

Severe Asthma

in Ireland and Europe - A Patient's Perspective



The Unmet Needs of Patients With Severe Asthma

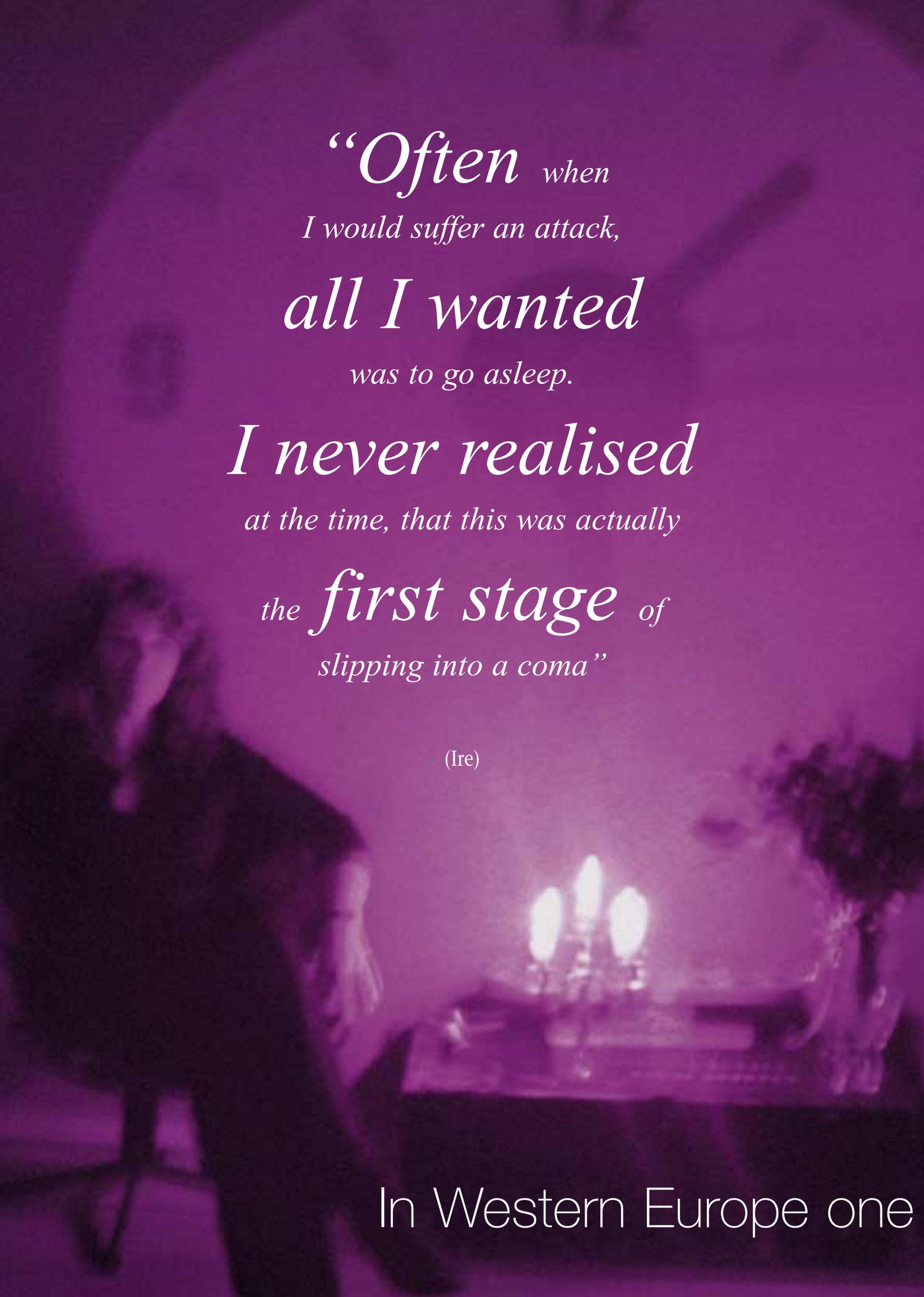
A report into the personal, social, health and economic burden of severe asthma

breathing.ie



SEVERE ASTHMA
ADVISORY GROUP



A woman in a dark dress stands in a dimly lit room. In the background, a chandelier with three lit candles hangs from the ceiling. The scene is bathed in a soft, purple light.

