Asthma UK submission to NICE MTA on Omalizumab

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The recommendations in this submission are supported by:

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Primary Care Respiratory Society UK

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Contents

Appendices

1. Executive summary

This document is Asthma UK's submission to the NICE Multiple Technology Appraisal of Omalizumab. It is presented in the following sections.

2. Introduction

This section gives background information about Asthma UK and about Omalizumab, the treatment being reviewed in this appraisal.

3. Asthma UK's views

This section outlines Asthma UK's key recommendations and the reasons for them. These recommendations are that:

- Omalizumab should be recommended for a clearly and carefully defined group of adults and children with severe allergic asthma
- it should continue to be necessary for people to be properly assessed by a specialist before being given Omalizumab
- it should not be necessary for someone to have had a specific number of hospital admissions before they can be given Omalizumab.

4. Experiences of severe asthma and Omalizumab

This section draws on research evidence and reported patient experience to describe what people with severe asthma go through before and after receiving Omalizumab.

It shows that some of those children and adults with the most severe asthma are failed by current standard practice, which gives them serious side effects and does not prevent severe asthma symptoms, including life-threatening asthma attacks requiring hospitalisation. It also describes a transformation in people's quality of life as a result of using Omalizumab, which has brought asthma symptoms under control, reduced the frequency of their hospital admissions and enabled them to reduce their doses of other harmful medicines.

5. The availability of Omalizumab from the NHS

This section describes people's experiences of trying to access Omalizumab from NHS services and their concerns about the impact of existing NICE criteria.

6. Conclusion

This section reaffirms Asthma UK's view that Omalizumab should be given a positive NICE recommendation for all appropriate age groups.

2. Introduction

Asthma UK is a charity for patients and listens to the stories of people with severe asthma in order to understand its impact on their daily lives.[i, ii] This document brings together research evidence with the experiences of people with severe asthma in order to inform the NICE Multiple Technology Appraisal (MTA) on Omalizumab.

Omalizumab (Xolair) is the first treatment of its kind to manage severe allergic asthma and has transformed the lives of a very small number of people who are among the worst affected by asthma. Without it, many of the people who use it would otherwise suffer daily symptoms which leave them housebound, life-threatening asthma attacks and serious side-effects from standard treatments. Indeed, it is an example of the kind of transformative innovation with significant benefits to patients and to society which Government policy on value based pricing seeks to better recognise in future.

Asthma UK endorses the evidence-based *British Guideline on the Management of Asthma*, produced by the British Thoracic Society and Scottish Intercollegiate Guidelines Network.[iii] This guideline recommends Omalizumab for use only in specialist centres, among people whose asthma remains uncontrolled despite high doses of other treatments. We believe that this treatment should be made available to children and adults with severe allergic asthma on that basis.

3. Asthma UK's views

- Omalizumab should be recommended for a clearly and carefully defined group of adults and children with severe allergic asthma.

- It should continue to be necessary for people to be properly assessed by a specialist before being given Omalizumab.

- It should not be necessary for someone to have had a specific number of hospital admissions before they can be given Omalizumab.

Benefits reported by patients and demonstrated in data on the use of Omalizumab in practice suggest that it is very effective in most of the people who are currently prescribed it in the UK, with significant reductions in hospital admissions and dramatic improvements in quality of life.[iv] As previous NICE guidance has acknowledged, published evidence on this treatment is very likely to understate its clinical and cost-effectiveness in practice in the UK. This is because clinical trial populations for the key INNOVATE and IA-05 studies were much broader than the population likely to be given Omalizumab in the UK.[v]

In a highly targeted group of people with severe asthma, clinical experience shows Omalizumab to be much more effective. Finding a systematic and reliable way to identify these people would reduce inappropriate use and maximise cost-effectiveness. Methods such as measuring blood eosinophil count, exhaled nitric oxide or allergen sensitivity show promise and we have noted a recent trial which showed that the reduction in asthma attacks due to Omalizumab treatment was three times higher in patients with a blood eosinophil count >2%.[vi] Such approaches may help to better define the appropriate population, although further validation may be needed.

