

PRE-BUDGET SUBMISSION



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FOREWORD



A chara,

Our vision is that everyone with asthma in Ireland lives a full life, symptom-free. We are the proud voice of the 380,000 people with asthma in Ireland and our mission is to stop asthma deaths in Ireland.

90% of asthma deaths are preventable. Steps need to be taken to eradicate all preventable asthma deaths in Ireland. It is vital that people with asthma are supported to ensure a high quality of life. A person centered approach to managing asthma requires investment in three main areas:

- 1. Affordable access to necessary medication
- 2. Affordable access to appropriate clinical care
- 3. Free access to asthma education

Children with asthma miss on average five school days, and adults with asthma miss on average seven working days annually due to their condition. Additional support towards asthma management and wellness is needed to allow people with asthma to live their life symptom free. Whether it is playing sport, operating a business, teaching in a classroom, or volunteering in their community, asthma should not affect people living a full life.

When the basics of asthma care are done well, there are long lasting benefits to the person and the wider health system. Timely access to affordable medication is key to keeping people with asthma well and reducing their experience of symptoms. Our values align with the Sláintecare key principle that if the right care is available at the right time and in the right place, early interventions become easier to achieve.

The Asthma Society of Ireland provides high quality asthma education, clinical advice, and direct support through our HSE funded services: the Asthma and COPD Adviceline and Beating Breathlessness patient support WhatsApp service. Whether it is supporting a parent to better understand good inhaler technique, or advising an older person as to how they can better recognize their triggers, our work is empowering people to manage their asthma at home and to stay well in their communities. As a charity, we need financial support to continue to provide these high-quality services. Our value has never been more evident than now during COVID 19. We continue to work tirelessly to ensure that people with asthma have access to reliable, evidenced based information on managing their condition through a pandemic and staying well while the country reopens.

We hope that you take the time to consider issues faced by people with asthma in Ireland raised in this submission.

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Emily Blennerhassett, Interim CEO of the Asthma Society of Ireland

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 reducing exposure to known triggers, use of correct preventer and reliever medication, and by having an **Asthma Action Plan** in place.

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.

THE ECONOMIC BURDEN OF ASTHMA

In 2019, the Asthma Society of Ireland published *Easing the Economic Burden of Asthma – The Impact of a Universal Asthma Self-Management Programme.* In this report, an estimated 890,000 people in Ireland have had asthma at some point in their life-time, including 380,000 people who experience asthma on an annual basis. It estimates the national economic burden of asthma to be €472 million in 2017!

Here are some key findings of this report:

- Asthma cost the Irish State €472 million in 2017 equating to €1,242 per person with asthma
- Secondary care for asthma was the area with the highest spend at €116 million
- There were 133,000 asthma related emergency department visits and almost 8,000 hospitalisations at a cost of €50 million in Ireland. A further €66 million was attributed to Specialist/Consultant visits in hospitals
- Asthma imposes a significant burden on the primary care system: 2.4 million GP visits were asthma related with a further 625,000 Practice Nurse consultations as a result of asthma in 2017
- The cost of asthma medication was estimated at €45 million in 2017. Combination preventer treatments and reliever inhalers represent 44% and 27% of total medication costs respectively
- Indirect costs accounted for 43% of the total cost of asthma (€202 million). This included the cost of absenteeism and premature mortality from asthma
- There was an estimated 1.4 million workdays lost due to asthma in 2017. On average people with asthma miss seven work-days per year
- National and international guidelines recommend that all people with asthma are provided with self-management programmes to help control their asthma and reduce the burden it imposes on health systems and patients. A key part of these programmes are written action plans, patient education, inhaler technique, adherence and regular medical review.

¹ Easing the Economic Burden of Asthma: The Impact of a Universal Self-Management Programme, Asthma Society of Ireland, June 2019.

