme
- Information about what to do in the event of an asthma attack
- Videos designed to help her and/or to engage her children
- Information about diagnosis process
- Reassurance

LET ME BREATHE - ASTHMA SOCIETY OF IRELAND PRE-BUDGET SUBMISSION 2019



### SOPHIE

Sophie is 15 years old, lives in Kerry and is studying for her Junior Cert. She's worried about missing school time.

Sophie was diagnosed with asthma as a child. She has missed huge amounts of time at school, and finds Autumn and Winter really challenging with the temperatures and the cold and the flu season. For her, asthma is an absolute constant in her life. She has been hospitalised three times in the last year, which would make her a candidate for Xolair but it's not available to her in Kerry.

Sophie's asthma is really hard to manage. Her parents give her physio to help her clear her airways. She takes her preventer and reliever medication religiously. She's very regularly prescribed weeks of steroids, which she hates, but she takes them as they're the only thing that can help.

She knows her asthma triggers include dogs, dust and cigarettes and she's careful about those. They had to give her childhood pet away and she won't stay over at friends' houses if they have dogs. She knows she can't manage it. Her parents removed all the carpets in the house after one particularly awful Winter for Sophie.

She's never really been able to exercise or to do PE. She's always had a note from her doctor. She walks around the perimeter of the PE Hall while other people participate.

Her friends are very understanding of her asthma and the limitations it puts on her. She's missed out of discos and school trips because she was in hospital or in bed sick.

#### WHAT DOES SOPHIE NEED?

- Access to Xolair or other severe asthma treatment suitable for her
- To have a normal life
- To be able to sit her exams
- Better specialist services in her area
- Financial support for her family with GP visits, hospital stays and the cost of medication
- Peer support
- Teacher involvement/ awareness
- Help with exercise so that she can enjoy being active
- In the long term, support for Sophie's planned transition to college and living away from home



### **KEVIN**

Kevin is from Mayo and is 22 years old. He lives in Dublin, where he is studying for a degree in business.

He was diagnosed with asthma as a child. Kevin hasn't been paying much attention to his asthma. He's always missed chunks of school or part-time jobs with chest infections and regular asthma attacks just go along with it, as far as he's concerned.

He doesn't take his preventative inhalers as he doesn't think they make a difference, and he generally doesn't bring his reliever inhaler with him in college or when he's out. He finds the cost of the inhalers excessive and he generally weighs it up against the money for a night out. The house Kevin lives in is not helpful – it's damp and cold, and there's also mould in his room. When friends come over, they smoke in the house, which Kevin won't make a fuss about but which does really make him wheezy and short of breath.

#### WHAT DOES KEVIN NEED?

- An annual review of his asthma and an asthma action plan
- Additional support from his student health centre and pharmacy
- Asthma attack information for him and his friends
- Help with how to recognise deterioration
- Psychological support
- To ensure he takes his preventer and to know his triggers



### JACK

Jack is eight years old. He is from Dublin and is adamant that he is going to win an All-Ireland Final medal playing with Dublin. He is obsessed with GAA, swimming and he loves watching cartoons on Netflix.

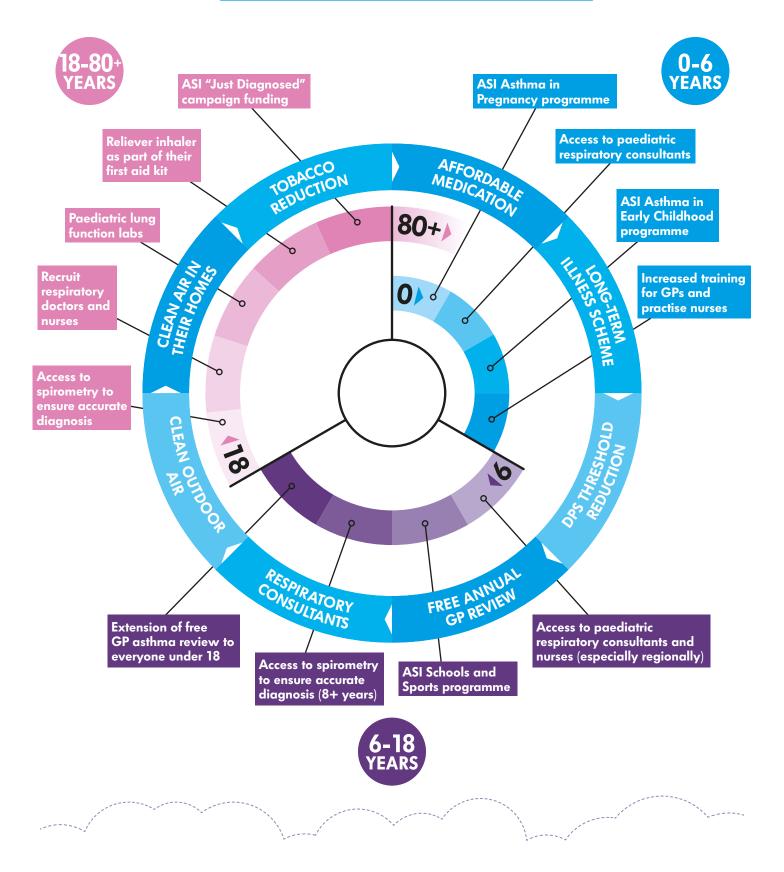
He coughs a lot at night, which can make him tired. When he gets sick, he gets really sick and he misses weeks of school and training at a time. He has to either stay at home with one of his parents, who take a day off work, or at his grandparents' house.