However, until such validation has been carried out, it remains vitally important that people with severe asthma are properly assessed by a specialist to ensure that treatment is already optimised, both to ensure that they receive proper care and to avoid over-prescribing of a relatively new and expensive drug. Asthma UK considers specialist expertise accompanied by appropriate diagnostic testing to be a better way of identifying who should be using Omalizumab than the current criteria stiplulated by NICE, which require a certain number of hospital admissions. The existing criteria create perverse incentives for patients to risk their health by allowing their asthma to deteriorate in order to be admitted to hospital or for clinicians to waste NHS resources by admitting patients who do not need to be in hospital in order to ensure they will qualify.

In 2007, NICE identified a target population of only 7,820 people aged over 12 for treatment with Omalizumab in England; this submission does not argue for increasing the numbers of people who are eligible to receive it but for identifying them more appropriately.[vii] Clinical guidelines recommend that Omalizumab should only be initiated in specialist centres and Asthma UK supports this view.[viii]

Previous appraisals of Omalizumab have also been unable to make full use of evidence about:

- side effects of current treatments, particularly oral corticosteroids
- potential steroid-sparing effects of Omalizumab
- potential improvements to quality of life in children with severe asthma.

This may have led to the development of Incremental Cost-Effectiveness Ratios (ICERs) which are unduly high. This submission recounts patient experiences in some of these areas and identifies some research publications where more information may be found to enable the Evidence Review Group to take fuller account of the impact of Omalizumab.

4. Experiences of severe asthma and Omalizumab

Here, we recount some of the experiences of 16 people in the UK who have severe asthma and have used Omalizumab. In order to protect their anonymity, names have been changed and certain identifying features have been removed. They appear in this document as:

Dominic (8)
Scott (10)
Joseph (13)
Carla (21)
Hannah (22)
Jill (22)
Alison (22)
Susan (32)
Francine (32)
Gemma (34)
Moira (37)
Barbara (40)
David (42)
Wendy (44)
Karen (47)
Jim (69)

4.1 Reflections on standard practice

Keeping symptoms under control is the main goal of asthma treatment, but the reality for some people with severe asthma is that this is not possible with current standard treatments.[ix] This means that they have to find a way to cope with dangerous and frustrating symptoms. Persistent symptoms can lead to lack of sleep, social isolation, feelings of despair and depression, low activity levels, weight gain and increased dependence on family and carers. [x] For children, coping with severe asthma can arrest educational and social development, as well as thwarting important life opportunities (see Table 1).

Francine (aged 32) describes her typical morning before Omalizumab: ‘Having been kept awake at night by breathlessness and a feeling of a tight chest, I would feel exhausted by morning. I would have to stop to rest between each stage of my morning routine and needed my young son’s help with simple tasks like washing my hair and getting in and out of the bath. I would arrive at work already exhausted and would then struggle with further asthma attacks throughout the day’.

Gemma (aged 34) describes a loss of independence after her asthma deteriorated rapidly when she was 21. Her quality of life became very poor and her breathlessness was so bad that she couldn’t walk or even speak very well. She lost her social life and her job and needed her family to care for her.

Table 1: social, financial and emotional problems reported by people with severe asthma

Issues for all people with severe asthma	Issues for adults	Issues for children
▪ Having to cope with multiple allergies ▪ Having to cope with multiple hospital admissions ▪ Risk of depression ▪ Risk of social isolation ▪ Risk of alienation from peer group ▪ Unable to make plans for future career ▪ Experiencing side effects from multiple medications ▪ High use of reliever medication ▪ Economic burden for families – having to give up employment to care/travel costs to hospitals ▪ Not being explicitly informed of possible side effects of medication by clinicians ▪ Having difficulty communicating with family and friends about the impact of their asthma and the support they need from them ▪ Embarrassed about	▪ Discrimination at work ▪ Having significant time off work ▪ Losing employment ▪ Interrupted sleep affecting job ▪ Inability to care for their children ▪ Becoming dependent on family members ▪ Loss of independence ▪ Financial difficulties	▪ Being treated in general ward regardless of age of other patients (most would prefer to be treated in a specialist respiratory ward) ▪ Discrimination at school ▪ Having significant time off school ▪ Experiencing teasing and bullying at school/college ▪ May be sensitive to triggers in the classroom ▪ Interrupted sleep affecting school work ▪ Sibling rivalry/jealousy ▪ Parents/carers becoming overprotective ▪ Unable to participate in physical activities/PE ▪ Unable to participate in a variety of school activities/trips ▪ Moving from children’s to adult services and taking responsibility for medicines management ▪ Medicines at school not easily and speedily

taking inhalers in public and if on IV infusions ▪ Embarrassment regarding weight gain or restricted growth/height ▪ Fear of and during life-threatening attacks ▪ Unable to exercise		accessible ▪ Feel as if they are a "problem" for school and school system