*“Often when
I would suffer an attack,
all I wanted
was to go asleep.*

*I never realised
at the time, that this was actually
the first stage of
slipping into a coma”*

(Ire)

In Western Europe one

Introduction

With some 32 million people in Europe with asthma and an associated cost of €17.7 billion per year¹, asthma represents one of the major medical challenges in respiratory medicine. There have been great advances in the development of new treatment options that enable patients achieve effective asthma control. With the marked increase in asthma over the past decade, these treatments are needed now more so than ever before.

Current management is guided by the approach described in the Global Initiative for Asthma (GINA) management guidelines. Despite GINA, the Asthma Insights and Reality in Ireland (AIRI, *Published IMJ 2005 Vol 98: Number 10*) survey found almost one in five asthmatics had suboptimal control of their symptoms. There are 80 - 100² asthma-related deaths reported annually in Ireland. This is over one death per week, due to asthma alone, which is very high. It is also cause for concern that an estimated 6,300² Irish asthmatics meet the GINA criteria for severe persistent asthma.

A growing body of clinical work also suggests that severe asthma is a completely different type of disease than mild or moderate asthma. The ENFUMOSA (*European Network for Understanding Mechanisms Of Severe Asthma*) study was the first comprehensive assessment of severe asthma across Europe. It concluded that features of severe asthma are distinct from those described for mild-to-moderate disease.

I welcome this report as it highlights, from a patient's perspective, the obstacles faced living with severe asthma. It also compares the Irish situation in relation to the rest of Europe.

Dr. Pat Manning

Chairman, Severe Asthma Advisory Group

There is a widespread popular misconception that asthma is a mild disease that only affects children. Not many people are aware of the severe consequences it can have on a person's quality of life.

Asthma is under-diagnosed and under-controlled, creating a substantial burden to individuals and families and possibly restricting individuals' activities for a lifetime.

Asthma is on the increase worldwide but the reasons for this are unclear. Ireland has the fourth highest² prevalence of asthma in the world. However, there is a lack of statistics and research on severe asthma in Ireland.

80-100² asthma related deaths are reported annually, however this may be under-reported as deaths from asthma are not notifiable. Equally, the real burden that severe asthma adds to emergency room visits and hospitalisations is unclear.

The Asthma Society of Ireland welcomes this report, and ongoing study, as a way to quantify and highlight the issues for severe asthma patients in Ireland.

Dr. Jean Holohan

CEO, Asthma Society of Ireland

person dies of asthma every hour

The Statistics

- Ireland and Europe

1 in 5 live in fear their next attack will be their last¹

In Western Europe, at least one person dies of asthma every hour, yet 90% of these deaths could be prevented.¹ Asthma deaths will increase by almost 20% in the next 10 years if urgent action is not taken.³

Introduction to Severe Asthma in Ireland

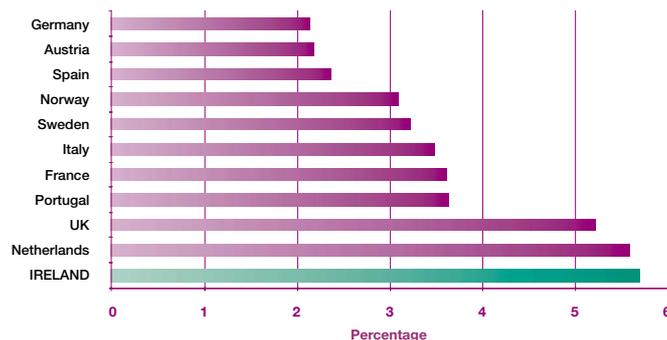
There are 470,000² people with asthma in Ireland. For the majority the condition is relatively mild and has little impact on their lives. But for approximately 6,300² people the reality is more serious. This group of people suffer from severe asthma, which has a huge impact on their daily lives, including debilitating breathlessness and attacks so bad they cannot speak. They also fear they may die and have frequent hospital admissions.

