

Fighting for breath

The hidden lives of people with severe asthma



Contents



‘My asthma became severe in my early twenties – it was devastating. I should have been out having fun. It was like someone had got a gun, shot my knees off and said now your life is over.’

Kerry-Anne Cooper, Middlesbrough

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Foreword



‘We have friends of the family who don’t understand why I spend so much time in hospital when I look “normal”. They don’t see me when I am struggling to breathe and my family is scared that I won’t survive the night.’

Sarah Jane Lewis, St Neots

Fighting for breath – the hidden lives of people with severe asthma is a call to action for us all to make a change and improve the lives of people like Kerry-Anne for the better. We hope through this report eyes will be opened to the reality of living with or caring for someone with severe asthma and show the changes that are needed now.

Healthcare professionals, commissioners, social workers, teachers, employers, regulators and policy makers all have a responsibility to people living with severe asthma, who we know have been marginalised for too long. This responsibility, though, also extends to the public who need to increase their awareness and understanding of what it can be like to live with this hidden condition.

With the NHS searching for ways to improve efficiency and better manage long-term conditions, there is a clear opportunity to make meaningful improvements to asthma care which will benefit those who need it the most. People with severe asthma are the heaviest users of health services, and around 80% of spending on treating those with asthma is spent on the 20% with the severest symptoms¹.

The benefits of targeting improvements for this group are clear and critical to both the quality and productivity of asthma care. If preventative care is productive care, then finding effective ways of keeping at-risk people like those with severe asthma well can point the way to a more

productive NHS. This means ensuring that everyone who needs access to specialist services gets it. People with severe asthma and their carers should be supported in the right way at every point of contact with the NHS, from effective emergency care to open discussions about their medicines. Our research for this report has highlighted that sadly this is often not the case.

The experiences of people with severe asthma in the future will also be a crucial test of how well the coalition government’s commitments to a fair society are being implemented. People with severe asthma want to work, to study and to reach their full potential, but they cannot know when their asthma will affect them. We need a new approach to disability from schools, employers and the public sector that recognises the variability of long-term conditions like severe asthma and adapts to support people when they need it.

Failing to act now could consign people with severe asthma to the outside – unable to fully work or participate in society and unable to cope with the severity of their symptoms without expensive acute care.

This is a price that we cannot afford to pay.

A handwritten signature in black ink that reads 'Neil Churchill'.

Neil Churchill
Chief Executive, Asthma UK

Severe asthma and this report



‘It feels like somebody sticking a pin in my chest and then it’s a hundred pins. Straight away my airways close and I can’t breathe, it’s not a gradual thing but sudden. I try not to panic and dial 999.’

Kerry-Anne Cooper, Middlesbrough

This report is the culmination of a project jointly conducted by Asthma UK and the Severe Asthma National Network (SANN). It brings together the experiences of people with asthma and healthcare professionals to highlight the hidden impact of living with severe asthma.

Asthma is one of the most common medical conditions in the UK, affecting over five million people². The usual symptoms of asthma are coughing, wheezing, shortness of breath and tightness in the chest, caused by narrowing and inflammation of the airways. Currently there is no cure, but with the right treatment, the majority of people with asthma can live a full and active life. However, for a small proportion – around 5% or a quarter of a million people³ – symptoms are more severe and the usual asthma treatments just don’t work properly.

This means that people with severe asthma may have to take high doses of a long list of medicines with harmful side effects. Even then, many have difficulty breathing almost all the time, as well as frequent serious asthma attacks needing hospital stays and an increased risk of permanent lung damage or developing chronic obstructive pulmonary disease (COPD)⁴. Reducing or stopping medicine can mean quickly going downhill, forcing people to either live with the appalling side effects of their medicines, or risk a life-threatening asthma attack.

We went to five hospitals which treat people from across the UK to hear in depth from 50 people affected by severe asthma⁵. Everyone who we heard from had either been diagnosed with severe asthma themselves or had a child diagnosed with severe asthma by a healthcare professional in a specialist centre⁶. Those who joined our discussions shared personal information about living with severe asthma. Their words, views, opinions and experiences appear anonymously in this report.

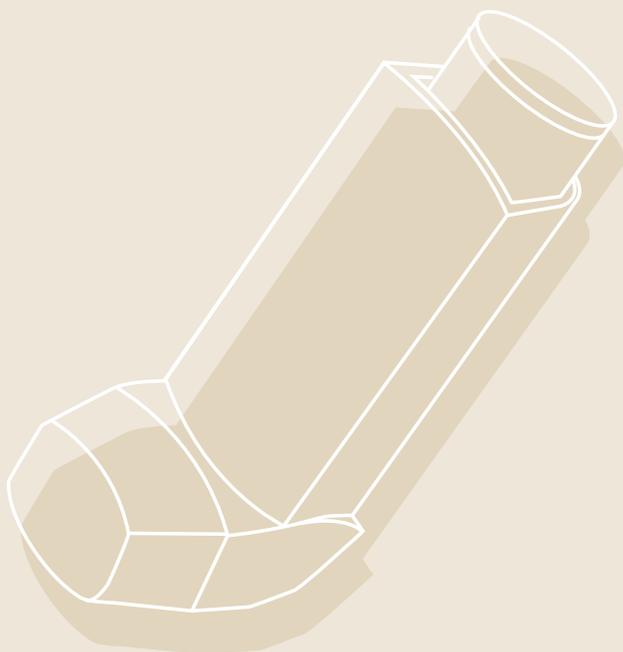
We also interviewed individuals from across the UK whose lives are affected by severe asthma who agreed to share their stories with us and be photographed for this report.

Asthma is a variable condition. Many people will have severe asthma throughout their lives, though the severity of asthma can change over time, getting better or worse on moving into adulthood or changing at other times such as during pregnancy. It is also different in different people – and there are also many definitions of what it means to have severe asthma. Moreover, many people with severe asthma also have other related conditions such as allergies. This means that we could never capture the full range of everyone's experiences of severe asthma in a report like this. Instead, we have chosen to highlight the main issues and themes the people we spoke to had in common. What is included here is a reflection of the subjective experiences of people with severe asthma.

We have heard from parents fighting to overcome life-limiting asthma to give their children the same chances that others take for granted; we have heard from young people consigned to weeks in hospital at a time, who are afraid that their asthma will never improve enough to enable them to have a permanent job; and we have heard from older adults who have lived with severe asthma for decades, constantly finding ways to adapt everything they do to fit around their asthma.

Very few people realise just how limiting asthma can be. It gets very little attention from policy makers who assume that nothing more needs to be done or that asthma has less impact than other 'more serious' long term conditions.

This report calls on everyone to take severe asthma seriously.



Managing symptoms, medicines and side effects



'I am currently taking 18 different drugs to try and keep some control of my asthma. Of course with all these drugs comes side effects – weight gain, steroid induced diabetes, potentially osteoporosis to name a few.'

Sarah Jane Lewis, St Neots

Asthma symptoms

What it means to have severe asthma is different from person to person. Some people live with breathing problems all the time; others have sudden severe asthma attacks with little warning. Keeping symptoms under control is the main goal of asthma treatment, but the reality for many people with severe asthma is that this is not possible. This means that they have to find a way to cope with dangerous and frustrating symptoms.

'For me, it's the constant ache in the back, literally trying to get air into yourself. You are using muscles permanently in your back, and then it's like somebody shoving you under the water or putting a cushion over your head. That is scary.'