4.1.1. Treatment regimes and side effects

Routine treatments are not always effective in achieving asthma control. People with severe asthma can often find themselves taking very high doses of medicines for a long time. The side effects of these medicines, especially long-term oral corticosteroids, are often very serious. These include osteoporosis, psychological symptoms, Cushing's syndrome, adrenal failure, diabetes, growth retardation, high blood pressure, cataracts and Addison's disease.[xi] [xii] [xiii] [xiv]This is particularly distressing for children and young people, who may continue to suffer the consequences of some of these side effects throughout their lives.

Research evidence assessing rates of side effects from oral corticosteroids specifically among people with severe asthma is limited, though a meta-analysis of their use in people with inflammatory diseases found an average adverse event rate of 150 per 100 patient-years, with much higher rates in some groups.[xv] Of the people we spoke to in preparing this document, 94% had been taking oral corticosteroids and 87% of those said they had suffered serious side effects.

People with severe asthma have reported the following side effects of standard treatments for severe asthma:

- Weight gain
- Increased appetite
- Growth problems
- Mood swings
- Disturbing dreams
- Depression
- Anxiety
- Dental problems
- Insomnia
- Osteoporosis
- Nausea
- Hair loss
- Skin problems
- Oral thrush
- Feeling weak and tired
- Diabetes
- Cataracts
- Shaking
- Cushingoid features ('moon face')

Where it is available, research evidence often corroborates patient experience. For example, oral corticosteroids have been shown to more than double the risk of diabetes in older people.[xvi] It is important that these side effects of standard treatments are recognised in NICE's cost-effectiveness model since the costs associated with them may be large. Insulin-dependent diabetes alone was estimated to cost the NHS £1,021 per person per year in 1995, though costs are likely to have risen since then and the full extent of the health and social service costs associated with all side effects combined is difficult to quantify.[xvii]

Jill (aged 22) described steroids as giving her unbearable side effects: she suffered from depression, was constantly tired, felt dizzy, sick and achy and was unable to attend most of her school lessons. She also gained six stone in weight, taking her from eight stone to 14 stone when she was 16 and 5'4". The change in her appearance affected her confidence greatly and made her feel that she had to tell everyone she met that it wasn't her fault she was overweight and it was down to her medication. She is currently having tests on her adrenal glands, as her doctors are worried she has developed Addison's disease.

Gemma (aged 34) was prescribed Prednisolone, salbutamol nebules, atrovent nebules, an intal inhaler, Salbutamol tablets, Singulair and Seretide. These drugs had such severe side effects, including migraine and osteoporosis, that she also had to take a number of other drugs to treat those. Her list of medicines included a total of 46 items.

By the age of eight, **Joseph (now aged 13)** had his Prednisolone dose increased to 40mgs per day. Any reduction in dose led to a hospital admission. His asthma specialist feared that Joseph would not live past 12 owing to the high levels of steroids and side effects. He had developed brittle bones, Cushing's syndrome, rounded chest, increased blood pressure and increased appetite.

4.1.2. Repeated hospital admissions

Ongoing severe symptoms and a complex medicine regime are often accompanied by frequent hospital admissions for many adults and children with severe asthma. According to a retrospective analysis, before treatment with Omalizumab, the mean admission rate for patients using Omalizumab in the UK was 3.67 per year.[xviii] Of course, this means that some patients experience fewer admissions than this and some experience many more. Numerous hospital admissions to respiratory wards, paediatric wards, paediatric intensive care units (PICU), intensive care units (ICU) and high dependency units (HDU) lead to further social isolation and economic disadvantage for families affected by asthma as well as high costs to the NHS.

Jim (aged 69) told us that in 2003, his asthma continued to worsen to the point when few months passed without a hospital admission. In that year he was admitted seven times. He has also been ventilated twice and experienced a number of HDU admissions for additional support. Admissions of this type are associated with increased risk of death.