Methodology

Research from the European Community Respiratory Health Survey (ECRHS), surveyed severe asthma patients aged 20 - 44 years across Europe. The Irish Quality of Life Study surveyed severe asthma patients aged 18 - 62. Both surveys used the same questionnaire. This report presents a combination of findings from both surveys.

The ECRHS survey monitored asthma attacks. Prevalence of an asthma attack in the last 12 months was the highest in Ireland at almost 6%.¹ The Netherlands and the UK were also high and reported rates above 5% - well above the reported prevalence for the other countries.

Prevalence of an asthma attack in past 12 months in 20-44 year olds. Selected European Countries.



Source: Variations in the prevalence of respiratory symptoms, self reported asthma attacks, and use of asthma medication in the European Community Respiratory Health Survey (ECRHS). European Community Health Survey. EurRespir J 1996: 9

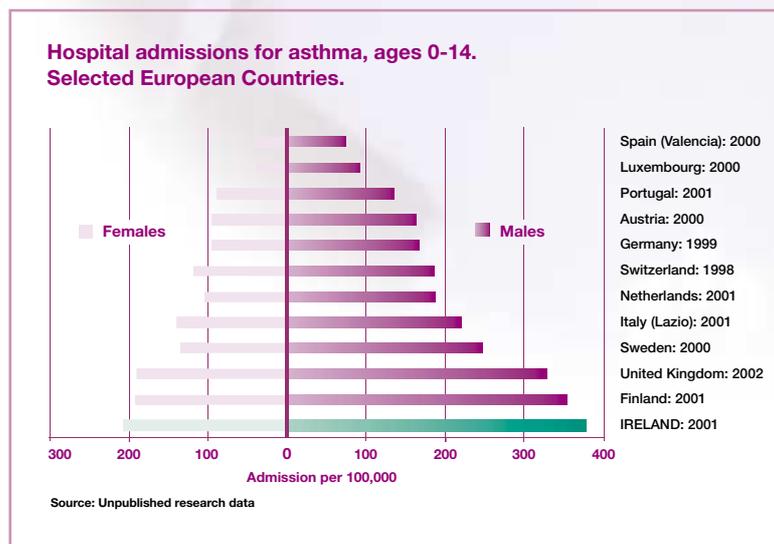
In Western Europe one

Hospital admissions for asthma¹

Hospital admission data is not routinely published in most countries, however admissions for asthma in certain countries have been obtained through approaching national registries as part of a separate research project.

The research found hospital admission rates were higher in children than adults, with the highest rate of child admissions in Ireland.

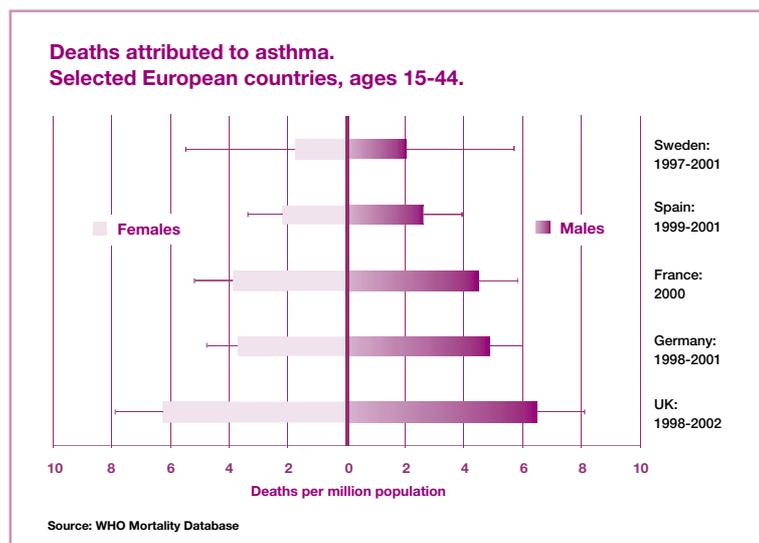
Switzerland and Finland had the highest admission rates in adult males, followed by Ireland and the UK. Switzerland also had the highest admission rate in adult females. The UK and Ireland, had the next highest figures.