He's afraid he won't be able to make the team with his asthma. His coach tells him he doesn't need his inhaler and that he shouldn't be depending on it. Asthma is a bad word for Jack. He takes his medication at home but doesn't in school. He never uses the spacer in school because he gets embarrassed about it. He doesn't like being different or missing out.

#### WHAT DOES JACK NEED?

- To keep his place on the team
- For his coach to be ok with his asthma
- Not to have to be embarrassed about his asthma
- To stop coughing at night
- The ASI Schools Programme and an asthma buddy
- Age-appropriate videos and leaflet about asthma
- To meet a sporting hero with asthma

### THE ASTHMA LIFECYCLE



### 1. SUBSTANTIALLY REDUCE THE COST OF ASTHMA MEDICATION

It is essential that the Government in Budget 2019 move to lower the cost of asthma medication. Given that asthma is a long term condition with no cure, asthma medication should be covered under the Long Term Illness scheme for all people with asthma. This would save lives, reduce pressure on our emergency departments, decrease hospital admissions and tackle the €500 million cost of asthma to the economy.

A key part of good asthma control is taking preventative medication every day, even when you are feeling well. Preventative asthma medication is very expensive in Ireland and can be prohibitive. As a result, our research shows that 40% of people with asthma do not take their medication as prescribed. Many forgo taking preventative medication and rely instead on taking cheaper reliever inhalers when they have an attack. This is an extremely dangerous practice as reliever inhalers are often insufficient to combat severe asthma attacks. Not taking their preventative asthma medicine as prescribed leaves people at risk of a serious asthma attack, hospitalisation and death.

A recent Review of Respiratory medicines published in the Irish Journal of Medical Science (2018) found that the Government could provide all respiratory drugs free of charge for around €20-33 million per annum.

The paper analysed data from the Primary Care Reimbursement Service schemes and found that 87% of respiratory medicines in the primary setting are funded by the Government through its public schemes and that only 13% of respiratory medicines are funded privately. These findings for the first time give us a sense of the costs involved in providing asthma medications free of charge through public schemes. We understand that asthma is a chronic disease, this extra cost could be paid through the Long Term Illness Scheme.

In addition, people with asthma, or families where multiple family members have asthma utilise the Drugs Payment Scheme for medication and devices. However, the threshold is simply too high and many families who do not have a medical card struggle with the cost of medical visits and medication.

(Expenditure in the Primary Care Reimbursement Services 2005 - 2015, O'Dwyer, J. & Murphy, A., 2018)

#### .....

- **1.1** Cover all asthma medication through the Long Term Illness Scheme. or
- **1.2** As an interim measure, cover the cost of asthma medication paid privately through the Long Term Illness Scheme, and
- **1.3** Significantly reduce the qualifying amount of €134 per month on the Drugs Payment Scheme.

### 2. A FREE ANNUAL ASTHMA REVIEW WITH THEIR GP

Effective primary care is an essential component of asthma control. GPs, nurses and pharmacists can help to dramatically improve the quality of life of their patients by ensuring that people are on the correct medication and by educating them about how to manage their asthma. They can also reduce the huge burden on our secondary health system of avoidable hospital admissions.

The importance of improving primary care for people with asthma was acknowledged as being fundamental in Ireland's 'National Clinical Programme for Asthma' (NCPA), which was published in 2011. Unfortunately, Ireland's current standard of primary care for people with asthma is far behind international best practice. Our research shows that 60% of people with asthma do not have their asthma under control, and a huge proportion of this group do not understand what is means to have their asthma under control.

Under the NCPA, everyone diagnosed with asthma was to be enrolled in a structured programme of free regular GP reviews, with a focus on patient education, empowerment and self-management. Doctors could check that the medication prescribed was the best option, review progress, and assess patients asthma. Patients would be educated on issues such as:

- the importance of taking preventative medication,
- how to use their inhalers properly,
- and how to recognise and avoid their personal triggers.

The programme was to be rolled out on a phased basis, starting with people with asthma who had attended a hospital emergency department in the previous year. Frustratingly, almost eight years since this commitment to this free annual review, children under six are still the only grouping who can avail of such a service.

We are calling for the scheme to be rapidly extended to everyone with asthma as per the original plan. We acknowledge that this may need to be done on a phased basis to ensure there is capacity within the system to deliver a structured asthma review. We would like to see the Government put in place the review for anyone under-18 and for anyone diagnosed with severe asthma as part of Budget 2019 and ensure it is included in the HSE Service plan.

- **2.1** Deliver on the NCPA commitment to a free structured asthma management programme for everyone with asthma, delivered on a phased basis.
- **2.2** Immediately extend the free annual review of asthma to everyone under-18 and those with severe asthma.