Man with severe asthma, Leicester

'My worst thing about being asthmatic is my cough, I work in an office and I had up until recently the filthiest cough you would want to have... I am sure, it used to come on suddenly, there must have been people beside me going, "Eugh!" There is a guy behind me, I have got a cough worse than him and he is a 40 a day smoker!'

Woman with severe asthma, Glasgow

‘The thing is, you get the asthma, you are living with asthma, you then get the attacks as well, they are that bad that you are on your knees, you are wringing wet with sweat and people come up and ask to help. There is only one person to help and that is yourself.’

Man with severe asthma, Leicester

Treatment regimes

Treatment regimes for people with severe asthma can be overwhelming – both in terms of their complexity and their impact on quality of life. Some people with asthma find it difficult to adhere to these regimes which can quickly lead to worsening symptoms, but almost everyone we spoke to said that they were taking their medicines as directed because the risks of not taking them were just too great.

A typical treatment regime can range from a few tablets to a multitude, in addition to injections and inhaled medicines with some people taking medicines every few hours. The constant presence and routine of a medicine regime takes its toll both emotionally and physically, making it difficult for people to carry out normal day to day activities and acting as a constant reminder of the severity of their condition.

‘I have been on 40 [tablets] a day and that is hard. Imagine being sick every day and still having to take 40 pills. That’s without all the nebulisers – I have them every four hours.’

Young woman with severe asthma, London

‘I hate having to take so many pills, potions every day at specific times, it annoys me, it makes me angry. I live by the clock, so I am basically constantly thinking about needing to take my medication, I am always conscious of it.’

Woman with severe asthma, Glasgow

Side effects

Routine treatments are not always effective for people with severe asthma. They can often find themselves taking very high doses of medicines for a long time. Almost all of the people we spoke to described severe side effects as a consequence of this; the role that side effects play in the lives of people with severe asthma cannot be emphasised enough. People at our discussions reported the following side effects (though not all are clinically recognised):

- weight gain
- growth problems
- depression
- anxiety
- dental problems
- insomnia
- osteoporosis
- nausea
- hair loss
- skin problems
- oral thrush
- feeling weak and tired
- diabetes
- shaking
- ‘moon face’ (round and swollen face, associated with taking oral steroids for a long period of time)

Many of the people that we spoke with felt that side effects from their medicines were the hardest thing to deal with about their asthma, even when coping with their daily symptoms and the constant threat of a life-threatening attack.

‘He says [his asthma medicine] makes things worse. It might make his asthma better, but he has side effects from taking the medicine, which makes him feel worse. He has got depression because of it, and he really resents that this is what the asthma medicine has done to him.’

Mother of a 13 year old boy with severe asthma, Glasgow

‘When I am on really high doses... I feel toxic. You shake, you feel awful, you have blotches and your skin is deadly pale... You look like you have got the plague. You have a massive moon face as well, it’s so round and disproportionate to the rest of your body.’

Young woman with severe asthma, London

‘I put on about two and a half stone in two years. With asthmatics, when you are little they always worry when you are off the bottom of the chart – and I was always tiny and suddenly absolutely shot up. My hair started falling out. I was standing in the shower and huge clumps of hair falling out.’

Young woman with severe asthma, London

Effectiveness

Taking asthma medicines for a long time can undermine people's confidence about the effectiveness of asthma treatment, adding to their struggle to stay positive.

'I have no idea whether they make a blind bit of difference or not, I give them to him and I just sometimes feel quite guilty.'

Mother of an 11 year old boy with severe asthma, London

New treatments often lead to high hopes – and new drugs are life-changing for some – but due to the variable nature of severe asthma new drugs or procedures aren't right for everyone, and it can be a great disappointment to find that a treatment can't be accessed or isn't suitable. This means that research into treatments for different groups of people with severe asthma is vital.

'The Xolair [a new drug for asthma, Omalizumab] has helped, he has bounced back, overall he has been much better... He has got energy, he can be involved with life and therefore he can be happier. When he is well like now, it's like somebody I haven't seen for three years...it's only when he started getting better I realised how low he had been.'

Mother of a 13 year old boy with severe asthma, London

'These injections [of Omalizumab] haven't worked, so what we are going to do now, I don't know.'

Mother of a nine year old boy with asthma, Leicester

Mental health

While side effects can have a profound effect on the quality of day to day life for people with severe asthma, depression is a particular problem as people feel that it is perpetuated by their medicines as well as their struggle to cope with their asthma symptoms. Moreover, research has shown that having asthma and depression together worsens the impact of asthma⁷ and confidential inquiries have found that psychosocial factors are a common risk factor for asthma deaths⁸.

'It's got to the point where I am on so much medication, sometimes I give up, and yes, because of the steroids, it causes depression, and I am not afraid to admit I am a manic depressive because of it. Sometimes I have come that close to committing suicide because of it, and I have ended up seeing psychiatrists.'

Man with severe asthma, Leicester

'I have lost friends because of my moods. People not understanding that you are really at rock bottom of life right now, and then just thinking well you have only got asthma, what is wrong with you?'

Young woman with severe asthma, Leicester

Information and support

People with severe asthma need support to deal with the side effects of their medicines. They also need access to comprehensive information about what the side effects of their medicines could be in order to help them make an informed choice about how to manage their own asthma. While they would not necessarily decide differently, young people in particular wanted information to be made available from an early age to avoid having to come to terms with this later on, particularly about the risk of long term effects such as the effect on growth and fertility.

'I have been on harmful drugs since I was young.... when I was 14 I started researching them and I was on drugs that can cause fertility problems when you are older ...I am on infusions and could be at risk of HIV, and no-one explains that to you when you are younger.... my mum was just as surprised as I was... I don't think I was lied to but sometimes during my adolescence I wasn't completely kept informed and that really bugs me. I might have osteoporosis because I wasn't told.'

Young woman with severe asthma, London

It is important that healthcare professionals managing people with severe asthma are able to understand and recognise the side effects of high dose treatment regimes and offer appropriate counselling and support.

Recommendation: Effectively manage the impact of severe asthma medicines

- Everyone with severe asthma should receive advice about potential side effects from their asthma medicines (and the likelihood of experiencing them) when they are prescribed.
- Healthcare professionals supporting people with severe asthma must have appropriate training in recognising and managing side effects, and support in dealing with them should be incorporated into regular care.



What Asthma UK is doing: the Asthma UK Adviceline

The Asthma UK Adviceline 0800 121 62 44 is staffed by asthma nurse specialists who provide independent confidential advice and support to people with asthma and their families, friends and carers. They also offer advice and support to healthcare professionals. The Adviceline receives an average of 7,500 calls a year and enquiries range from questions about what asthma is and what causes it, triggers, symptoms, treatments and inhaler devices to what to do in an asthma attack. Calls are free from a BT landline.

Living with severe asthma



‘Asthma just isn’t that blue inhaler, it’s everything else that comes with it. Normal things take longer, like washing and dressing. I can’t play properly with my son. It’s all the things that other people take for granted.’

Simon Savill, Stevenage

Everyday life

Severe asthma places a huge strain on people. For many families, it is a constant presence in the background, always forcing them to plan exactly what they can do and where they can go.

‘It is hard, though, because there doesn’t seem to be any light at the end of the tunnel. When [my son] is in hospital... there will be a child next to him and he will have a broken arm or whatever... This lad said to [my son], “I am going to be all better and home by Christmas, are you?” And [my son] was like, “Yes, but I am not going to be better.” There is never that finish to it, never a line underneath it, it’s always ongoing.’