Death from Asthma¹

Although the statistics on causes of death are published by WHO, asthma deaths have only recently been listed separately from other respiratory illnesses and are not available for all countries. As a result, asthma death is still under reported.

Although Sweden had relatively high hospital admission rates for both children and adults, its mortality rates were the lowest of the five countries.¹ To improve healthcare policy in asthma, national governments should make greater efforts to compile surveillance data in asthma.



person dies of asthma every hour

The Patient's Experience

- Ireland and Europe

People with severe asthma in Ireland were asked about their experiences of living with severe asthma. These results have been compared with a European survey on severe asthma patients.

People were identified with severe asthma if they met with one of the following criteria in the last year.

- Sleep disturbance once a week or more often
- A wheezing attack once a week, or more often
- One or more speech-limiting attacks

Living with Severe Asthma

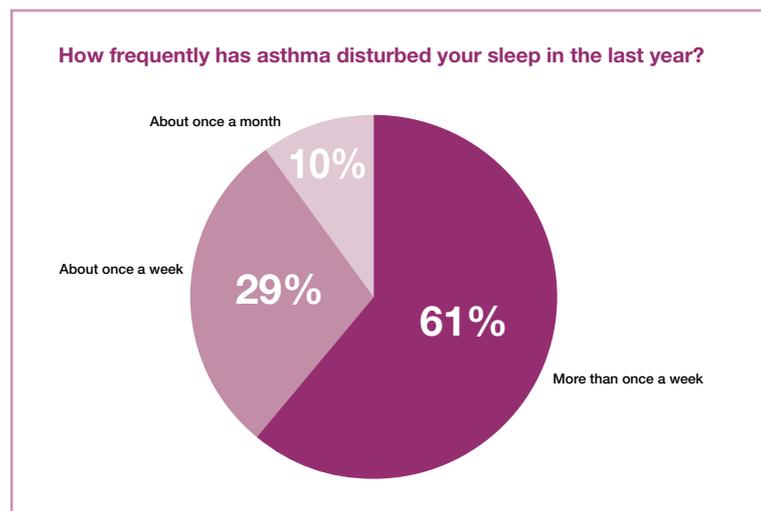
The three most common words used by people to describe severe asthma are breathlessness, suffocation and fear.¹ In Ireland 62% of patients use the word, "frightening" to describe their asthma.³

Severe asthma affects people every day of their life. 86% are affected by their asthma on a weekly basis, 62% of people have attacks of wheezing more than once a week.³

Disturbed nights

For many people with severe asthma, symptoms are worse at night than during the day. Constant coughing and gasping for breath make it hard to have an undisturbed night's sleep, leaving a person feeling exhausted the following day.