### 3. SPECIALISED HOSPITAL DOCTORS, NURSES AND DIAGNOSTICS FOR CHILDREN

Ireland has the lowest number of respiratory consultants in Europe after Macedonia at 1.3 per 100,000 people, while the mean for Europe is 4.4 per 100,000 people.

We also have a shortage of paediatric respiratory consultants in Ireland, which is not in alignment with the scale of the asthma problem in Ireland – we have the fourth highest instance of asthma internationally. As a result, children are waiting up to six months on average to see a respiratory consultant after a GP referral. Many parents have been forced to go private to avoid these long waiting periods. Others cannot afford to do so and so are left with the worry that their child will have a serious and possibly fatal asthma attack while waiting to see a respiratory specialist.

Asthma nurses also have a critical role to play in helping to manage asthma. However, there is a huge shortage of paediatric asthma trained nurses in all the regional centres throughout the country (Cork, Galway or Limerick). Where one in five children in Ireland have asthma, there is a huge disparity in the care experienced by children with asthma regionally.

There are also no dedicated paediatric lung function labs with paediatric-trained lung function physiologists outside the children's hospitals in Dublin. As a result, consultants in other hospitals are forced to try to assess children using adult equipment, even in the case with children who have severe and poorly controlled asthma.

- 3.1 Recruit additional paediatric consultants to reduce waiting times for children.
- **3.2** Develop and implement a recruitment plan for specialised asthma paediatric nurses plan for children's hospitals and for all hospital groups.
- **3.3** Fund and staff paediatric lung function labs in Cork, Limerick and Galway, with trained paediatric physiologists.
- **3.4** Ensure the New National Children's Hospital and planned satellite hospitals are adequately resourced with specialist respiratory doctors, nurses and diagnostic equipment.

### 4. END THE POST-CODE LOTTERY FOR PEOPLE WITH SEVERE ASTHMA

In Ireland, approximately 5-10% of patients with asthma have severe asthma. Severe asthma is where a person requires considerably more medications, which bring with them more problematic side effects, in order to try and keep a good quality of life.

For some people with severe asthma, the condition can still be extremely difficult to control, even with the treatments and they can struggle to live a normal life, with frequent hospitalisations and serious escalations of their asthma.

These people face enormous emotional and financial challenges in coping with the condition on a daily basis. Some estimates put the cost of severe asthma to the person as much as being as six times greater than those with lesser severity, when you factor in missed days at work and increased medical treatment for asthma exacerbations.

At present, there are only a small number of high-tech treatments in various stages of development, with many expected on track in the coming months.

The only licensed treatment currently available is called Xolair. Xolair was licensed for use in Ireland in 2005, but is not reimbursable under any government schemes. Access to the medication is extremely limited. Severe asthma patients must rely on the generosity of hospital pharmacy budgets, meaning access to this life-changing treatment is based on geographic location and is not guaranteed, even if it is the most suitable treatment. Essentially this operates like a post-code lottery for severe asthma.

These treatments are not suitable for everyone who has severe asthma, but, for a cohort of these patients, they are a genuinely transformative option. It can mean the difference between completely debilitating symptoms requiring very frequent hospitalisation and leading a happy, healthy and full life.

Xolair is a recognised treatment for severe allergic asthma in the international best practice GINA Guidelines and is widely available through a national scheme in many other EU countries, including France, Spain and the UK.

The Government needs to put in place a national funding scheme for Xolair and other severe asthma treatments as they become available.

#### **RECOMMENDATIONS:**

**4.1** Establish a national funding model for high-tech severe asthma treatments to ensure access for all.

### 5. RE-VISIT THE NATIONAL CLINICAL PROGRAMME FOR ASTHMA (NCPA)

The NCPA was launched in 2011 and the Asthma Society has continuously been involved as a key stakeholder. The vision of the NCPA was that every child and every adult with asthma in Ireland should reach their maximal health and quality-of-life potential through the prevention, early detection and effective treatment of asthma.

Since its launch, the NCPA has developed a Model of Care designed towards achieving this.

The aims of the programme are to:

- Maximise health and quality of life of people with asthma.
- Prevent avoidable mortality due to asthma.

Over the last seven years, much has been achieved by the NCPA, particularly around drawing up clinical guidelines and delivering health care professional education programmes. However, with changes to the clinical programme structures within the HSE, the Asthma Society is of the view that the programme needs to revisit its original strategy to ensure it continues to drive improvements and continues to champion international best practise for asthma care in Ireland.

- 5.1 Undertake an Asthma Mortality Audit.
- 5.2 Commence an Asthma Prevalence Study as a priority.
- **5.3** Conduct an Asthma Service Gap Analysis and develop a National Asthma Strategy.
- 5.4 Develop standardised clinical asthma diagnosis programme.
- 5.5 Establish a national asthma registry.

### 6. AN INHALER CAN SAVE A LIFE

An asthma attack is a medical emergency and can be fatal. In the event of an asthma attack, having immediate access to a reliever inhaler could be the difference between life and death.

As one in five Irish children and one in ten adults have asthma, it is imperative that staff and volunteers in schools, workplaces, sports clubs, and community organisations know how to assist someone having an asthma attack.

However, sometimes a person with asthma may not have their own inhaler with them. To cater for such eventualities, all schools, colleges, sports clubs, gyms and other appropriate organisations need to keep a spare reliever inhaler onsite.