Mother of nine year old boy with asthma, Leicester

Mundane activities that most people take for granted can be a real challenge because of shortness of breath – things like doing the shopping, going out with friends or joining in with sports. Holidays are also extremely difficult; planning accommodation with easy access to the nearest hospital in case of an emergency is not easy, while travel insurance is often prohibitively expensive.

‘As you get older, for me it gets more frustrating. The fact that I had to put off university, [I] can’t go out clubbing. I’ve been out and had to go to a nightclub and for them to call an ambulance... it was actually mortifying.’

Young woman with severe asthma, London

‘I can’t get up the stairs, that is the difference... You wouldn’t think about it, would you? You have to think about everything you do so that you are not putting yourself into danger.’

Woman with severe asthma, Leicester

‘[My life] has completely changed in the last year, I was a very busy special needs classroom assistant, jumping about, I collected children after school and also had another job. Now I am lucky if I can get washed and dressed in the morning, my life has completely changed for the worse. I loved my job and I’m in the process of maybe having to stop due to ill health.’

Woman with severe asthma, Belfast

Financial support

Some people with severe asthma are seriously disabled by it and cannot work. Many of the people we spoke to depend on the financial support of the benefits system to enable them to live their lives – but their experiences of trying to make a claim are not always positive or consistent. Moreover, there were others who were not even aware that they might be able to get some financial help. People talk of being unable to find information about their benefits and about being routinely turned down at the initial application, or of losing entitlements when reapplying.

Often, the problem is unpredictability. Asthma is an extremely variable condition, meaning that even clinical examinations that are taken at a fixed point in time can underestimate its severity⁹. For the same reason, benefit entitlement assessment, which can be geared to how well people appear at the time of assessment, can rule out some people with severe asthma from the help they need.

‘I didn’t even know about DLA [Disability Living Allowance] until [the nurse] actually mentioned it to me. She was saying, “Why don’t you apply?” I got it, then it got stopped... his asthma was fine at the time so I didn’t do anything, then I reapplied after his last respiratory [arrest] and they said, “There is nothing wrong with him.” I phoned up, I said, “OK, you sent me this letter, but he is in hospital at the moment; this is a list of his medication.” They noted all that down, a week later I got a letter saying you have got it for six years.’

Mother of a 13 year old boy with severe asthma, Leicester

‘The doctor that came out first when I applied [for benefits], he looked at me and... he was very disparaging... he turned me down and I would not reapply... my pride got in the way.’

Woman with severe asthma, Belfast

‘I am a single parent so it’s really difficult for me. [My son] was in hospital for nine weeks, so that is over £100 worth of fares getting to and from the hospital. They told me to apply for a community care grant, they turned me down. The social worker from the hospital put a letter in to say, “It says on the form her child is sick, she is going to visit him in hospital, it would be detrimental to him if he never saw his mother because she couldn’t afford to get there,” and I have just got a letter turning me down for my appeal.’

Mother of a 13 year old boy with severe asthma, London

Benefit assessments are notoriously inconsistent at present – with a recent report finding that 40% of appeals lead to decisions about Employment and Support Allowance (ESA) being reversed¹⁰. This means that the UK Government’s plans to reduce the welfare bill by introducing new assessments for some benefits and reassessing claimants for others are a major concern. It is vital that assessors are better trained and processes are implemented more effectively to avoid discriminating against those who have variable medical conditions like severe asthma.

It is unjust for some people to be able to access benefits that others in similar circumstances cannot, and for people to have to repeatedly apply for something that they are entitled to.

Recommendation: Improve access to benefits for people with severe asthma

- Healthcare professionals should routinely refer people who are disabled by severe asthma (and their carers) to reliable sources of information about benefit entitlements and how to apply.
- Assessment and reassessment for entitlement to disability benefits must take account of variable conditions like asthma by improving training and making sure implementation is consistent.

Relationships

With the constant need to make compromises for severe asthma, relationships can suffer. People told us that they sometimes find it difficult to communicate with family or friends about the impact of their asthma and the support they needed from them. Some felt that their families downplayed the seriousness of their asthma, others that they worried too much, but almost all had had difficulties in adapting.

‘When I was a child, I spent a lot of time in the hospital. My parents were always with me, my sister resented me, consequently she lost a lot of time with my parents as well because they were always by my bedside. In a way, me and my sister have never really had a relationship. She thinks I took all the time up with me.’

Man with severe asthma, Leicester

‘There are times when I felt I have kept my child in a cage. It feels like I kept him locked up because he has not been able to go from this side of the hospital to another without my say-so, my knowing which room he is taken, where, who he is with, everything.’

Mother of a 13 year old boy with severe asthma, Leicester

The impact of caring for someone with severe asthma is substantial – many parents struggle to maintain a job because their child needs their support. This doesn’t just affect parents – other family members, or even children can also be carers. Sadly, because asthma isn’t usually seen as something that has a big impact, those who spend a lot of time caring for people with severe asthma get even less recognition and support than other carers.

‘I was...upset with the fact that I couldn’t go to the shops myself... When the kids are small, you get them to carry the bread home, and you carry the heavy stuff. It’s completely reversed, I can only go to the shops when I have my girls with me and they would carry all the heavy stuff and I would carry the loaf of bread!’

Woman with severe asthma, Glasgow

‘Socially, my husband and I rarely go out together at night. My parents are very good but they are in their mid-70s. My mum now seems to get a bit flustered, there is no way they could do the nebuliser, it’s just too much to ask, so we are looking into maybe having a nurse who could come in occasionally.’

Mother of an 11 year old boy with severe asthma, London

‘I got called to the head office and said, “You have had so many days off... You are going to have to look at your options, what about job share?” I said, “Well, I can’t arrange for [my daughter] to be ill on a day that I have a job share in”.’

Mother of a 12 year old girl with severe asthma, Glasgow

‘What I tend to do is say, “Let’s take one day at a time and make the most of it.” That has been something she has latched on to, she wakes up every morning and says, “Dad, I feel good today!” and I say, “Fine. Enjoy your day.” It’s not a case of waking up every morning thinking, “Are we going to the hospital today or not?” It’s a case of saying, “If we have to go to the hospital, we will go. If we don’t, we will make the most of the day.’

Father of a 14 year old girl with severe asthma, London

Services for carers are extremely variable around the country – support services such as respite breaks, home help and carer needs assessments are not always offered where they are needed. One investigation found that 80% of funding intended for breaks for carers was being diverted elsewhere¹¹. Moreover, benefits for carers are limited, so those who are also students or who are aged over 65 get no financial support for their caring role. Carer’s Allowance is linked to Disability Living Allowance, meaning that if someone with severe asthma is not recognised as disabled, then the people who care for them will not be entitled to any benefits either.

Despite the unpredictability of severe asthma and the frequent need to make compromises for it, many families affected by severe asthma try to stay positive about dealing with it, and take each day as it comes. Many of the people that we spoke to had very inspiring stories of how they cope with severe asthma on a good day – but there is still a great deal more to do to support them on a bad day.

Recommendation: Improve support for carers of people with severe asthma

- Carers of people with severe asthma should be offered a needs assessment and referred to appropriate services to meet the needs identified.

Severe asthma and education



‘Pip went to Cardiff for three days with the school. At the start her Head Mistress didn’t want her to go but Pip was adamant she was going. In the end a new Head started and she said if she wants to come and feels able then we should let her.’