WHY OUR WORK IS SO IMPORTANT



ASTHMA SOCIETY OF IRELAND 2021 BUDGET PROPOSALS

Our five budget proposals are based on the **Sláintecare** principles of the right care, at the right time, in the right place, and from the right person. The Asthma Society of Ireland is asking the State to:

- 1. Introduce universal full subsidisation of asthma medications
- 2. Expand national fund for severe asthma medication
- 3. Fund the extension of the current asthma management programme for all people with asthma
- 4. Increase the number of registered Advanced Nurse Practitioners to meet 2% Department of Health guidelines
- 5. Provide the Asthma Society of Ireland with annual core funding

We are continually working to learn more about the issues raised in the budget proposals and hope to be able to provide ongoing information in the coming weeks and months. Each of our five asks are focused on improving asthma management, access to medication, and improving asthma care in the hope of achieving the following benefits:

- Asthma related deaths are reduced
- Ensure all people with asthma have an equal opportunity to live life, symptom free
- Remove cost barriers to life saving medication for people with asthma in Ireland so that they can experience a high quality of life and achieve the outcomes that matter to them
- Tackle health inequalities for people with asthma by ensuring that medication is accessible and affordable
- Reduce the economic burden of asthma on the Irish health system and Irish State by keeping people well in their communities

1. INTRODUCE UNIVERSAL FULL SUBSIDISATION OF ASTHMA MEDICATIONS

ACTION

The Irish State introduces full subsidisation of all asthma medication necessary for proper asthma management as outlined in the Global Initiative for Asthma (GINA)'s 2020 Report: **Global Strategy for** Asthma Management and Prevention.

CONTEXT

Asthma is a lifelong, respiratory illness with no cure. Of the 380,000 people in Ireland living with asthma, it is estimated that more than half do not have their symptoms under control. Poor asthma control is linked to increased risk of asthma attacks, hospitalisations, absenteeism, and even premature death.

Daily medication compliance is key part of good asthma control, even when well. Unfortunately, asthma medication is expensive in Ireland. A 2016 survey of our members showed that 40% of respondents did not take their medication as prescribed because of cost. A further 25% travel outside of Ireland to buy their medication because they could not afford to buy it here.² The Asthma Society strongly believes that no one should forgo life-saving medication due to cost barriers. Unaffordable medication results in health inequalities and widens the gap in health between those of different socio-economic status.

We called for asthma to be recognised as a long term illness and included under the Long Term Illness Scheme in our **2020 General Election #AsthmaMatters manifesto**. However, it has been made clear that this is not an option. We are calling for a subsidisation of all asthma mediation outlined in steps 1 to 4 of GINA guidelines which categorise medications for the main treatment of asthma for those with mild to moderate asthma.³

Asthma medication including combination preventer treatments and reliever inhalers in 2017 cost the State €45.4 million. Increasing this investment in asthma medication could reduce other direct and indirect costs from asthma due to an improvement in management. In the same year:

- asthma is estimated to have resulted in 133,000 emergency department visits and 8,000 hospitalisations (day-case and inpatient stays) at a cost of €50 million
- Specialist/Consultant visits in hospitals cost the State an additional €66 million
- absenteeism and premature mortality from asthma (indirect costs) cost ${\in}202$ million

AIMS

- To reduce and eradicate asthma related deaths in Ireland
- Remove cost barriers to life saving medication for people with asthma in Ireland so that they can experience a high quality of life and achieve the outcomes that matter to them
- Tackle health inequalities by ensuring that medication is accessible and affordable
- Reduce the economic burden of asthma on the Irish health system and Irish State by keeping people well in their communities

² https://www.asthma.ie/faq/have-asthma-recognised-under-long-term-illness-scheme

³ Global Strategy for Asthma Management and Prevention, GINA 2020:51. Available from: www.ginasthma.org

2. EXPAND NATIONAL FUND FOR SEVERE ASTHMA MEDICATION

ACTION Expand national fund for biologic medication for severe asthma to ensure every person who would benefit from this life changing treatment has equitable access to it in a timely way.