In October 2015, the Minister for Health signed new regulations allowing trained members of the public to administer life-saving rescue medicines such as epi pens, glucagon for diabetic hypoglycaemia and reliever asthma inhalers in emergency situations.

The Asthma Society has learnt through a parliamentary question submitted on our behalf that **NO SCHOOLS HAVE REGISTERED FOR THE SCHEME TO DATE** (June 2017). This means that in the event of an emergency, there may be no inhaler onsite to administer – this puts all asthma children and adults at risk.

We believe that the scheme is not in use because the conditions attached are overly onerous.

The regulations state that the training must be three days in duration in order to qualify a person to administer the inhaler and the training must be renewed every two years.

We accept such a lengthy training period may be appropriate for administering emergency medication such as epi pens. However, it is totally unnecessary for administering a reliever inhaler. The risks of not giving someone a reliever inhaler who is having an asthma attack are very serious. The potential side effect of delivering a reliever inhaler is a temporary and minor level of dizziness.

- **6.1** Immediate replacement of current ministerial regulations for the administration of salbutamol in emergency situations with more workable arrangements.
- **6.2** Funding from the Department of Health to support the Asthma Society to develop a public engagement campaign for schools, workplaces sports clubs and other organisations on the administration of salbutamol in emergency situations.

### 7. ERADICATE OUTDOOR AIR POLLUTION

Air quality was recently described by the World Health Organization (WHO) as the world's largest single environmental health risk, and Ireland is no exception to this problem. The European Environmental Agency estimates that 1,229 lives are lost prematurely in Ireland because of poor air quality in a single year.

Pollution from motor vehicles, industrial plants, domestic solid fuels and other sources is bad for everyone's health but it has a very serious impact on people with asthma. Air pollution is absorbed into the sinus, the airways and the lungs, triggering asthma symptoms.

While Ireland is largely within the EU limits for air pollution, it fairs poorly when measured against the World Health Organisation guidelines for emissions.

We believe the Government should end the favourable tax treatment of motor diesel, in light of research showing that the emissions from diesel cars are just as high as those from petrol cars on short journeys. The Government needs to adequately resource the EPA to provide an extensive air monitoring network across the country in both the urban and rural setting as per the EPA's recent clean air strategy for Ireland. Irish air quality experts state that Ireland's air quality monitoring is ten to fifteen years behind its international counterparts.

The Asthma Society welcomes the Government's intention to introduce a national ban on smoky coal in Autumn 2019. However, we are concerned about emerging research which shows that solid fuels like wood and peat are also high in PM2.5 omissions.

- 7.1 End the favourable tax treatment of motor diesel over petrol.
- **7.2** Fund the EPA to create a nationwide network of real-time air quality monitoring stations.
- **7.3** Ensure the necessary resources are in place to enforce the nationwide ban on the selling and burning of smoky coal.
- 7.4 Investigate the health consequences of burning wood and peat.

### 8. PROTECT INDOOR AIR QUALITY

Where we live affects our health - this is especially true for people with asthma.

Some indoor asthma triggers – such as dust, aerosol emissions and animal fur – can be managed relatively easily when a person with asthma is aware of their impact on their health. Other indoor asthma triggers, like poor insulation, inadequate ventilation, serious mould, inappropriate heating systems and the use of carpet rather than wood/laminate floors, are more problematic. These are expensive for people to remedy. As a result, many low-income people with asthma are living in environments which are seriously damaging to their health – their home exacerbates their asthma.

The Government should fund the cost of essential home improvements for all low-income households (not just those on social welfare) where at least one person has asthma or COPD. Given the number of low income families living in private rented accommodation, this sector should also be included. The programme could be rolled out on a phased basis, starting with families of children with asthma.

We welcome the 2016 Warmth and Wellbeing Pilot Scheme for people over 55 with asthma or COPD and for children under-12 with asthma in the Dublin 8, 10, 12, 22, and 24 areas living in households in receipt of the fuel allowance. The grant covers the full cost of having a new energy and/or heating system installed. The Better Energy Warmer Homes Scheme also funds home energy improvements for certain categories of social welfare recipients.

#### **RECOMMENDATION:**

**8.1** Build on the success of the Warmth and Wellbeing Pilot Scheme and Better Energy Warmer Homes Scheme by providing funding for essential home improvements on a phased basis, starting with families of children with asthma.

### 9. REDUCE THE TOBACCO THREAT

Tobacco smoke is one of the most common and dangerous triggers of asthma symptoms. Almost a quarter of asthmatics smoke.

Smoking with asthma decreases lung function, reduces the effectiveness of medication, and increases the risk of virus and infection. Being subjected to passive smoking increases a person's likelihood of developing asthma. For example, babies born to mothers who smoke while pregnant are more likely to develop asthma, as are children exposed to tobacco smoke in the home. Passive smoking is also a common trigger of asthma symptoms and can lead to serious attacks. Research also shows that passive smoking can be more dangerous than smoking directly, as the smoke is not inhaled through a filter.

The Government in recent years has taken many positive steps in the 'war against tobacco', most notably the introduction of plain packs. However, new initiatives need to be introduced to reduce the threat from passive smoking.