4.1.3. Mortality

The factor with the greatest impact on the Incremental Cost Effectiveness Ratio (ICER) in previous appraisals has been identified as mortality rates associated with severe exacerbations. A mortality rate of 3.1% for clinically significant severe exacerbations was used for the TA 133 appraisal of Omalizumab in adults and a rate of 0.097% for the TA 201 appraisal of Omalizumab in children aged 6-12. These figures may be underestimates, since the studies on which they were based do not include asthma deaths outside hospital; a small number of such deaths are reported and may affect mortality rates since the total number of asthma deaths – particularly in children - is also relatively low compared to some other conditions.[xix] Moreover, these rates do not take account of mortality associated with the side effects of asthma treatments; incorporating this in the cost-effectiveness model would be helpful.

Fear of a fatal asthma attack also puts families and people with asthma are under extreme emotional stress.

In June 2007, a doctor phoned Jill's mother and told her there was nothing more they could do to help **Jill (now aged 22)**. The doctor warned her that Jill's body was shutting down and she was going to die.

4.2 The advantages of Omalizumab over standard practice

People with severe asthma have very limited treatment options that do not involve high doses of drugs with very poor side effect profiles. When offered the opportunity to receive Omalizumab, all of our volunteers said that they were faced with no alternative but to try it. On receiving Omalizumab, some people observed immediate changes in their condition, whilst for others it took many months before noticing a difference. Nevertheless, for most, the improvement was very dramatic.

Table 2: Benefits of Omalizumab reported by volunteers

Health benefits	Quality of life benefits
▪ Reduced asthma symptoms ▪ Reduced number of asthma exacerbations ▪ Reduced symptoms of other allergic conditions ▪ Reduced number of emergency contacts with the NHS ▪ Reduced doses of other medicines ▪ Reduced side effects of other medicines	▪ Reduced need for care ▪ Increased physical activity ▪ Increased participation in education and employment ▪ Improved mental health ▪ Improved relationships ▪ Improved ability to plan for the future

Karen (aged 47) noticed she was feeling better after ten weeks on the drug. She says: 'By 16 weeks it was like I didn't even have asthma'. She started swimming again and was even able to complete a 200-length swim to raise money for her hospital. Doctors reduced her steroid dose, she didn't need her nebuliser anymore and her Aminophylline was reduced. Karen also lost three stone in weight and said she felt a 'whole new lease of life'. Her family stopped worrying about her health as much and she was finally able to plan holidays with her husband because she knew she'd be well enough to go on them.

Prior to Omalizumab, **Joseph (aged 13)** was admitted to an open access ward in emergencies approximately ten times per year. He has not been admitted to hospital since commencing Omalizumab treatment four years ago.

4.2.1. Changes in drug therapy

In addition to reducing symptoms and the number of hospital admissions, many people taking Omalizumab have been able to reduce their medication or at least stabilise their treatment regime. A real-life study of Omalizumab use in France and Germany found that 50.6% of people who had been taking oral corticosteroids were able to reduce their dose or stop it altogether.[xx] Even more dramatic improvements have been reported in the UK, with the mean dose of oral corticosteroids in a UK cohort being treated at specialist centres dropping from 5.49mg to 3.62mg.[xxi] This is one of the most important outcomes to patients, because reducing doses of oral steroids also reduces the side effects that they suffer as a result.

It was not until **David (aged 42)** had been taking Omalizumab for nine months that he started to see really significant improvements, but at that stage, his symptoms improved so much that he now rarely uses his reliever inhaler. He has also reduced his steroid dose from 50mg to 10mg, enabling him to lose 25kg of weight between May and October 2011.