CONTEXT

Unlike many western European countries, Ireland does not have a severe asthma register. It is estimated that between 3% and 5% (11,400 - 19,000) of asthma patients have a severe asthma diagnosis. Severe asthma is a costly chronic disease. Severe uncontrolled asthma has been estimated to account for 60% of all asthma costs⁴ due to healthcare costs including medications, physician and specialist visits, hospitalisations, and the cost of OCS side effects associated with severe asthma patients.⁵

Patients with severe asthma can often experience a challenging and curtailing burden of symptoms including frequent shortness of breath, wheeze, chest tightness and cough, in addition to common side-effects from steroids such as osteoporotic hip fractures and cataracts. These symptoms severely interfere with day-to-day living, good quality sleep and being physically active. People with severe asthma often experience frightening or unpredictable exacerbations (also called attacks or severe flare-ups)⁶ which may impact their confidence and quality of life.

The Asthma Society of Ireland strongly believes that no one should be denied life-changing medication which could drastically improve their quality of life and greatly reduce side effects. The current level of funding for biologic medication means that people with severe asthma – whose lives could improve dramatically from the treatment – are not receiving sufficient treatment. This will negatively impacts quality of life, increases the need for hospitalisations and HCP visits (biologic asthma medications can reduce this by >50%), and in turn affect attendance to school and work. People with severe asthma need timely equitable and affordable access to necessary medication so that they can live full, high quality lives and have access to opportunities for work, school and play that are only possible when their condition and symptoms are well managed.

AIMS

- To reduce and eradicate asthma related deaths in Ireland
- To ensure people with severe asthma have timely and equitable access to the medication that will work best for them and they are able to achieve the outcomes that are important to them
- Remove cost barriers to life saving medication for people with severe asthma in Ireland so that they can experience a high quality of life
- Reduce the economic burden of asthma on the Irish health system and Irish State by keeping people well in their communities
- Tackle health inequalities for people with asthma by ensuring that medication is accessible and affordable
- 4 Sadatsafavi M, Lynd L, Marra C, Carleton B, Tan WC, Sullivan S, FitzGerald JM. Direct health care costs associated with asthma in Brittish Columbia. Can Respir J 2010; 17:74-80
- 5 Adverse effects of long-term OCS include obesity, diabetes, hypertension and edrenal suppression; psychological side-effects such as depression and anxiety are particularly concerning for patients. Short tern OCS use is associated with sleep disturbance, and increased risk of infection, fracture and thromboembolism
- 6 Global Strategy for Asthma Management and Prevention, GINA 2020. Available from: www.ginasthma.org

3. FUND THE EXTENSION OF THE CURRENT ASTHMA MANAGEMENT PROGRAMME FOR ALL PEOPLE WITH ASTHMA



Fund the extension of the current asthma management programme for the under 6's to not only include under 12's, but all people with asthma.

CONTEXT

The Department of Health's June 2020 Briefing reports that people with chronic diseases – including those with asthma – are more likely to visit their GP, present at Emergency Departments, be admitted as inpatients and spend more time in hospital, than people without such conditions. OECD data shows that Ireland records the second highest hospitalisation rate for asthma across EU countries and is around 50% above the EU average.⁷ This signals an urgent need to improve the management of asthma in primary care.

Regular structured reviews of chronic medical conditions leads to improved patient outcomes through better condition management. With the right investment and support, self-management programmes delivered in primary care could have a significant role to play in reducing reliance on unscheduled and emergency health care for people with asthma. The Asthma Society of Ireland is calling for urgent investment in a Universal Asthma Self-Management Programme so that the 380,000 people in Ireland with asthma are supported to achieve good management of their asthma and are able stay well.

