

Executive summary



Millions of Europeans suffer uncontrolled serious asthma symptoms, and thousands die of the disease every year. Severe symptoms such as chest tightness and breathlessness affect around 6 million people in Europe¹, taking their toll at work and at home, reducing the capacity for personal and economic fulfilment, and aggravating a sense of isolation. Exclusion from work, from physical activity and even from public spaces (where the right to smoke is more important than the right to breathe) – each of these slices away at people's well-being, undermining their capacity to take control of their own asthma. A severe attack is a terrifying experience, leading to emergency hospitalisation and even in the case of 12,000 Europeans a year, to death.²

3

In the majority of patients, severe asthma symptoms should be manageable, although there is still a smaller number of around 1.2 million in Europe for whom current treatment approaches are not enough.⁴

Asthma control in Europe has improved significantly in recent years but still falls well below international treatment goals, and those with severe asthma symptoms expect their symptom control to worsen in the next five years. They have become accustomed to compromising their lives on a daily basis, without expecting – or demanding – any improvement.

Any optimism about future treatment choices is tempered by pessimism about national healthcare systems' capacity to keep pace. Most recognise that their doctor is trying to achieve treatment targets but many feel they are failing to meet them. Greater patient involvement and two-way communication may help to address this and allow patients to feel more in control of their asthma. As it is, lack of empowerment adds to their feelings of isolation and contributes to their pessimism about their future care.

Severe asthma

The hard facts:

- Every hour, at least one person dies of asthma in Western Europe²
- 32 million people have asthma in Europe¹ - 6 million of whom live with severe asthma symptoms, which can include waking at night breathless or coughing, frequent shortness of breath, regular attacks and limitations on daily activity
- Fewer than half feel they are close to achieving international treatment goals
- People with asthma are being widely exposed to second-hand smoke and pollutants which can trigger a serious attack
- More women die of asthma than men
- More adults have severe asthma than children, but significantly more children are admitted to hospital
- The total cost of asthma in Europe is €17.7bn per year, and productivity lost to poor asthma control is estimated at €9.8bn per annum³
- The UK has one of the highest rates of both emergency and mortality rates in adults and children
- Annual treatment reviews are rarely reported in France but commonly reported in Germany
- French respondents seem the most concerned about potential side effects of their medication
- Ninety-nine percent of French respondents rely on reliever medications - an indicator of poor control
- German respondents are more pessimistic than other countries about the possibility of asthma care deteriorating in five years. They also report the highest level of emergency visits
- Spanish respondents are concerned about access to specialist care. Although the majority are failing to reach current treatment goals, they are the most optimistic about improvements in the future
- Swedish respondents are the most likely to feel that they have missed out on career opportunities because of their asthma

The personal experience:

- At least one in five live in fear that the next attack could kill them
- Three in four have disturbed sleep at least once a week due to night-time breathlessness, often leading to exhaustion the next day
- Once a week, one in four have attacks so severe they cannot even call out for help
- One in five feel disadvantaged at work or study
- Almost 70 percent have to restrict their physical activities
- One in three miss going out socially because of the fear of an attack
- The three most common words used by people to describe severe asthma were 'breathlessness', 'suffocation' and 'fear'
- Others expressed how they felt ignored by society, encaged by their asthma and lived with a sense of shame and embarrassment

National differences:

- Sweden has high hospital admission rates in children but one of the lowest rates in adults. They also report one of the lowest mortality rates

Expectations for the future:

- One in three expect their prospects to deteriorate over the next five years
- Fewer than half expect asthma management to improve, although they do expect treatments to get better

What people with asthma want:

- One in three want to see more investment in research for new treatments
- Many want a total ban on smoking in public places, particularly in the UK
- People in Sweden want free prescriptions
- Input into treatment plans, better access to a specialist and new more effective medicines are all considered essential to improving asthma symptoms
- Other priorities include experiencing fewer limitations because of their asthma, fewer night-time attacks, having more energy and being less exposed to environmental pollution and fumes at work

References

1. GINA Global Initiative for Asthma. The Global Burden of Asthma Report, 2004
2. World Health Organization; <http://www.who.int/mediacentre/factsheets/fs206/en/>
3. European Respiratory Society. The European White Lung Book: The First Comprehensive Survey in Respiratory Health in Europe 2003
4. Rabe KF, Adachi M, Lai CK, et al. Worldwide severity and control of asthma in children and adults: the global Asthma Insights and Reality surveys. *J Allergy Clin Immunol* 2004;114:40-47

*“On a bad day I feel like I’m drowning and I can’t reach the surface of the water and I am going to burst, yet a tiny, tiny bit of air keeps me alive. It’s very scary - I feel like I’m living with a time bomb and if I have a bad attack I say to myself:
Is this the one that will kill me?”*



Catherine Tunnicliffe