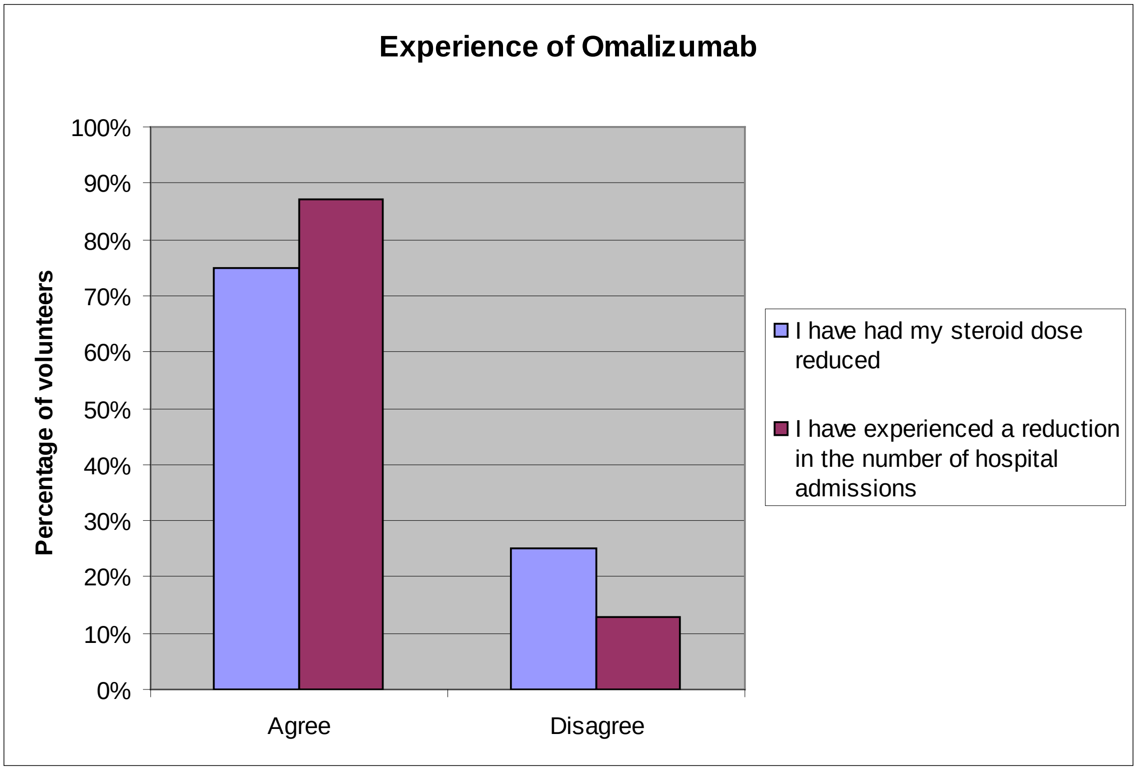
Three months after starting the treatment, **Jill (aged 22)** started to notice the differences it was making to her life. She could walk more easily, didn't need to use her inhalers as much and barely needed her nebuliser. Doctors were also able to dramatically reduce the dosage of her steroids, from 40mg a day to 7mg, relieving her side effects of depression, tiredness, dizziness and weight gain.

4.2.2. Reduced exacerbations and hospital admissions

The key INNOVATE trial showed a 26% reduction in clinically significant severe exacerbations for Omalizumab compared with placebo in people aged over 12.[xxii] A review of literature on Omalizumab found significant reductions in both number and length of exacerbations in older age groups.[xxiii]

A reduction in exacerbations and school absences must also be considered as a relevant end point when considering the efficacy of Omalizumab in children.[xxiv, xxv] In a trial among children aged 6 to 12, Omalizumab reduced the rate of clinically significant asthma exacerbations by 31% versus placebo over 24 weeks. Over a period of 52 weeks, the exacerbation rate was reduced by 43% versus placebo.[xxvi] Although evidence about Omalizumab is more limited in children than adults, many of the characteristics of severe asthma are the same across both age groups, meaning that some data will be relevant to all age groups.[xxvii]

Graph 1: Volunteer self-reported benefits of Omalizumab (n=16)



Josie always used to keep a bag packed for the hospital in case of emergency admissions for her young son **Dominic (aged 8)**. Constant admissions to hospital meant that the whole family was virtually spending every other week living in the hospital with him. She had to take him to hospital for four to five days every fortnight before he received Omalizumab. This meant that she and her baby son had to stay in hospital with Dominic and that Dominic was rarely at school.

Over the last year, on Omalizumab, Dominic has only had three admissions. He is able to do sports and play. Josie was proud that he was able to run all day at the local Tesco sports day recently. He did not need his reliever inhaler and he loved the experience.