The ban on smoking in workplaces and in cars with children have been effective but asthmatics are still exposed to secondhand smoke in other public places, including in parks, on beaches, at bus stops, at sports pitches, and immediately outside the exits of shops and other buildings. Smoking at such locations is banned in many parts of the United States and should also be banned here.

The Asthma Society recognises that e-cigarettes can help some people to quit smoking. However, we share the World Health Organisation's concern that vaping may undermine the success of anti-tobacco initiatives by re-normalising smoking and acting as a smoking gateway for young people. We are also concerned about the potential health impacts of passive vaping. We therefore believe the advertising, sale and use of e-cigarettes should be regulated in the same way as tobacco and that the workplace smoking ban should be extended to e-cigarettes.

Finally, we are aware that many tobacco companies plan to introduce Heated Tobacco products into the Irish market in the coming months. It is vital that these products are treated in the same way as traditional cigarettes when it comes to excise duty. Little to no independent research is available on the health effects of heated tobacco products and the Government should not facilitate the belief among smokers or potential smokers that they are 'healthier'. Price point is a key factor in smoking behavior and Heated Tobacco products should not be cheaper than cigarettes.

- 9.1 Extend the smoking ban to other public places as outlined above.
- **9.2** Ban the use of e-cigarettes in workplaces restaurants, bars and cafes and regulate their advertising, sale and use.
- 9.3 Ensure that Heated Tobacco products are taxed exactly like tobacco products.
- **9.4** Continue to deliver targeted measures to help people with respiratory disorders to quit smoking as recommended in the 'Tobacco Free Ireland' report.

# 10. FUND THE ASTHMA SOCIETY'SVITAL WORK

The Asthma Society is the only national representative body for the 470,000 people with asthma in Ireland. We help save and improve the lives of people with asthma by providing:

- Essential health promotion services such as our free Adviceline, pharmacy clinics and training for healthcare professionals;
- Collaboration with NGOs, outreach and community organisations to deliver training on how to manage asthma;
- Engaging with people with asthma at vital points during their "asthma journey" to enable them to self-manage their condition;
- Providing information for patients about asthma management through public information campaigns, our website, our social media channels and via printed booklets;
- · Giving the the patients with asthma in Ireland a voice;
- Lobbying the Government to improve services for people with asthma and participating in the working group for the HSE's National Clinical Programme for Asthma; and
- Supporting research into the prevalence, cost, causes and treatment of asthma.

However, our ability to do this work has been hampered by the loss of Government funding, particularly the Charitable Lotteries Fund. While we have had some success in attracting funding from other sources, including other statutory schemes, we have been unable to compensate for losing such a large amount of income.

#### AS A RESULT:

- We are unable to do as much patient and stakeholder education work in particular as is necessary to reach the 470,000 people with asthma.
- We are launching new schools and exercise awareness campaigns, which will be more engaging for young people, more inclusive for all types of sports and which will be toolkits that all schools and clubs will want to avail of but we are struggling to find resources to run these transformative programmes. These materials could save lives.
- We are unable to accommodate all the requests we receive for nurse talks, participation in public events, and health seminars.
- We want to start Asthma in Early Education, Asthma in Pregnancy, and "Just Diagnosed" campaigns but currently lack the capacity to deliver these.
- We are unable to update prevalence research and a mortality audit of asthma deaths to further our knowledge of the necessary solutions to the problems faced by those with asthma in Ireland.

Government funding for the Asthma Society's patient education and public information campaigns would enable us to help more people manage their asthma better, reducing their reliance on the health service and their risk of hospitalisation.

#### **10. FUND THE ASTHMA SOCIETY'S VITAL WORK (CONT.)**

- **10.1** Retain and increase HSE funding for Asthma Society (COPD) Adviceline following the conclusion of a successful HSE evaluation in 2017 and a strong performance in 2018.
- **10.2** Fund our new schools and sports club programmes.
- 10.3 Fund our public information campaigns about all aspects of the asthma journey, including our planned "just diagnosed" campaign and our Asthma in Pregnancy and in Early Childhood campaigns.
- **10.4** Fund us to provide information to the HCP community, building a better understanding of asthma among healthcare professionals throughout the country.
- **10.5** Fund us to examine asthma prevalence studies in Ireland, a huge current research gap, preventing us from understanding asthma in Ireland.

- **1.1** Cover all asthma medication through the Long Term Illness Scheme. or
- **1.2** As an interim measure, cover the cost of asthma medication paid privately through the Long Term Illness Scheme, and
- **1.3** Significantly reduce the qualifying amount of €134 per month on the Drugs Payment Scheme.
- **2.1** Deliver on the NCPA commitment to a free structured asthma management programme for everyone with asthma, delivered on a phased basis.
- **2.2** Immediately extend the free annual review of asthma to everyone under-18 and those with severe asthma.
- **3.1** Recruit additional paediatric consultants to reduce waiting times for children.
- **3.2** Develop and implement a recruitment plan for specialised asthma paediatric nurses plan for children's hospitals and for all hospital groups.
- **3.3** Fund and staff paediatric lung function labs in Cork, Limerick and Galway, with trained paediatric physiologists.
- **3.4** Ensure the New National Children's Hospital and planned satellite hospitals are adequately resourced with specialist respiratory doctors, nurses and diagnostic equipment.
- **4.1** Establish a national funding model for high-tech severe asthma treatments to ensure access for all.
- 5.1 Undertake an Asthma Mortality Audit.
- 5.2 Commence an Asthma Prevalence Study as a priority.
- **5.3** Conduct an Asthma Service Gap Analysis and develop a National Asthma Strategy.
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- **6.2** Funding from the Department of Health to support the Asthma Society to develop a public engagement campaign for schools, workplaces sports clubs and other organisations on the administration of salbutamol in emergency situations.

