

STOPPING ASTHMA DEATHS IN IRELAND

**ASTHMA SOCIETY OF IRELAND
STRATEGIC PLAN**

2020 – 2025



Asthma is a symptom severity communication problem. Patients struggle to translate night-time asthma to daytime GP appointment. **Asthma is a hospital loop problem.** These patients are particularly at risk of asthma deaths. Our lack of e-health records places patients at risk. **Asthma is a wellness understanding problem.** The patient's "normal" is not the real normal. Asthma attacks are "normal" – not a respiratory crisis. **Asthma is a steroid fear problem.** Patients are afraid of being dependent on their medication. "We'll think about if the baby/I should take the medication." **Asthma is a switch-on, switch-off problem.** Patients only think about their asthma when their asthma is really impacting on them. **Asthma is a predictability problem.** A proportion of asthma deaths defy logic, even to the best clinicians. **Asthma is an inhaler concept problem.** Lots of asthma patients don't even think of their "puffers" as being medication. **Asthma is an inequality problem.** The asthma prevalence map directly overlaps with the inequality map. **Asthma is a reliever over-reliance problem.** Patients believe passionately in their reliever inhaler, trusting it above all else. **Asthma is a sudden symptom versus build-up of symptom problem.** The suddenness of an attack prompts patients to act, but then management drifts again. **Asthma is a 'golden hour' problem.** The slow build-up over days means it's hard for patients to know they are getting worse - they do not then act in the hour before a life-threatening attack. **Asthma is an early onset problem.** Parents believe at every opportunity that their child will grow out of it. Adult onset patients don't believe diagnosis. **Asthma is an inhaler technique problem.** Inhaler technique is everyone else's job in health care provision. Patients don't even know inhaler technique is a real

thing. **Asthma is an invisible healthcare problem.** It doesn't cost as many bed nights and is invisible to health decision makers. It materialises in the invisible repeat GP prescription visit – often with repeated unsatisfactory outcomes. It's invisible to patients as they're so used to it. **Asthma is a family problem.** Patients medicate each other within families rather than get help. **Asthma is call-for-help problem.** During the final fatal attack of asthma, 45% died without seeking medical assistance or before emergency medical care could be provided - they were dying from their totally-used-to-it-chronic-condition. **Asthma is a 60% control problem.** And patients don't even know control is possible. **Asthma is a work problem.** Adults miss seven days from work. Children miss five days from school. Adults miss additional days, minding their child. **Asthma is a missing out problem.** People miss out on holidays, trips, family occasions, exercise, outdoors, pets, snow, winter, study, exams, work. People miss out on breathing deeply. **Asthma is a knowledge problem in Ireland.** We don't know who dies or why. We don't know who has severe asthma. **Asthma is an anxiety problem.** People can't tell the difference between an anxiety attack and an asthma attack. **Asthma is a fear problem.** Nobody should have to watch someone they care about struggling to breathe. **Asthma is a money problem.** Patients cannot afford their medication and ration it, putting themselves at risk. **Asthma is a living problem.** There is no cure, only management. **Asthma is a deaths problem.** We are fighting asthma with every breath.

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INTRODUCTION



The Asthma Society of Ireland is embarking on its fifth decade with the same essential purpose – to save lives and improve the lives of people with asthma. With *Stopping Asthma Deaths in Ireland*, our new 2020-2025 strategic plan, we've thrown down the gauntlet – for ourselves, for Government and for our health system.

It is vital now in the current pandemic scenario, more than ever, that a respiratory charity has a powerful and realistic statement of intention. Further, a strategy is a core part of the governance structure a charity needs to function well. The board has engaged with this strategy, learning and discussing, challenging ourselves and the Executive Team of the Asthma Society to draw up the best plan for the coming five years. We have listened to our patients, their families and health professionals. The challenges for the next five years are numerous. The Society is challenged to build the scale of our programmes and to play a role in building a different healthcare system, while we also have to fundraise in a diverse and secure way to survive in uncertain times.