4.2.3. Improved quality of life

The asthma quality of life questionnaire (AQLQ) was used as an outcome measure in the key trial of Omalizumab.[xxviii] Clinically meaningful improvements were shown in quality of life for 60% of the Omalizumab group; this was significantly better than the placebo group.[xxix] What this means for patients is enormous. Both adults who had severe asthma themselves and parents of children with severe asthma reported major improvements to their family lives and felt that this was one of the greatest benefits of the treatment.

Francine (aged 32) wrote a set of goals for her treatment at the outset and has now met all of them – meaning that she can now do things like fly a kite with her son, rather than only watching from the sidelines. She feels much more positive and she can plan for her future again. Family members no longer need to spend all their time caring for her and she has some colleagues who don't even know that she has asthma. She says, 'I used to feel that I had to fit my life around my asthma, but now I can fit my asthma into my life. It has given me my life back'.

Andrea, Joseph's mum, reports that **Joseph (aged 13)** loves sport, football, and hockey and is now very fit since commencing Omalizumab. He is playing locally at a high level and also plays on the school football and rugby teams. It is now easier for Joseph's family to go on holiday without the numerous medications prior to Omalizumab. The whole family gets more sleep and has greater peace of mind. It is less stressful as Andrea does not need to constantly assess Joseph's symptoms.

4.3 Disadvantages of Omalizumab

On the whole, Omalizumab is highly acceptable to the type of patients who are prescribed it in the UK. For most people, side effects to date appear relatively minor and are widely perceived as acceptable and an improvement on standard practice. Discomfort and anxiety arising from injections is generally outweighed by the expectation of substantial improvements to asthma management and consequent improvements in quality of life including reduced fear of attacks. Nevertheless, people with asthma ought to be made aware of possible side effects of Omalizumab; continued pharmacovigilance is also essential.

Table 3: Problems with Omalizumab

Side effects	Other disadvantages
▪ Urticaria ▪ Lethargy after injection ▪ Dizziness ▪ Nausea	▪ Pain at injection site ▪ Time and costs incurred for travel to receive injection every 2-4 weeks ▪ Fear of unknown long-term side effects

Susan (aged 32) experiences lethargy after receiving the Omalizumab injection. Her employers have agreed for her to work extra hours during the week in order to take the afternoon off work when she receives the injection.

Joseph (aged 13) struggled at first when getting the injections but he has since overcome his fear of needles and attends for the injection by himself. **Scott (aged 10),** who also does not like receiving injections, feels that the benefits from being on Omalizumab are so huge that he is willing to put up with the discomfort of the four weekly injections.

Hannah (aged 22) is anxious about the possibility of having children in future and what might happen if she had to stop taking Omalizumab while pregnant.

Alison (aged 22) fears that she is a 'guinea pig' owing to uncertainty regarding potential side effects from short or long-term use of Omalizumab. Since the initial trial, she has not received comprehensive health checks on a regular basis from the hospital. Alison would like to have an open discussion with her doctors about future options and risks regarding her Omalizumab treatment and her medication regime.

We spoke to two people for whom Omalizumab had not worked as hoped; some others had found its effectiveness seeming to deteriorate over time. Their experiences further highlight the need for ongoing specialist assessment and treatment for people receiving Omalizumab.

Moira (aged 37) has extensive allergies to food additives, drugs, latex, dogs, horses, house dust mites and many types of pollen. She was offered a trial of Omalizumab. Her first and only dose was given in 2001, after which Moira had such a severe reaction to the Omalizumab she ended up in Intensive Care and on life support within 24 hours of having the injection.

Barbara (aged 40) does not have particularly 'allergic' asthma, but in spite of this, her consultant suggested a trial of Omalizumab for four months, due to her ongoing asthma symptoms. After three injections, she has not yet observed a difference to her asthma symptoms.

5. The availability of Omalizumab from the NHS

Omalizumab has offered a new approach to the management of asthma that is very difficult to treat with other medicines on the market. There has been little change in asthma management and treatments in recent years, making Omalizumab a last resort for some people. This makes it vitally important for it to be made available to people with severe allergic asthma.

Most people with severe asthma would not be able to afford to buy this medicine and the associated care privately. Many have already lost their job or income owing to their asthma, and now find themselves struggling to cope on a low income.

The severity of **Dominic's** asthma has made life a financial struggle for his mum **Josie**. Josie had not been able to work because of Dominic's asthma, but was refused disability living allowance and the family had never had a holiday. In contrast, since he has been prescribed Omalizumab, Josie has managed to secure a part-time job.