#### **RECOMMENDATIONS** (CONT.)

- 7.1 End the favourable tax treatment of motor diesel over petrol.
- **7.2** Fund the EPA to create a nationwide network of real-time air quality monitoring stations.
- **7.3** Ensure the necessary resources enforce the nationwide ban on the selling and burning of smoky coal.
- 7.4 Investigate the health consequences of burning wood and peat.
- **8.1** Build on the success of the Warmth and Wellbeing Pilot Scheme and Better Energy Warmer Homes Scheme by providing funding for essential home improvements on a phased basis, starting with families of children with asthma.
- 9.1 Extend the smoking ban to other public places as outlined above.
- **9.2** Ban the use of e-cigarettes in workplaces restaurants, bars and cafes and regulate their advertising, sale and use.
- 9.3 Ensure that Heated Tobacco products are taxed exactly like tobacco products.
- **9.4** Continue to deliver targeted measures to help people with respiratory disorders to quit smoking as recommended in the 'Tobacco Free Ireland' report.
- 10.1 Retain and increase HSE funding for Asthma Society (COPD) Adviceline following the conclusion of a successful HSE evaluation in 2017 and a strong performance in 2018.
- **10.2** Fund our new schools and sports club programmes.
- 10.3 Fund our public information campaigns about all aspects of the asthma journey, including our planned "just diagnosed" campaign and our Asthma in Pregnancy and in Early Childhood campaigns.
- **10.4** Fund us to provide information to the HCP community, building a better understanding of asthma among healthcare professionals throughout the country.
- **10.5** Fund us to examine asthma prevalence studies in Ireland, a huge current research gap, preventing us from understanding asthma in Ireland.

### **Every patient empowered**

to know their asthma, to control their asthma, to feel well and to stay well is a patient that is not troubled by emergency department visits, hospital admissions, days missed from work and school.

### **ASTHMA DEATHS**

## In Ireland, one person a week dies from an asthma attack.

#### Tragically, 90% of these deaths are preventable.

There is a popular misconception that only those with severe asthma are at risk of a serious attack or death. This is not the case.

In fact, a 2014 study of asthma deaths in the UK found the majority of those who died had mild or moderate asthma. Of people with asthma in Ireland, 60% do not have their condition under control. They are at risk of having a serious attack at any time.

Every 26 minutes someone ends up in a hospital emergency department with a life threatening attack, a total of 20,000 ED visits every year. Asthma also accounts for 50,000 visits per annum to GP out-of-hours services.

These stats clearly prove that many people with mild or moderate asthma in Ireland underestimate their condition. They don't realise how serious asthma can be and don't appreciate the importance of taking preventative medication every single day even when they are feeling well. As outlined earlier in this submission, Irish people with asthma know they should take a preventer inhaler every day but they can't afford it.

Please help us save the lives of people with asthma by fighting for the recommendations in this submission to be implemented. We are passionate about the need to eliminate preventable asthma deaths in Ireland.

### WHAT BEREAVED FAMILIES SAY:

Irish families have lost loved ones to asthma attacks – at least one every week. One boy was seven years old. One was 16. One was 19. Two were 21 .

These families have told us they had no idea asthma could kill. They have urged us to do more to make people aware of this and highlight the importance of taking preventative medication every single day.

Chris Martin was a fit and healthy young man who played rugby for UCC. He had had asthma since he was a kid and used his reliever inhaler while playing sports. His Dad , Michael, has said he would often forget to take his preventative medication. Neither Michael or Chris had any idea that doing so could cost have such a terrible impact on their lives. On Stephen's Day in 2015, Michael was suffering from cancer at the time and was on his way to Knock to pray for a cure. He got a phone call from home telling him Chris was having a bad asthma attack. Michael rushed home to Wexford but Chris died before he got there.

Dylan McLoughlin was just sixteen years old when he died in February 2016. He loved cycling, surfing and playing rugby for his local club in Naas. He was out mountain biking with his friends during the mid-term break, when he tragically suffered a fatal asthma attack. Dylan lived in Naas with his Mum and Dad, Joan and Tom, his younger brothers Fionn and Glen, and beloved dog Drisco.



Chris Martin



Dylan McLoughlin



	ASTHMA SOCIETY OF IRELAND
GET AHEAD HAYFEVER DAILY POLL asthma.ie	O OF YOUR WITH OUR EN TRACKER
Leinster Connacht	Munster Ulster
Low Moderate High Very High	
gsk dyson	

## ASTHMA IN THE PHARMACY



Avail of a free appointment with an Asthma Nurse Specialist in your local pharmacy.