Ireland remains the only western European country without universal access to primary care. Since 2015, all children under six have been eligible to access general GP services without charges, along with periodic health assessments and the asthma cycle of care programme. The Asthma Society believes that plans to extend this programme to include all children under the age of 12, while welcome, could go further and, we are asking the Government to make Asthma Self-Management Programmes universally available for all people with asthma. In taking this action we estimate that the total cost savings for the Irish exchequer (direct and indirect) could be as much as $\epsilon 68-\epsilon 102$ million a year.⁸

AIMS

- Asthma related deaths are reduced
- People with asthma are supported and empowered to manage their condition, stay well in their community and avoid preventable hospital admissions.

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- Reduce the economic burden of asthma on the Irish health system and Irish State by keeping people well in their communities.
- · Remove cost barriers accessing primary care for people with asthma in Ireland
- Tackle health inequalities for people with asthma by ensuring that primary care support is accessible and affordable

⁷ State of Health in the EU · Ireland · Country Health Profile 2019, OECD, November 2019

⁸ Easing the Economic Burden of Asthma: The Impact of a Universal Self-Management Programme, Asthma Society of Ireland, June 2019.

4. INCREASE THE NUMBER OF REGISTERED ADVANCED NURSE PRACTITIONERS TO MEET 2% DEPARTMENT OF HEALTH GUIDELINES

ACTION

Increase the number of registered Advanced Nurse Practitioners to meet Department of Health's policy of having 2% of the nursing and midwifery workforce working at advanced practice level.

CONTEXT

A fundamental aspect of good asthma care is having the right skills and levels of asthma education within the healthcare workforce.

High quality primary and secondary care will help to ensure good management of asthma and is vital in the prevention of unnecessary asthma related deaths. Advanced Nurse Practitioners (ANPs) are highly valuable members of multidisciplinary healthcare teams and their "ability to provide a full episode of care for a patient; assessing, carrying out an intervention, prescribing medication and discharging"⁹ means that they are well positioned to provide effective, high quality secondary care to people with asthma. This was proven in the ANP pilot scheme in one hospital which saw, the "Advanced Nurse Practitioner delivering early respiratory specialist care, [resulting] in hospital admissions decreasing from 100% to 22%, with every patient admitted seeing a respiratory consultant within 24 hours."¹⁰

We welcome the Department of Health's 2019 policy to grow the ANP workforce so that up to 2% of the overall nursing and midwifery workforce are practicing at an advanced level. Increasing this workforce and extending the level of advanced practice in secondary care, could help people with asthma access the right care, at the right time, in the right place and from the right person. We ask that investment continues in this area and that workforce considerations such as part time working are taken into account when workforce targets are being reviewed/ assessed. For example, while 750 new ANPs is a very welcome step, depending on working arrangements this may not translate to 750 whole time equivalent posts being filled.

AIMS

• Asthma related deaths are reduced due to improved care access

- People with asthma are supported and empowered to manage their condition and spend as little time in acute settings as possible.
- Reduce the economic burden of asthma on the Irish health system and Irish State by reducing the amount of time people spend in acute care

https://www.gov.ie/en/press-release/715a21-new-policy-on-advanced-nursing-and-midwifery-practice-launched-by-mi/
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ASTHMA SOCIETY OF IRELAND PRE-BUDGET SUBMISSION 2021

5. PROVIDE THE ASTHMA SOCIETY OF IRELAND WITH ANNUAL CORE FUNDING

ACTION

Increase funding to the Asthma Society from 28% to 50% to ensure basic needs are met. These funds would be used to cover core costs of the Society and provide a solid financial base on which to build its support programmes.

CONTEXT

The Asthma Society of Ireland is a relatively small non-profit with a dedicated team. We work tirelessly to support the healthcare system in the provision of free primary care to the 380,000 people in Ireland with asthma. Securing funding is a daily struggle for the organisation. We rely heavily on generous fundraising events and projects funded by corporates. Statutory funding in 2019 comprised 28% of the funding received by the Asthma Society which covered 27% of the annual expenditure. Given the relatively low level of guaranteed statutory funding, the Asthma Society is constantly battling to achieve the financial stability which will allow it to fully implement a medium to long term strategy.