Natasha, mother of Epiphany Adamou, 11, Gwent

Educational opportunities are very important to children and young people with severe asthma, as well as their parents. Where children and young people have missed out, it is important for schools to have effective systems in place to help them catch up, and where they have medical needs at school, they need to be looked after in the right way. However, not all schools, colleges and universities are well equipped to offer the support they need, meaning that many children and young people with severe asthma can end up being unnecessarily marginalised by their condition.

Some children with severe asthma struggle to get through school because their symptoms make it difficult to attend regularly or to keep up. Several parents and young people also told us of social problems – being bullied, missing out on activities or struggling to stay in touch with friends because of long absences.

‘There was about a year when he [was nine], where he was at home more than he was at school. We were in hospital more than we were at home. We did encourage him to do a bit [of school work] at home, but at that time, because if he got himself stressed that was another attack, so we never forced him. I honestly haven’t a clue how he has caught up.’

Mother of a 13 year old boy with severe asthma, Leicester

‘[My son] has missed up to a year’s school over the last three years so you drop out socially, you get left out of sport, he is behind on his work, he’s got very depressed...’

Mother of a 13 year old boy with severe asthma, London

‘I was bullied severely for a long time. When I was able to go to school and not be schooled in the hospital, I was always the fat kid, I was always on steroids... my first day at secondary school I had my intravenous drip on so everyone was looking at me like a weirdo... I was at a sports college, I couldn’t do any of the sports, yet I loved rugby and I couldn’t play it because I had a needle stuck in my leg.’

Young man with severe asthma, Leicester

‘[My son] gets teased quite a lot at school. Kids will say, “I don’t want to sit next to you, I don’t want to catch it.” They call him moon face, he gets a pretty hard time of it at school.’

Mother of a nine year old boy with severe asthma, Leicester

Schools can make the problems of dealing with severe asthma easier or harder for families. A small number of people said that they had received good support from schools, but far more said that teachers handled asthma attacks badly and schools didn't have the right procedures in place to help them. A particular concern for many parents is that the medicines used for immediate relief of symptoms in an asthma attack are often left somewhere inaccessible, which can be very dangerous if they are needed in an emergency.

The experiences of the people we spoke to are far from unique. According to research conducted by Asthma UK and the National Foundation for Educational Research in 2009, around three quarters of teachers in England would not be certain of what to do if a child in their class had an asthma attack¹². At present, there is no requirement for schools to have policies in place to guide their staff on how to manage asthma and other long-term conditions, nor is there any systematic approach to staff training.

'My daughter is in primary school and the last time she got admitted into hospital was because of her teacher never letting her go for her medication. She doesn't look as if she was wheezing, but she asked all day and they kept saying, "Wait until break or lunchtime."... She came home and collapsed on the sofa and it just so happened I was home at that time, and between her getting home and me getting her to a doctor, a blue light ambulance was called and she was rushed in... I had to go down to the school and have it out with them.'

Mother of a 14 year old girl with severe asthma, Glasgow

'I don't think there has been a week at school where he has been there all week since he started high school. Maybe there are times I could be sending him, but I don't want to take that chance of sending him and his box is locked away in a cupboard and he has got to walk... I don't want to sit and worry all day.'

Mother of a 13 year old boy with severe asthma, Glasgow

School nurses have a vital role to play in the effective management of severe asthma at school. As well as directly monitoring the health and well-being of individual pupils, they can support the planning of effective policies and arrange or provide training for other school staff¹³. Although their numbers have increased in some parts of the UK, there are still too few to ensure that every school has the clinical support it needs, meaning that some parents see effective school nursing as the exception rather than the norm.

'The secondary school, the school nurse, she is brilliant, she has got the nebuliser, everything. She has spent a lot of time with me going through a care plan, how to react to it, he has got a card to excuse him from any lesson if need be to go straight to the nurse.'

Mother of a 13 year old boy with severe asthma, Leicester



Many young people with severe asthma feel that they have had to fight to get through the system. Problems in school are often duplicated in further and higher education, spilling into adulthood and undermining hopes for the future.

‘I am a student and should have graduated about two years ago and that gets me down but I have this fight to carry on, I feel that I have got this far with my asthma and I am not going to let it bring me down.’

Young woman with severe asthma, London

‘I had to battle through school because school did not want me there. I had 30% attendance, and I would like my job to be something that I love and I don’t want my asthma to stop it and it really bugs me that it won’t ever stop and that you will just have to get into a pattern of having to settle because you can’t do the things you want.’

Young woman with severe asthma, London

Recommendation: Support children and young people with severe asthma in education

- All educational institutions should have a policy to support children and young people with asthma and other long term conditions.
- All relevant school staff should attend regular asthma awareness sessions.
- School inspections should measure the performance of schools in supporting and including children with health conditions.
- Every school should have sufficient access to a school nurse.

What Asthma UK is doing: Alert to Asthma

Asthma UK runs a programme of awareness sessions called Alert to Asthma for those who care for or have a responsibility for people with asthma. The information sessions aim to improve knowledge about asthma and better equip people to respond to someone in their care having an asthma attack. Sessions are run by an asthma nurse specialist and have taken place in hundreds of schools, nurseries and other community settings across the UK.

Healthcare needs and experiences



‘Patients living with severe asthma often feel that their voice within the wider community, or within general healthcare practice, is not being heard. It is the job of the specialist respiratory nurse to ensure a platform is provided for their fears and concerns to be expressed.’

Suzie Regan, Asthma Clinical Nurse Specialist, Royal Brompton Hospital

Asthma care and specialist support

People with severe asthma rely on the NHS – and need to use many different NHS services. From their visits to their GP or pharmacist, to the ambulances and Accident & Emergency (A&E) departments that treat them when they have an asthma attack, to the specialist respiratory centre where their asthma is managed over the long term, everyone we spoke to is in regular contact with the health service. Most also have a positive story about how a part of the NHS has helped them – but unfortunately, there is often a corresponding story about another part of the NHS which has let them down.

‘My daughter has been [hospitalised] hundreds of times. The first serious one, she was in intensive care and we nearly lost her. She was just a week before her third birthday, she had croup, pneumonia, severe asthma attack and her lungs had collapsed and I had taken her to hospital and got sent home and told I was a panicky mother, steam up your bathroom, which I did, by which time she had turned blue and I had to call an ambulance.’

Mother of a 15 year old girl with severe asthma, Glasgow

Most people with severe asthma need specialist care because the severity of their condition requires specialist knowledge to help them manage it^{14, 15}. We spoke to people who were already using specialist services, meaning that – for the most part – they were receiving the best care available in their area. This really showed in their assessment of the healthcare professionals who provide these services, and made a stark comparison with their views of primary care or of the services they had received before referral to the specialist centre.

‘At one stage I was seeing the doctor almost every week and in and out of hospital. I was admitted here eight times in one year and it was just getting that every time the asthma flared up, I was crying, and saying, “Is this my life?” I have not been able to breathe, it’s dreadful, I actually cried so much I burst blood vessels in my eyes and everything so when I came to see my GP he put me on anti depressants and [the asthma specialist] admitted me that week as well. They got a psychiatrist over from the other part of the hospital to speak to me. So I am still on them and I think it’s helping me.’

Woman with severe asthma, Belfast

‘One of the reasons this current episode of uncontrolled asthma popped up was because my GP refused to give me steroids citing...the side effects... and I eventually ended up in casualty and admitted to hospital because my asthma got out of control.’

Woman with severe asthma, Glasgow

Quality of care is particularly important for people at the times when they are most vulnerable – for example, in an emergency, or for young people starting to use adult services for the first time.