#### **DISCUSS:**

- Your or your child's asthma,
- What to do in the event of an asthma attack,
- Trigger management,
- Hayfever and asthma,
- Correct inhaler technique.

Visit **www.asthma.ie**/**events** to see if there is an upcoming Asthma in the Pharmacy day in your area.

asthma.ie

#### THE ASTHMA SOCIETY WILL LAUNCH A NEW VERSION OF THE

ASTHMA SOCIETY

SCHOOLS

ТНМА

00

#### PRIMARY AND SECONDARY ASTHMA FRIENDLY SCHOOLS PROGRAMME

#### **LATER IN 2018**

All schools that take part will receive an asthma information pack, video resources, online resources and friendly props to create awareness in their school. We also offer specialist asthma nurse talks for teachers and parents as part of the programme.

The lesson plan built around asthma will help children:

- Engage with science;
- Learn about asthma;
- Learn about the air we breathe; and
- Remove any stigma around asthma in their classroom.

Please email schools@asthmasociety.ie to register your interest



# PUBLIC CAMPAIGNS

The Asthma Society of Ireland runs campaigns to explain asthma to the public, helping to save and improve the lives of people with asthma.

#### THESE CAMPAIGNS ARE DELIVERED TO:

#### PEOPLE WITH ASTHMA AND THEIR CARERS

COMMUNITY & VOLUNTARY ORGANISATIONS

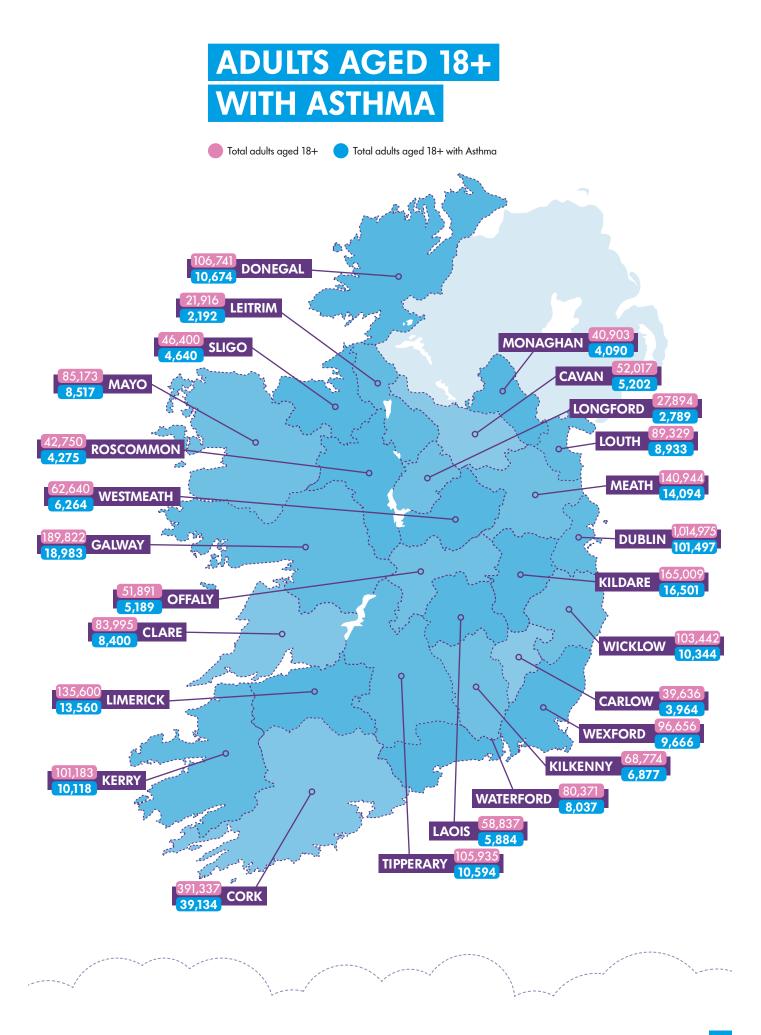
#### **SPORTS CLUBS**

HEALTHCARE PROFESSIONALS

#### CONTACT THE ASTHMA SOCIETY TO ARRANGE A NURSE TALK.

We love to collaborate with other organisations to help people understand and manage asthma.