Many adults and parents of children who currently receive Omalizumab are very afraid that they will not be able to keep using it if there are health service cuts. Several of the people for whom it has been most successful have already had to fight to be able to access it through exceptional funding routes. A particular concern for them is the NICE criterion requiring emergency hospital admissions. This creates a perverse incentive for clinicians to admit people to hospital at a time when they may not need it and a disincentive to patients to take responsibility for managing their asthma. Either of these issues leads to a waste of NHS resources. We believe that this criterion should not be used in new NICE guidance but should be replaced by a more robustly expressed requirement that specialist assessment and treatment optimisation should take place before it is prescribed.

Funding was initially refused for **Dominic (aged 8)**, and Josie had to attend an appeal where the request was granted. The PCT agreed to fund a trial of Omalizumab and if successful continue funding indefinitely.

Asthma UK, a local MP and doctors had to lobby for funding to obtain the drug for **Jill (aged 22)**. Jill says: 'Doctors had said nothing else would work so being offered Omalizumab felt like a lifeline… if I got a phone call saying I couldn't have it any more I don't know what I'd do.'

Jim (aged 69) expressed concerns regarding the criteria for prescribing Omalizumab and suggests that this should be reviewed to ensure that all people with severe asthma are fully considered regarding their suitability for Omalizumab. Jim says: 'The NICE criteria for prescribing Xolair [Omalizumab] are too tight and inflexible. NICE requires hospital admissions in the previous two years. There are patients who are so ill that they require hospital admission during an attack but they themselves refuse, risking loss of life. These patients could also benefit but are not entitled because they refused admission when advised.'

Whilst away at university, funding was denied for **Hannah (aged 22)** because she had not had a hospital admission and therefore did not meet NICE's criteria. She then applied to her own PCT for exceptional funding, but was declined. However, after an eight day hospital admission and transfer to a new consultant, it was decided that she did meet the criteria, so funding would be made available. Hannah feels that as a result of the delay in accessing Omalizumab, she ended up taking high doses of a lot of other dangerous medication that she wouldn't otherwise have needed.

6. Conclusion

Omalizumab can make an enormous difference for a small group of people who have had little other hope of being able to keep their asthma under control. It is vital that these people have an opportunity to benefit. A positive recommendation could be life-changing for more people with severe asthma, leading to reduced symptoms and treatment side effects, improved quality of life, and fewer asthma exacerbations.

Jill (aged 22) says: 'Xolair has given me my life back. I can do what everyone else can do now. It's helped me to think positive now and I think I'm lucky to be here.'

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Type: Known Uncertainty; Evidence Summary
Source: DUETS

What are the long term side effects of steroids for asthma?
Url:
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Type: Known Uncertainty; Evidence Summary
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Url: http://www.tripanswers.org/answer.aspx?qid=4924
Type: Clinical Question
Description: Question: Ç In children with asthma on long term inhaled steroid therapy and with chronic eczema are...
Source: TRIP Questions and Answers

Is it safe to use steroids in children under two with asthma? What are the side effects and will I damage my child in the long term?
Url:
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Type: Known Uncertainty; Evidence Summary
Source: DUETS

Teen Info on Cancer : steroids
Url:
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Appendix B: patient stories

Contents

[redacted]

[redacted] is a young woman who has lived with asthma since early childhood. She is now 22 years old and has been receiving Omalizumab for six years. From the age of 12, Alison's asthma became extremely unstable.

In order to attempt to control her asthma, and prior to being prescribed Omalizumab, [redacted] was receiving hormone medication, Singulair, Symbicort, Salbutamol and Prednisolone 30-50mg per day. [redacted] kept a reliever in every jacket and never left the house without two reliever inhalers.

Her condition disrupted her schooling, her love of sporting activities, her general health and well-being. [redacted] had to struggle through school years balancing asthma symptoms and the side-effects of medication, as well as experiencing bullying and isolation within the school environment. [redacted] had to put up with being called names because of her constant wheeze. She was particularly self-conscious of her wheeze causing annoyance to other pupils during exams. Although an extremely conscientious pupil, [redacted] was blamed by teachers for not being able to tolerate exercise during PE lessons and for not being able to tolerate environmental triggers in classes such as chemistry.