‘I have been through the transition with [my son] and it was horrendous. It’s really horrible, it’s worrying for you as a parent. When my kids are in hospital, I stick with them... when [my son] went to adult care, the first time he was admitted as an adult, he was 17... and I remember going into the ward and he was in a ward with three old men, he was 17 and he cried and he said, “Get me out of here”.’

Mother of two children with severe asthma, Glasgow

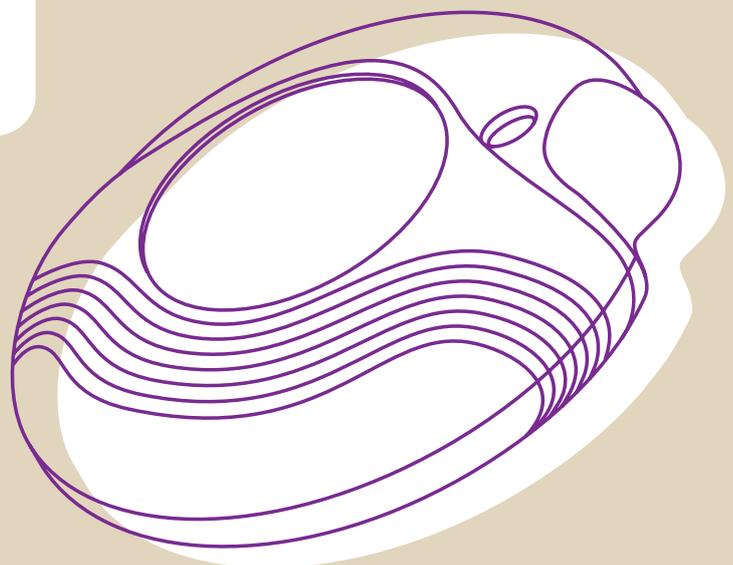
A fully effective severe asthma service needs access to multidisciplinary support, including consultants, asthma nurses, physiotherapy, dietary support, psychological support, pharmacy services, lung function testing, speech therapy, smoking cessation and allergy specialists, as well as social services. Not everyone with severe asthma needs all of these services – but having them available can make all the difference to those people who do.

‘When I got my referral here, I couldn’t have done that walk to those chairs, and I actually thought I was going to lose my job because I was so ill, but after a year of attending here my health really improved to gradually reduce the tablets...This clinic, this hospital has really given me my life back. I have improved. I wouldn’t be here today, I was so ill.’

Woman with severe asthma, Belfast

‘Those girls and boys up the there, they are absolutely fantastic if you are admitted, they know exactly what they are doing, they know how to help you, they are fantastic so it’s a big back up support as well. Plus I have great trust in [the consultant] and [the respiratory nurses]. You have that back up as well, it’s knowing that you have the support there, you are not going to be ignored.’

Woman with severe asthma, Belfast



With a need to find efficiency savings in the NHS, it is vital that there are no cutbacks to the services that people need most – like specialist nursing. As well as being a lifeline for many people, the work of specialist asthma nurses has been shown to reduce costly unscheduled care and emergency hospital admissions^{16,17} so reducing the number of these roles would be a false economy. Current fears that specialist nursing posts are at risk must not be realised.

‘You have got to realise that [the specialist nurse] is the best support you can have. When you know that type of person is there, that is the support you need. You are not there on your own and that is what you are, you are on your knees, the sweats have got you, you are not getting any air in and when you can think to yourself there is somebody there at the end of the phone... what I am trying to say is that you have only got it at this hospital, we are lucky.’

Man with severe asthma, Leicester

Recommendation: Ensure everyone with severe asthma has access to specialist care

- Referral pathways to severe asthma services should be improved, and there must be adequate capacity in specialist services to meet the needs of everyone with severe asthma.
- NHS organisations must not reduce the number of specialist respiratory nursing posts.
- Adequate training for specialist respiratory nurses should be made available.
- Severe asthma services should offer a multidisciplinary range of support services including physiotherapy, mental health support and special support for young people in transition from child to adult services.

‘I had a clinic yesterday... but her asthma wasn’t great and I just went to the office. [The respiratory nurse] was busy at the time but we sat and waited and she came out and... we talked things through and we didn’t need to go and see the doctor then because of [the respiratory nurse]. She put my mind at rest. When [my daughter]’s asthma would get progressively worse, [the respiratory nurse] came up and spent a considerable time explaining, this is what they are doing, this is why they are doing it, and these might be the side effects.’

Mother of a 12 year old girl with severe asthma, Glasgow

Emergency care

Even with the best multidisciplinary specialist treatment, there are times when people need to use emergency care for an asthma attack. Unfortunately, the quality of A&E services seems to be particularly concerning for many of them. Some of the people we spoke to were getting an adequate service – but others were afraid to use it at all.

‘If I was on my own I would probably just die because I hate going to A&E, imagine someone asking you a hundred questions, you can’t even talk, you are so out of breath, so they don’t know what to do with you.’

Young woman with severe asthma, London

‘My experience is that once she goes past A&E to the hospital, everything is different. It’s just that stumbling block, it’s like going through a brick wall, once you go through it everything is fine on the other side. The main concern for me is what happens at A&E. I still believe that if they take proactive action as quickly as possible, but most likely they won’t... it’s the few occasions that people have been slow to react and we ended up having to ventilate her.’

Father of a 14 year old girl with severe asthma, London

‘My hospital isn’t as good as this one so I used to take him to A&E and they would just say, “It’s not an asthma attack.” An hour later I go back and, “His lips are going blue, can we have something?” They would say, “We can’t do that, you will have to wait for a paediatrician.”... so we would be giving him his inhaler in A&E waiting for them to do something.’

Mother of a nine year old boy with severe asthma, Leicester

Many A&E departments see hundreds of people with asthma a year – in 2008–2009, there were over 79,000 emergency hospital admissions for asthma – and at least two thirds came through A&E¹⁸. However, many people with severe asthma need care according to a personalised plan agreed with their usual specialist – which is where problems can arise. People speak of not being taken seriously in A&E departments, of poor communication and of their emergency treatment plans being ignored.

Some hospitals do have direct admission schemes for people with severe asthma, others use patient-held records, and some have specialists on hand and make use of the right advice. Until this good practice is spread across the UK, people with severe asthma will continue to have problems in A&E.



‘At the Royal Alexandra we use a care pathway for children presenting at A&E with acute exacerbation of asthma/wheeze. The pathway incorporates the recommended treatment according to the British Thoracic Society Guidelines and includes the indicators for determining the severity of illness in children.

We also use emergency passports that allow children to have easy access to paediatric expertise and specific management plans related to their condition. Certain children respond better to certain treatments for their asthma and the emergency passport indicates these to clinicians who are unfamiliar with the child’s condition. In addition, clinicians can respond appropriately and in a timely manner to prevent further deterioration of the child. Some children

with severe asthma need treatment to be activated quickly and patients and parents are reassured that they have the facility to access care quickly avoiding long anxious waits in emergency departments.’

Jason Gray, Advanced Paediatric Emergency Nurse Practitioner, Royal Alexandra Children’s Hospital

Recommendation: Give everyone with severe asthma the right emergency treatment

- Everyone with severe asthma should be able to hold their own emergency treatment plan agreed with their specialist – and these should be followed by every A&E and ambulance service.
- Healthcare professionals in A&E should be appropriately trained in asthma management.
- Everyone admitted to hospital with asthma should have access to a respiratory nurse specialist.