61% of people in Ireland have their sleep disturbed more than once a week³, compared to almost one quarter of people surveyed in Europe (24%).¹

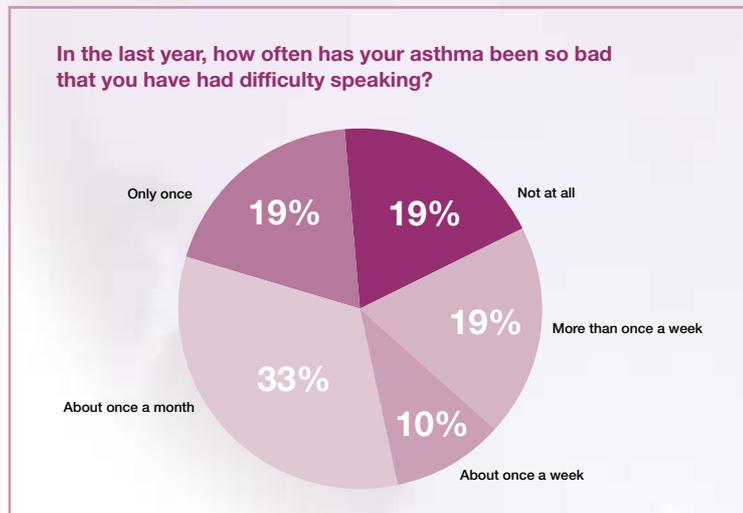


In Western Europe one

So breathless you can't speak

29% of people in Ireland surveyed suffer from severe speech-limiting attacks on a weekly basis.³

In Ireland, one third (33%) of people suffer from such an attack about once a month compared to 19% of people surveyed in Europe.^{1,3}



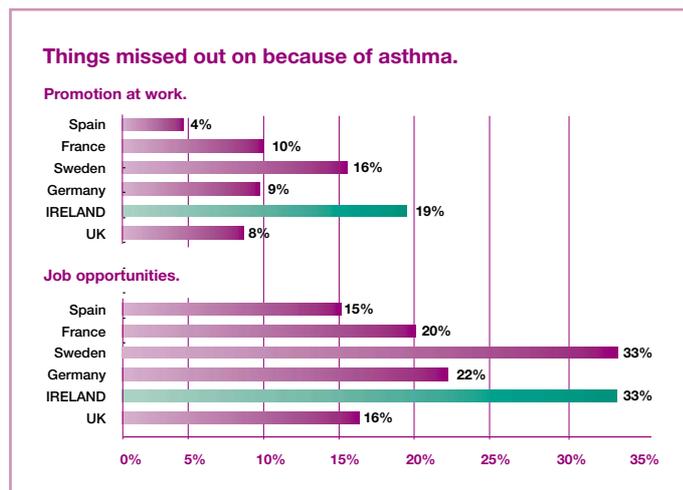
"I was often worried about having an asthma attack in the middle of the night and not being able to call out for help. I would keep a shoe by my bed and would bang on the floor for my mother to hear in case I suffered an attack" (Ire)

Severe Asthma in the Workplace

Severe asthma reduces a person's capacity for personal and economic fulfilment and increases a sense of isolation. Stigma and stress are common obstacles that asthma sufferers have to face and disadvantage at work is not unusual among people suffering with severe asthma.

"They know that once a month I won't come in because I'll have a bad attack in the morning"¹ (France)

In Europe, overall, nine percent say their asthma denied them a promotion.¹ In Ireland the figure is even higher at 19%.³ The sense of constrained job opportunities is even greater, with one in five people reported missing out on job opportunities due to their asthma, rising to one in three in Ireland.^{1,3}



The main problem people have with their workplace is allergens such as chemicals or dust. On average it takes 1 week to recover from an asthma attack, so it is no surprise that asthma has a direct impact on a worker's attendance or performance.