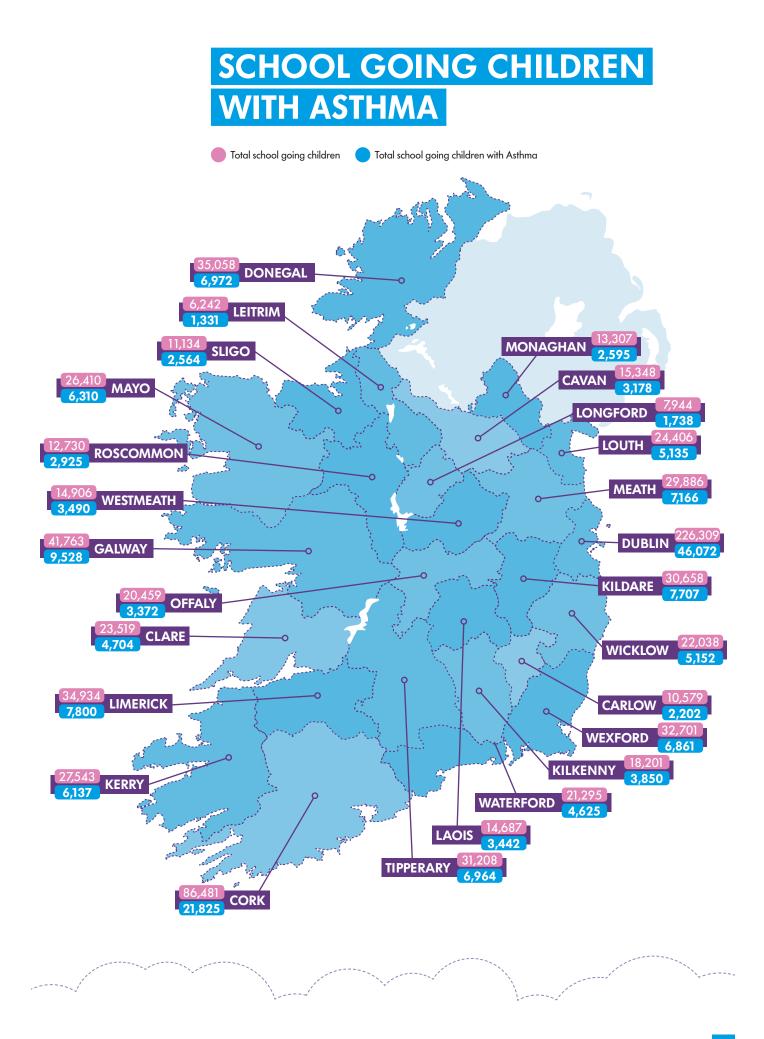
asthma.ie



### ADULTS AGED 18+ WITH ASTHMA

COUNTY	TOTAL	ASTHMA		
Carlow	39,636	3,964		
Cavan	52,017	5,202		
Clare	83,995	8,400		
Cork	391,337	39,134		
Donegal	106,741	10,674		
Dublin	1,014,975	101,497		
Galway	189,822	18,983		
Kerry	101,183	10,1 18		
Kildare	165,009	16,501		
Kilkenny	68,774	6,877		
Laois	58,837	5,884		
Leitrim	21,916	2,192		
Limerick	135,600	13,560		
Longford	27,894	2,789		
Louth	89,329	8,933		
Мауо	85,173	8,517		
Meath	140,944	14,094		
Monaghan	40,903	4,090		
Offaly	51,891	5,189		
Roscommon	42,750	4,275		
Sligo	46,400	4,640		
Tipperary	105,935	10,594		
Waterford	80,371	8,037		
Westmeath	62,640	6,264		
Wexford	96,656	9,666		
Wicklow	103,442	10,344		
TOTAL	3,404,170	340,418		

LET ME BREATHE - ASTHMA SOCIETY OF IRELAND PRE-BUDGET SUBMISSION 2019



### SCHOOL GOING CHILDREN WITH ASTHMA

	PRIMARY SCHOOLS		SECONDARY SCHOOLS		ALL SCHOOL GOING CHILDREN	
COUNTY	TOTAL	ASTHMA	TOTAL	ASTHMA	TOTAL	ASTHMA
Carlow	4,295	859	6,284	1,343	10,579	2,202
Cavan	7,082	1,416	8,266	1,762	15,348	3,178
Clare	7,719	1,544	15,800	3,160	23,519	4,704
Cork	33,701	6,740	52,780	10,556	86,481	17,296
Donegal	17,464	3,493	17,594	3,479	35,058	6,972
Dublin	124,289	24,857	102,020	20,404	226,309	45,261
Galway	17,645	3,529	24,109	4,821	41,763	8,350
Kerry	11,704	2,341	15,839	3,796	27,543	6,137
Kildare	11,700	2,340	18,958	5,367	30,658	7,707
Kilkenny	6,995	1,399	11,206	2,451	18,201	3,850
Laois	6,036	1,207	8,651	2,235	14,687	3,442
Leitrim	2,769	554	3,473	777	6,242	1,331
Limerick	14,636	2,927	20,298	4,873	34,934	7,800
Longford	3,656	731	4,288	1,007	7,944	1,738
Louth	10,531	2,106	13,875	3,029	24,406	5,135
Мауо	12,624	2,525	13,786	3,785	26,410	6,310
Meath	11,622	2,324	18,264	4,842	29,886	7,166
Monaghan	5,798	1,160	7,509	1,435	13,307	2,595
Offaly	6,673	1,335	13,786	2,037	20,459	3,372
Roscommon	5,559	1,112	7,171	1,813	12,730	2,925
Sligo	4,822	964	6,312	1,600	11,134	2,564
Tipperary	12,412	2,482	18,796	4,482	31,208	6,964
Waterford	8,615	1,723	12,680	2,902	21,295	4,625
Westmeath	6,225	1,245	8,681	2,245	14,906	3,490
Wexford	13,998	2,800	18,703	4,061	32,701	6,861
Wicklow	8,816	1,763	13,222	3,389	22,038	5,152



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Available at: https://bit.ly/2KX1Kq5

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asthma.ie