What Asthma UK is doing: the *Emergency Asthma Care Pack*

The *Emergency Asthma Care Pack* is a resource to assist healthcare professionals who work in settings where they are likely to encounter people having an asthma attack and ensure a better level of service for people with asthma. It shows the process of care from when a person with asthma first presents, to their follow up arrangements and discharge. It is available free from Asthma UK (0800 121 62 55) and so far over 8,000 copies have been distributed to healthcare professionals.

Making asthma a priority

As people with severe asthma need to use services much more than most other people with asthma¹⁹, they are disproportionately affected when the NHS performs badly. Many of the problems in services for people with severe asthma are related to a lack of prioritisation and communication. Despite the commitment of a small number of dedicated healthcare professionals, in most parts of the UK there is no overarching policy framework dedicated to tackling asthma at a national level, meaning that it can be constantly sidelined for other issues.

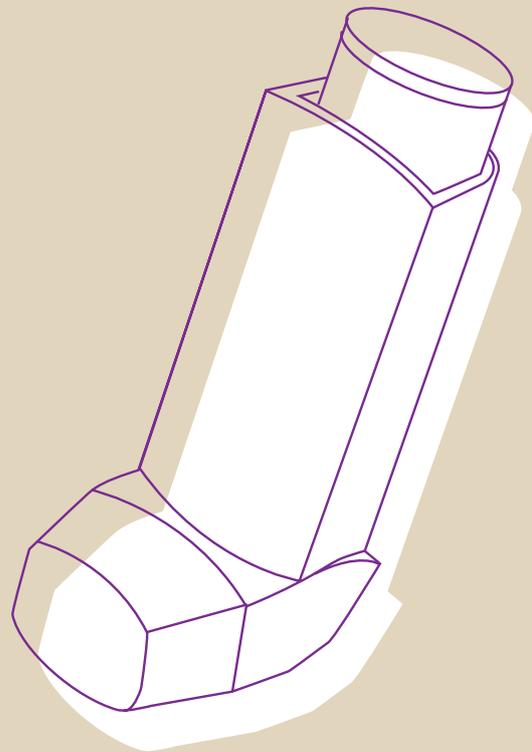
The people we spoke to were quick to draw comparisons between the treatment they get for their asthma, and the treatment they get for other conditions. Asthma care was consistently less comprehensive and joined up, perhaps because not all respiratory services have access to the different kinds of support that people with severe asthma need.

‘There is a different approach to it. I had a heart attack a good few years ago, and after the heart attack you have rehabilitation of six weeks afterwards, relaxation exercises, dieticians and the rest of it – you don’t get that as an asthmatic, perhaps there should be something. Then they have groups afterwards as well, you all meet up for a cup of tea or coffee and discuss the effects of the heart attack on you as an individual, the psychology. There is a correlation there between having asthma and having a heart attack – except the asthma lasts a lot longer.’

Man with severe asthma, Leicester

Nowhere in the UK has yet delivered the consistently high standard of care needed by people with severe asthma. Indeed, in England, the National Quality Board recently named asthma as one of the conditions that has been most neglected by the Department of Health²⁰. Despite the inclusion of a short chapter on asthma in the draft *National Strategy for COPD* and the ongoing development of good practice guidance, securing a good asthma service remains too low down the national list of priorities.

In Northern Ireland, clear and specific standards for asthma care across different age groups and levels of severity were published in *Service Framework for Respiratory Health and Wellbeing*, which was launched in December 2009. These include requirements for appropriate management of severe asthma and emergency asthma treatment. It will be extremely important that resources are forthcoming to ensure that these progressive standards are fully implemented.



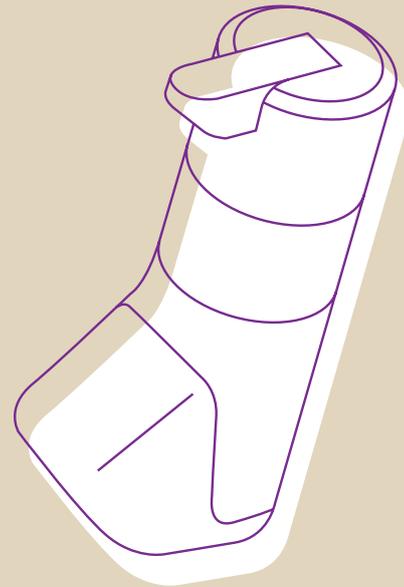
In 2007, NHS Quality Improvement Scotland (NHS QIS) developed seven clinical standards for asthma services for children and young people. Health boards are now expected to implement these standards and multi-disciplinary groups within each health board have been set up for this purpose. The Scottish Government has chosen to set up respiratory managed clinical networks (MCNs) within each health board, overseen by a steering group, in order to implement the BTS/SIGN guideline for asthma and monitor standards of care for all respiratory conditions. However, there are no plans for NHS QIS to develop clinical standards for asthma services for adults.

In Wales, asthma has not been given a high enough priority. A real opportunity was missed with the *2007 Service development and commissioning directives for chronic respiratory conditions*, which were weak on asthma specific standards and have not been adequately monitored or funded since their development.

Asthma is one of the commonest long-term conditions in the UK, which means that national standards could benefit far more people than existing strategies for other conditions. There is a real opportunity to reduce the impact of asthma by bringing in the best standards of care to limit the need for hospital admissions, and refusing to tolerate the 1,200 asthma deaths a year²¹.

Recommendation: Develop and implement national standards for asthma care

- In England, the Department of Health must publish and resource a national strategy for asthma. In the interim, emerging respiratory clinical networks should ensure asthma is a priority alongside COPD.
- In Northern Ireland, resources must be made available to make sure the standards of the Service Framework for Respiratory Health and Wellbeing are fully implemented.
- The Scottish Government must identify and prioritise the development of clinical standards for asthma services for adults as part of the work programme of NHS Quality Improvement Scotland. Respiratory MCNs must identify and share best practice across Scotland regarding services for people with asthma.
- The Welsh Assembly Government must urgently carry out a clinical audit of the commissioning directives leading to an updating of the directives to include asthma specific standards, costed and with a realistic timeframe.



What Asthma UK is doing: the Good Asthma Services Model

The Good Asthma Service Model has been developed by Asthma UK to provide a clear and detailed definition of what constitutes an optimal asthma service. It is for all people with asthma, as well as parents and carers. It is based on an understanding that healthcare professionals who provide asthma care should have received accredited training in asthma management, and those working with children and young people to have specific knowledge, skills and training in children's asthma. The model includes sections on acute exacerbations (emergencies) and severe asthma which covers many of the issues outlined in this report.

Equality for people with severe asthma



‘When my asthma became severe I was constantly in and out of hospital and was eventually sacked from my job, as they said I was off too much. Some of my early stays have been four and a half months.’

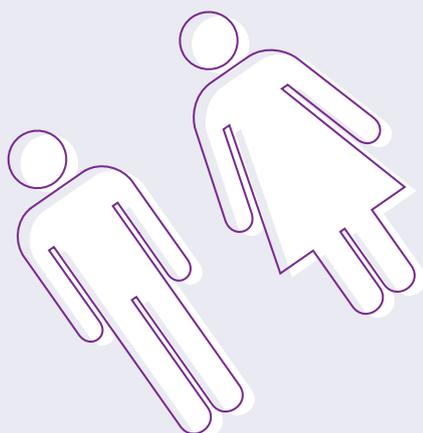
Sarah Jane Lewis, St Neots

On top of the challenges of living with a long-term condition, people with severe asthma are also forced to cope with a complete lack of awareness about its seriousness and impact. In some cases this lack of awareness has led to discrimination, often by those whose job it is to care for them.