In the long-term, to prepare to achieve this ambitious five year strategic plan, *Stopping Asthma Deaths in Ireland*, we have been steadily transforming ourselves as a charity. Our volunteer board is more diverse than ever. We have built a new research capacity with the Society, recognising that evidence-based advocacy is vital to making progress. Our use of technology is expanding our reach – we have launched only this month a new WhatsApp advice service complementing our traditional phone-based Adviceline. We continue to prioritise governance so our many stakeholders can have confidence in us.

As has been the case since its establishment over forty years ago, the Society will rely heavily on a dedicated team of colleagues, volunteers and funders to fulfil our *Stopping Asthma Deaths in Ireland* strategic plan to deliver for patients, their families and carers.

Chair of the Board of the Asthma Society, Dr. Allan Kearns



We've challenged ourselves to become a force for change in the Irish healthcare landscape. One person dies as a result of their asthma every seven days in Ireland; children die as a result of their asthma. We can no longer accept that as a healthcare outcome – that is sewn into the fabric of this strategic plan.

Our services play an important part in achieving the aims of this strategic plan. These services deliver over and above for patients as it stands – across our health promotion programmes, our advocacy and research work, our awareness-building, our work to support healthcare professionals as they too transform asthma management in Ireland. We plan that they will grow in impact, scale and will create a real improvement in health and wellbeing for patients.

But our work will only truly be impactful on the level we want if it is operating within the right national framework. Right now, that framework isn't there. We need a Government asthma deaths strategy to identify system failings and to lead the way in resolving them. We need the Long Term Illness Scheme to provide affordable medication; we need the new Chronic Illness Management Programme to be extended to all asthma patients. We need an Asthma Action Plan delivered for patients, with regular GP review, adequate respiratory consultant and nurse staffing levels. We need Sláintecare implemented in full. We need cleaner air.

Chief Executive of the Asthma Society, Sarah O'Connor



OUR MISSION

Our mission is to stop asthma deaths in Ireland.

**We are the voice of the 380,000 people
with asthma in Ireland, and our work
radically transforms their quality of life.**

OUR VISION

**Our vision is that everyone with asthma in Ireland
lives a full life, symptom-free.**



THE FIVE PILLARS OF THE ASTHMA SOCIETY

TO ACHIEVE OUR MISSION AND VISION:

1

WE CHAMPION CHANGE
by advocating to prevent asthma deaths.

2

WE COMMUNICATE ABOUT ASTHMA
to ensure it is taken seriously as a health challenge.

3

WE SUPPORT WITH SERVICES
for all people with asthma, empowering them to control the condition and providing health promotion programmes which deliver impactful asthma interventions.

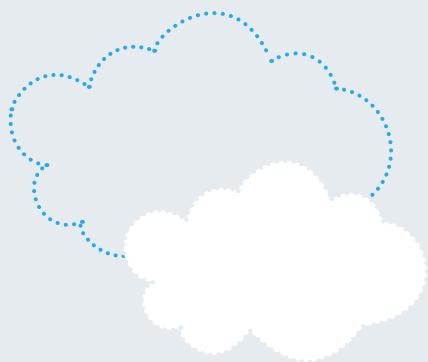
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WE LEARN TOGETHER
and collaborate with healthcare, research and education professionals (and always with patients) to improve our understanding of how asthma works and how to combat it.

5

WE BUILD OUR CAPACITY
to deliver for patients by growing and diversifying our funding streams, by innovating and by being best-in-class as a charity.

Asthma Society of Ireland – fighting asthma with every breath



WHAT WOULD SUCCESS LOOK LIKE?

We commit to bringing an end to asthma deaths in Ireland by 2030, with a reduction by half by 2025 – our dedication to this overarching outcome means:

- Every person or child with asthma or their carer in Ireland will need to have an Asthma Action Plan to better manage their asthma, through our services and campaigns and through interventions by empowered healthcare professionals.
- Patients with severe asthma will need to have equal access to medications and expert care across Ireland.
- The economic burden of asthma will need to be lifted, giving people with asthma better access to healthcare, health outcomes and improving the quality of their lives.