person dies of asthma every hour

The Patient's Experience

- Ireland and Europe

Isolating factors

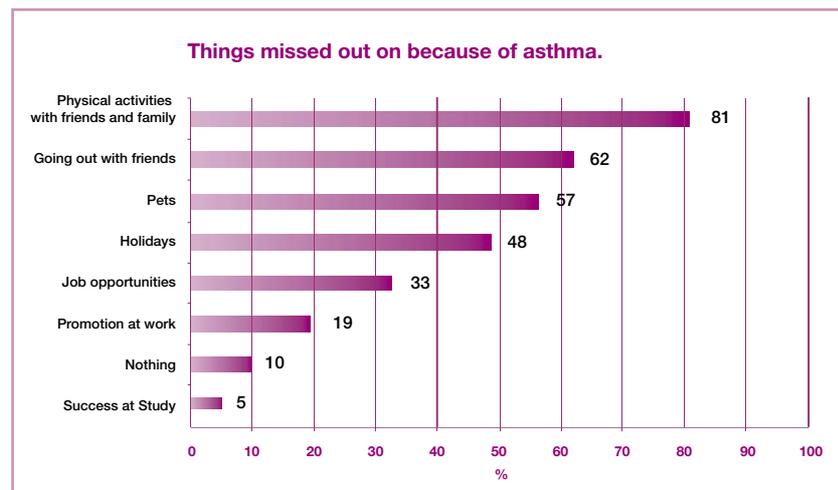
The critical issue for those who suffer from severe asthma is the effect on quality of life.

Social situations that are taken for granted such as going on holidays, going out with friends, or taking a walk in the countryside are avenues of social interaction that can be shut to those suffering with severe asthma.

Almost seven in ten (69%) participants in the European study say their asthma prevents them taking part in sport or other physical activities.¹

"The severity of my asthma means I don't have much of a social life and I feel very isolated. I have lost a lot of friends because of my illness. My relationship with my partner broke down because of my asthma"¹ (UK)

The two most common things people in Ireland cited as missing out on include physical activity with friends and family (81%) and going out with friends (62%). Almost one in three Irish severe asthma patients (29%) reported restrictions in their daily activities.³



In Ireland, 86% of people reported that the smoking ban in the workplace has made a difference to their asthma.³

"I cannot spend the whole night in a bar, I have to keep popping outside. Most places you go to have smokers and many places have very small no-smoking areas, or people just don't care and smoke next to you"¹ (Spain)

"Its great, it used to be so difficult to go out with everyone smoking around you, sometimes I just would not be able to go to pubs and music venues, but now I can" (Ire)

In Western Europe one

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*I have **lost a lot** of friends
because of my illness.*

*My relationship with my partner
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person dies of asthma every hour

The Future

The Irish and European studies yielded different results in people's expectations in relation to their national healthcare system providing better asthma care in the future. In Europe, fewer than half of participants (47%) expect their national healthcare system will be providing better asthma care in the next 5 years, compared to 57% of people in Ireland.^{1,3}

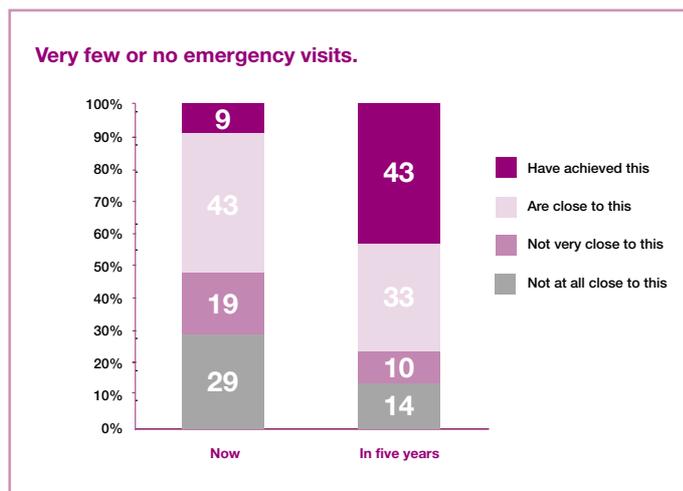
However, both Europe and Ireland report similar figures in relation to future asthma medicines. 71% of people in Europe and 67% of people in Ireland are pinning their hopes on a better choice of asthma medicines in the years to come.^{1,3}

Nearly half the Irish respondents (48%) say they are far from their goal of achieving very few or no long term asthma symptoms.¹

The Economic Burden

The economic burden of asthma is very substantial. In Europe the cost of asthma is €17.7 billion per year.¹ In 2003 in Ireland the total cost to the state was €463 million and of this, emergency care and hospitalisation accounted €227 million.⁴ With asthma on the increase worldwide, there is no doubt that this figure will increase in the future.