‘You are disabled and people don’t actually class it as disabled. When you apply for disabled people’s rights, you don’t get them.’

Young woman with severe asthma, London

The people we spoke to explained the huge drain they experience in striving to have their needs taken into account while at the same time trying to live a ‘normal’ life. The constant battle of always having to explain the impact and seriousness of their condition, trying to make people understand as well as worrying about how others will judge them further adds to the stress that they are already under in simply coping with their condition.



‘I just feel that people look at you and say, “But there is nothing wrong with you, you have only got asthma,” but they don’t understand...’

Woman with severe asthma, Glasgow

Discrimination at work

A person is legally defined as having a disability if they have a physical or mental impairment which has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. Many people with severe asthma fit these criteria – and although not all see themselves as disabled, the fact remains that they often experience discrimination as a result of their condition.

Despite a requirement for employers to make reasonable adjustments to avoid disadvantaging people with disabilities, relatively few seem prepared to do so for people with severe asthma. Many people told us that they had left their jobs because of their asthma – occasionally because they didn't feel that they could cope with their symptoms as well as a full-time job, but more often because their employer was not able or not willing to accommodate the unpredictability of an asthma attack. Several people had actively covered up the severity of their asthma because they were afraid that it would put their jobs at risk.

'Financially it has been depressing for me. I can't emphasise that more. I worked from 16 and used to start a job and in the three months probation I would usually have an asthma attack which would put me out of work for a week-ten days and then the employer would... let me go... I am just going to have to class myself as ill, but admitting that to yourself at 21 years of age is really difficult. Now I haven't worked for two and a half years.'

Young woman with severe asthma, London

'When I had my spell when I was clear, I went and joined the TA, up until last year, two years ago. They discharged me because they found out about my asthma. I had never told them about my health, I lied, and they discharged me.'

Man with severe asthma, Leicester

'At one point I was in hospital for three and a half months and came out, and then two weeks later I was hospitalised again. My employer was getting fed up and basically said, "We are terminating your contract".'

Man with severe asthma, Leicester

'There are days when I have taken annual leave so that I am not using work time... I have had a rubbish night, I can't breathe, I know I am not going to be able to go in... but I will take the morning as an annual leave day... I never really get warnings or anything because I mask any sick absence by taking leave as best I can.'

Woman with severe asthma, Glasgow

None of these people said that they had received support or advice to help them challenge their employers' actions. Sadly, most of them seemed to assume that having severe asthma would automatically make them less employable.

This is unacceptable. Nobody with severe asthma should feel they have to hide their condition from employers – and nobody should be forced out of a job without their employer attempting to make reasonable adjustments.

Equality duties

All public sector organisations have a legal duty – the disability equality duty, soon to be replaced by an overarching general public sector equality duty – to promote equality of opportunity between disabled people and others and to eliminate unlawful discrimination. They are expected to take account of a disability, even where that involves treating a disabled person more favourably – for example, by providing a parking space for them.

However, it is clear that many of the public bodies that people with severe asthma rely on – such as their school, university, hospital or public sector employer – are far from meeting this requirement. This is unlikely to change soon unless action is taken. Enforcement is a huge task and does not yet form a routine part of the inspection and regulation of all public sector organisations, but some progress is being made. For example, in England, the Care Quality Commission's equality scheme commits it to various measures to support the inspection of equalities issues in health and social care, though these are unlikely to be implemented until 2011.

'My lecturers record the lectures in order to send them to a linked campus down in Cornwall but they refused to give me them although they had them recorded.'

Young woman with severe asthma, London

'If you ask for a deadline extension on your essay... just try taking into account the fact that you get two hours sleep a night, they just don't listen to you.'

Young woman with severe asthma, London

‘When they first start secondary school they went on a bonding week and [my son] wasn’t allowed to go. He was excluded straight away.’

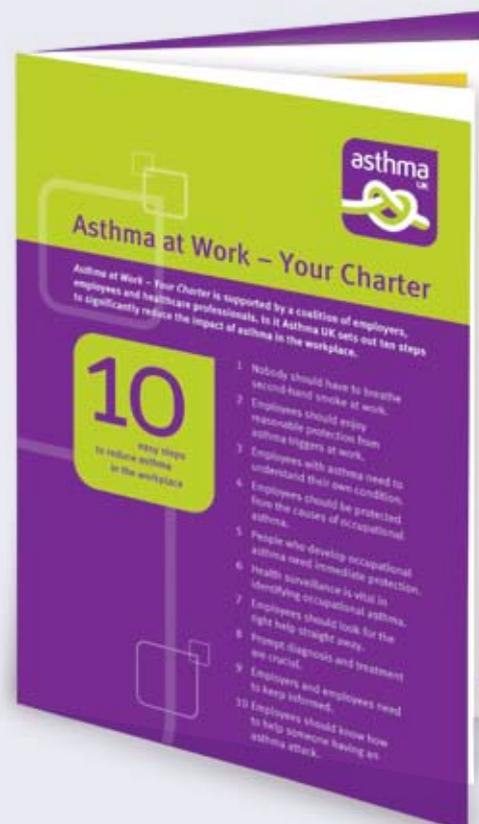
Mother of a 13 year old boy with severe asthma, London

Recommendation: Treat people fairly if they are disabled by severe asthma

- Public authorities must deliver on their duty to promote equality for people with severe asthma and similar conditions by including specific reference to variable disabilities in their equality schemes.
- Employers in all sectors should always consider making adjustments – such as offering flexible working patterns or supporting home working – for people affected by severe asthma.
- The Equality & Human Rights Commission and the Equality Commission for Northern Ireland must investigate cases of discrimination against people with variable disabilities like severe asthma.
- Health and education regulators must take on greater responsibility for monitoring adherence to equalities legislation.

What Asthma UK is doing: the Workplace Charter

Asthma at Work – Your Charter sets out five key measures to significantly reduce asthma and its impact in the workplace and is aimed at employers, employees and healthcare professionals. It was launched in 2004 with the belief that no-one should have to work in an environment that compromises their health and well-being. A number of small, medium and large organisations across the UK are already signed up as Charter partners, including Sainsbury’s, the HSE, the TUC, Volvo Car UK, The Body Shop, London Underground, South Wales Construction Safety Group and local councils.



‘It’s an illness they can’t see, it’s a disease they know nothing about.’

Man with severe asthma, Leicester

Public awareness

Many people we spoke to felt that the discrimination that they experience is a direct result of a lack of awareness of severe asthma and its impact. The perceptions of others, particularly the misconception that all asthma is mild, means that often they do not get the help and support they need from their employers, friends and colleagues as well as from society as a whole.

‘You hear about these people like Austin Healey, he is an asthma sufferer, he plays rugby and he said that it doesn’t stop you from doing anything. Well, that is a different type of asthma that they have got.’

Woman with severe asthma, Leicester

Some of the people who joined our discussions described how they can be perceived as ‘attention seekers’ or ‘skivers’ and the difficulty and stress this can cause them particularly with regard to work and study. For young people at school this can be particularly hard as it is not just the perceptions of their peers which affect them but also their teachers. Experiences vary from not being taken seriously enough to the opposite end of the spectrum, being singled out and highlighted as being different.

‘It’s taken me a long time to convince my lecturers that I am not just bunking off and even if I am at home and I can’t be in lectures it’s not because I don’t want to, it’s because I can’t physically get from home to uni.’