The Asthma Society's Adviceline and Beating Breathlessness service is currently funded by the HSE and Pobal. This pays for time covered by the nurses and materials produced/required. However, these funds make no contribution towards the core costs without which the ASI cannot operate such as office, governance, and operational staff costs. Also not covered by current statutory funding is the time taken to advertise these free services across our social media platforms, the graphics created to ensure reach is maximized, and the time that goes into analyzing data gathered through the services.

Our services align with the Sláintecare ethos: right care, right place, and at the right time. We too want to keep people as well as possible in their homes through early intervention that our services provide which enable and empower patients to manage their diseases. Such early intervention through primary care has proven to reduce and prevent exacerbations which can lead to hospitalisation, increased pressure on health care services, and an increase to health care service costs.

Appropriate and secure funding would enable us to provide the following necessary services:

- National review of asthma deaths in Ireland
- Increase the number of asthma and COPD patients accessing our Adviceline and WhatApp messaging service
- According to GINA guidelines, a follow-up appointment is needed for asthma patients 2-7 days after discharge from hospital following an asthma exacerbation. The Asthma Society could better support HCPs at this vulnerable time when additional support is critically needed as risk of further exacerbation and death are significantly higher
- The development of an asthma bereavement support group
- Patient research to support the 5% of asthma patients with a severe asthma diagnosis

Demand for our services increased dramatically from the outbreak of COVID-19. In comparison to the previous year, April 2020 showed an increase of:

- 611% increase in website visits
- 210% increase of Adviceline nurse appointments
- 768% increase in the number of support calls and queries
- 1,744% increase in Asthma Action Plan downloads
- 1,043% increase in Facebook engagements: our main digital platform for patient outreach

In addition to this, we expanded our team and doubled the number of hours worked by our nurse specialists to manage the upsurge in demand. As a non-profit organisation, we request the necessary funding that will allow us to continually provide our essential services

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AIM

With sufficient funding, the Asthma Society can – without barriers – support in the provision of base line primary care for the 380,000 people in Ireland with asthma through our vital services.

ACTIONS

1. INTRODUCE UNIVERSAL FULL SUBSIDISATION OF ASTHMA MEDICATIONS

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2. EXPAND NATIONAL FUND FOR SEVERE ASTHMA MEDICATION

Expand national fund for biologic medication for severe asthma to ensure every person who would benefit from this life changing treatment has equitable access to it in a timely way.

3. FUND THE EXTENSION OF THE CURRENT ASTHMA MANAGEMENT PROGRAMME FOR ALL PEOPLE WITH ASTHMA

Fund the extension of the current asthma management programme for the under 6's to not only include under 12's, but all people with asthma.

4. INCREASE THE NUMBER OF REGISTERED ADVANCED NURSE PRACTITIONERS TO MEET 2% DEPARTMENT OF HEALTH GUIDELINES

Increase the number of registered Advanced Nurse Practitioners to meet Department of Health's policy of having 2% of the nursing and midwifery workforce working at advanced practice level.

5. PROVIDE THE ASTHMA SOCIETY OF IRELAND WITH ANNUAL CORE FUNDING

Increase funding to the Asthma Society from 28% to 50% to ensure basic needs are met. These funds would be used to cover core costs of the Society and provide a solid financial base on which to build its support programmes.



Asthma Society of Ireland 42-43 Amiens Street Dublin 1

Cumann Asma na hÉireann 42-43 Sráid Amiens Áth Cliath 1

Tel 01 817 8886 Email reception@asthma.ie

Asthma Adviceline 1800 44 54 64

COPD Adviceline 1800 83 21 46

Asthma & COPD Beating Breathlessness WhatsApp Patient Service MESSAGE 086 059 0132



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CHY no: 6100