29% of Irish people with severe asthma do not feel they are close to having few or no emergency hospital visits, at present. In future, they are hoping this will improve.³



"You try to live as normal a life as possible but this means listening to your body, taking your medicine, managing your symptoms and always, always thinking about what might be around the next corner"¹

In Western Europe one

Kim's Experience

of Living with Severe Asthma

41 year old Kim has suffered from severe asthma all her life, however it was not until she was 7 years of age that she was first diagnosed with asthma and put on an inhaler.

When Kim was a child, she missed out on a lot of school because the frequency of her asthma attacks left her feeling exhausted. She constantly felt wheezy and out of breath and had trouble trying to keep up with her class mates. Kim had missed out on so much school, that she decided to leave school after transition year and got a job working in a local supermarket.

Kim's asthma became so bad that she had it constantly and she couldn't get any relief from her symptoms. She couldn't sleep at night and was always tired.

"I was often worried about having an asthma attack in the middle of the night and not being able to call out for help. I would keep a shoe by my bed and would bang on the floor for my mother to hear in case I suffered an attack".

As Kim got older, she began to spend more and more time in hospital. "In one year, I had 25 admissions to hospital and five critical admissions". On average this was one admission to hospital, nearly every two weeks.

Having severe asthma was upsetting and frustrating for Kim. "I used to cry and get annoyed that this was happening to me. I would see all my friends going out and I wouldn't be able to go and then eventually I lost interest in going out altogether".

It can take up to one week for a patient to recover from a severe asthma attack and because of Kim's asthma she was often absent from work.

"I was lucky my company were very understanding and realised how unwell I was".

Kim started a new medication and she is much better now. It has been a turning point in her life.

"It has been a miracle. I've been able to go back to work full-time and I am also able to go out for the night with my friends and even dance. This was something I could never do before", Kim said.

"My friends and the girl's in work just can't believe the change in me", she continued.

After three months, the wheeze in Kim's chest disappeared.

"After having a wheeze for my whole life, it was amazing that after only three months the wheeze went away, I just couldn't believe it", said Kim.

Like many people suffering from severe asthma, Kim did not realise how serious her condition was.

"Often when my wheeze would get really bad and I would suffer an attack, all I wanted was for people to leave me alone and to go to sleep. I never realised at the time, that this was actually the first stage of slipping in to a coma. I really never realised how bad my asthma was".

person dies of asthma every hour

Facts and Figures

Ireland's Facts and Figures

- Approximately 470,000 people have asthma²
- Ireland has the fourth highest prevalence of asthma in the world²
- 6,300 people have severe asthma²
- There are 80 - 100 reported asthma related deaths per year²
- 25,000 Accident and Emergency visits per year are asthma related²
- There are between 6,000 and 7,000 asthma-related hospital admissions per year²

European Facts and Figures

- In Western Europe 1 person dies of asthma every hour¹
- The three most common words used by people to describe severe asthma are breathlessness, suffocation and fear¹
- The UK has one of the highest rates of both emergency and mortality rates in adult and children¹
- Ireland has a highest rate of hospitalisations¹
- Germany has the highest level of emergency visits¹
- Irish and Swedish respondents are the most likely to feel that they have missed out on career opportunities because of their asthma¹
- One in three people expected their prospects to deteriorate over the next five years¹

Many thanks to Dr. Stephen Lane, Consultant Respiratory Physician, Dr. Peter Greally, Consultant in Paediatric Respiratory Medicine and the staff and patients at the respiratory centres in the Adelaide & Meath Hospital who took part in this research.

References

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