Young woman with severe asthma, London

‘They refused to let me go to matron. They made me sit in class and I was sitting and it was the teacher turned around at the end and said, “[Name], just go down to the matron, you are disturbing us all”.’

Young man with severe asthma, Belfast

‘They make him the different one, they pull him out if he is in assembly and the whole school is there... they get him up in front of everybody... “Oh no, you have got to sit next to the teacher”.’

Mother of a nine year old boy with severe asthma, Leicester

An increase in understanding of severe asthma would have an enormous positive impact – indeed, several people told us that if they had one wish it would be that others understood what they had to go through.

Recommendation: Raise awareness about severe asthma

- Throughout the UK, healthcare professionals and people with asthma should work with Asthma UK to call attention to how serious asthma can be and the powerful effect it can have on quality of life.
- In England, the Department of Health’s prospective lung health awareness programme should include a strand on severe asthma.

Conclusion



‘If I wasn’t getting specialist care for my asthma I suspect that one of my four intensive care admissions would have been my last.’

Simon Savill, Stevenage

We have heard directly from people with severe asthma about the way in which it touches every aspect of their lives. Severe asthma – and other people’s attitudes towards it – permeates their relationships with friends, colleagues and family. At school, at work and at home, it too often determines what they can and can’t do.

This is why it is so important to take action. Effective health care may not make severe asthma go away, but it gives people the support they need to control it as well as possible. Making benefits assessments fairer may not reduce the impact of asthma, but it will give people the resources they need to adapt to it. Improving management of long term conditions in schools may not enable children with severe asthma to attend every day, but it will mean that they and their parents can be more confident that if there is an emergency, it will be handled in the right way.

Asthma UK is already making plans to reduce the isolation of people with severe asthma. Our findings will shape our future work with people with severe asthma. We want to be able to give better services, information and support, as well as campaigning for improvements in primary, secondary and tertiary care. Most importantly, we also want to raise awareness about severe asthma, so that healthcare professionals, teachers and community groups are just as motivated to bring about a change in attitudes to severe asthma as we are.

We would like to thank all of the participants in our discussions about severe asthma. Without them this report would not exist. We are also grateful to everyone who helped with the project at the Royal Brompton Hospital, Gartnavel General Hospital, Royal Hospital for Sick Children (Yorkhill), Belfast City Hospital, Leicester Royal Infirmary and Glenfield Hospital.

Summary of recommendations

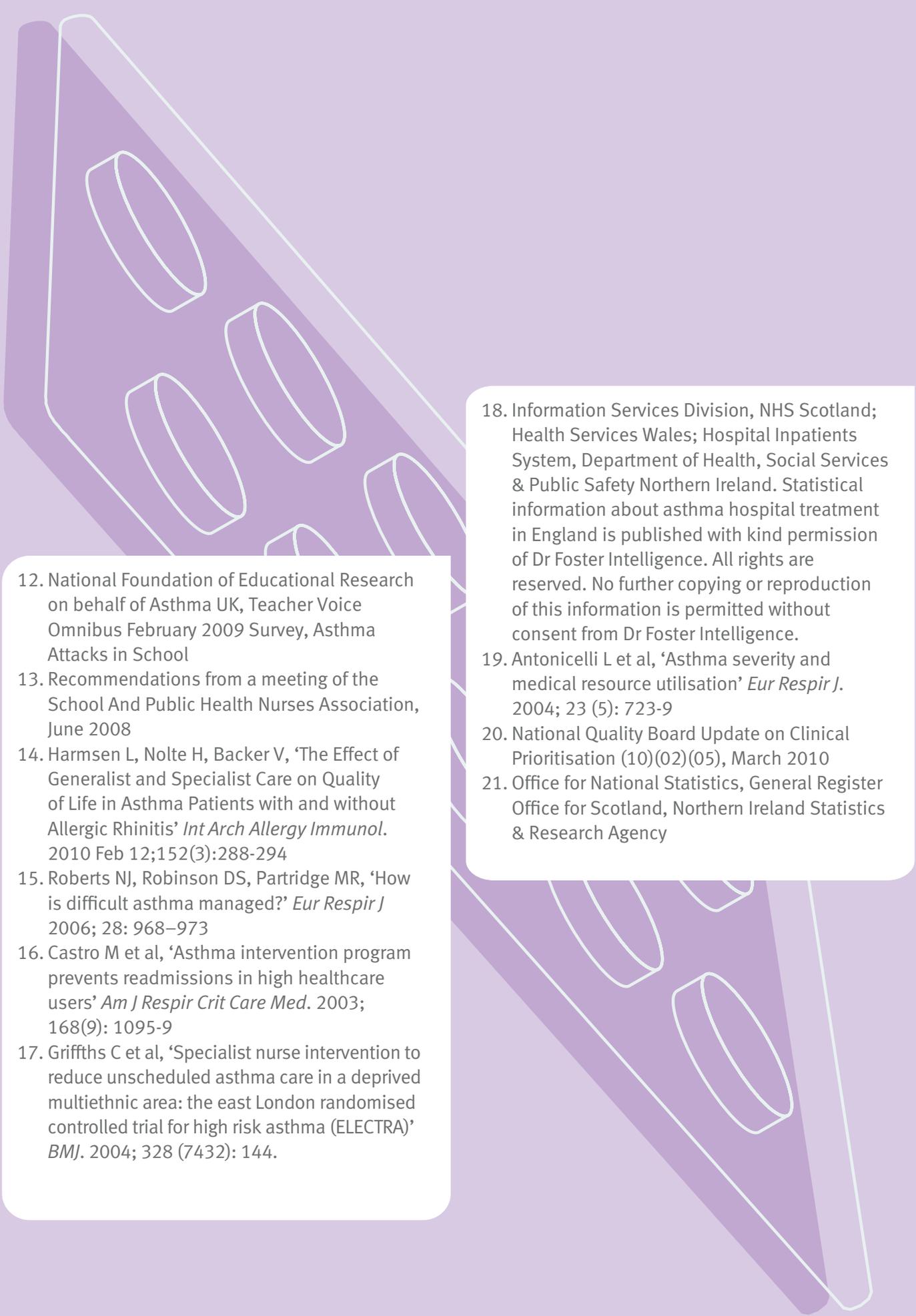
Asthma UK and the Severe Asthma National Network are calling on everyone who can make a difference to the lives of people with severe asthma to take action.

Healthcare professionals, commissioners, social workers, teachers, employers, regulators and policymakers must work together to:

- effectively manage the impact of severe asthma medicines
- improve access to benefits for people with severe asthma
- improve support for carers of people with severe asthma
- support children and young people with severe asthma in education
- give everyone with severe asthma access to specialist care
- give everyone with severe asthma the right emergency treatment
- develop and implement national standards for asthma care
- treat people fairly if they are disabled by severe asthma.

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 - Belfast City Hospital
 - Gartnavel General Hospital, Glasgow
 - Glenfield Hospital, Leicester
 - Leicester Royal Infirmary
 - Royal Brompton Hospital, London
 - Royal Hospital for Sick Children (Yorkhill), GlasgowBecause of a lack of specialist service provision, it was not possible to identify a suitable host site in Wales.
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‘Everyone who knows me knows my asthma is severe but they still think it’s “normal” asthma that can be controlled with a few puffs of an inhaler. People need to be educated about the difference.’

Kerry-Anne Cooper

Asthma UK is dedicated to improving the health and well-being of those affected by asthma, including the quarter of a million people who live with severe asthma.

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