PILLAR 1

WE CHAMPION

CHANGE

GOAL 1:

To draft and implement an Asthma Deaths Strategy aiming to halve asthma deaths from the current level by 2025, and stop asthma deaths by 2030.

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GOAL 2:

To build awareness of the financial cost of asthma among key health decision makers and to effectively lobby for better management of State spending on asthma, to reduce the burden on individual patients.

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GOAL 3:

To create an awareness of severe asthma and its impact on quality of life and to lobby all relevant agencies to ensure equality of access to necessary treatments and healthcare.

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GOAL 4:

To change Irish society to create a more asthma-friendly environment in homes, schools, clubs and workplaces and in our wider environment.



PILLAR 2

WE

COMMUNICATE

ABOUT ASTHMA

GOAL 5:

To create better public awareness of the 5 Step Rule, how to recognise and manage an asthma attack.

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GOAL 6:

To communicate with the wider public about asthma, its management, its challenges. To do so, we must create memorable campaigns that last, kick-starting behaviour change among people with asthma.



PILLAR 3

WE SUPPORT

WITH SERVICES

GOAL 7:

To help people with asthma through our services to create and follow their Asthma Action Plan, as a key tool to combat asthma deaths.

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GOAL 8:

To ever improve our new and existing health promotion programmes and support services, working closely with the HSE and other partners, ensuring that they are excellent and impactful, and especially assisting those who are socially excluded.



PILLAR 4

WE LEARN

TOGETHER

GOAL 9:

To deepen our relationships and collaboration with all relevant healthcare and scientific professionals, helping them to become a fulcrum for change in patients, ultimately creating the best healthcare landscape and outcomes for people with asthma.

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GOAL 10:

To undertake and facilitate research to improve our understanding of asthma in Ireland and its potential treatment and management.



PILLAR 5

WE BUILD OUR CAPACITY

GOAL 11:

To diversify, deepen and sustain our future finances by growing our statutory, corporate, philanthropic and public fundraising.

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GOAL 12:

To substantially grow our ability by developing our team, services, systems and ways of thinking, delivering nationally and impactfully for patients by leading in the charity sector.



CHANGING ATTITUDES – OUR BIG CHALLENGE

We work on a daily basis to inform and change prevailing attitudes to asthma in Ireland, to make our country a more asthma-friendly place.

PATIENTS AND CARERS



Asthma is just a wheeze
 I have asthma so I'll always feel unwell
 Asthma attacks are normal for me
 Kids grow out of asthma – it's no big deal
 I can't do anything about my asthma
 I don't want to become dependent on my medication
 It can't be asthma because I'm not a child

HEALTHCARE PROFESSIONALS / POLICY DECISION MAKERS

Asthma is easy for me to treat
 Asthma is easy for a patient to manage
 I can't do anything about my patient's asthma
 It's someone else's job to help this patient manage the basics of asthma
 Asthma is too expensive a healthcare challenge
 Asthma patients in Ireland are doing fine
 I've already delivered self-management advice to this patient



HOW DO WE DO THIS? OUR VALUES

We put the person with asthma, their experiences and their needs at the heart of all our services and activities.

EMPOWERING

The Asthma Society is dedicated to empowering the 380,000 people with asthma in Ireland to take control of their asthma, by providing them and their families with information, services and support.

PIONEERING

The Asthma Society is pioneering in its work to represent the best interests of people with asthma and to improve their health outcomes. We retain this pioneering spirit through our high calibre medical oversight, our research to learn more about asthma, our continuous innovation to support patients and our lobbying for universal access to best practice asthma care.

EXPERT

The Asthma Society collaborates with patients, healthcare professionals, industry, researchers and government to provide expert information on asthma and allergies, devise professional guidelines, and implement international best practice for asthma management.

ACCOUNTABLE

The Asthma Society commits itself to the highest possible standards of accountability, governance and transparency in all its operations.



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