[redacted] has many allergies and suffers from hay fever. Cigarette smoke triggers her asthma and this led to her making the decision not to travel on the school bus where pupils continued to smoke. Running for a bus, being exposed to cigarette smoke and climbing stairs for registration each day meant [redacted] had to use her reliever several times before starting her school day. By the end of the day she could not remember the number of times she had to use her reliever. Owing to the severity of her asthma, [redacted] was only able to attend school for 80% of fifth year.

When [redacted] was in fourth year at secondary school, she had to attend the hospital on a weekly basis to receive a steroid injection. Her consultant offered to put her on a trial of Omalizumab. [redacted] agreed to this and after a year, when the trial was completed, the health board agreed to fund Omalizumab in the medium term. Having been prescribed Omalizumab, [redacted] was able to sit her final exams in sixth year without the burden of her asthma and the resulting lack of sleep.

Since receiving Omalizumab in 2006, [redacted] has only required two hospital admissions in comparison to being admitted four to six times per year for four or five days at a time. She still requires courses of Prednisolone 30mg per day usually in the winter months when she gets a cold or chest infection. These courses may last several weeks or months at a time. She is also on Seretide 250mcg four times a day and Singulair. She attempts to reduce the dose of Seretide when she is well but she does not manage to sustain being on a lower dose. She only uses her reliever medication occasionally and prior to exercise.

[redacted] continues to experience side effects from her steroid medication. She constantly struggles against weight gain, lack of sleep resulting in excess hunger, mood swings and she suspects that her broken bones and tendons, which have been slow to heal, may be due to her previous and current high steroid load.

[redacted] feels that being on Omalizumab enables her to gain some control over her asthma and medication regime, and allows her to self manage her condition. She can forward plan year on year rather than having to live her life taking one day at a time. She is able to tolerate extreme weather conditions, for example, snowboarding in the mountains at winter time.

Having been on Omalizumab for six years, [redacted] now feels frustrated that she still can't live her life fully owing to attendance at the hospital for fortnightly injections. This has caused her problems at work where her employer has been intolerant of time required for the hospital visit leaving [redacted] feeling very stressed. She also fears that she is a 'guinea pig' owing to uncertainty regarding potential side effects from short or long term use of Omalizumab. She finds information about its potential side effects from national organisations and on government websites. Since being on the trial, she has not received comprehensive health checks on a regular basis from the hospital and she questions why she cannot receive the injection nearer home at her GP surgery. Even though she has considered coming off Omalizumab, she has been told that she must stay on it for seven years. Her dose of Omalizumab has not reduced since the trial and she would like to try a lower dose but does not think her doctor would agree to this. As an adult, her perspective on Omalizumab has altered since starting the trial. She longs to be free from the fortnightly injection so she can be free to travel and gain work experience in other countries similarly to her friends.

On reflection, [redacted] would like everybody with asthma to obtain Omalizumab if they require it. However, she would like to have an open discussion with her doctors about future options and risks regarding her Omalizumab treatment and medication regime.

[redacted]

[redacted] is a 40 year old woman, who has had asthma since her late teens, though it wasn't diagnosed until she was 21. After a referral to a specialist tertiary centre at the age of 22, she was diagnosed with brittle asthma. Over the years [redacted] has been on various asthma medications and treatment regimes to try and control her asthma symptoms, including subcutaneous Terbutaline. [redacted] felt reliant on subcutaneous Terbutaline and used it until January 2011.

Despite the severity of her asthma [redacted] was determined to train and qualify as a nurse, which she succeeded in doing in 1995. After qualifying, [redacted] worked in a busy inner city teaching hospital specialising in respiratory medicine. [redacted] worked on the chest clinic from 1999-2000; during this time her asthma became increasingly unpredictable and her nursing colleagues would often comment that she sounded wheezy. [redacted] often found herself working with continuous asthma symptoms of chest tightness and feeling short of breath.

By the time [redacted] was 30 years of age her asthma had become so unpredictable that she was being admitted to hospital on average twice a month, for overnight stays. During several of these admissions she almost went in to respiratory arrest. Due to the severity and unpredictability of [redacted] asthma she was often unable to work and in 2001 she was medically retired from her respiratory nursing job on a busy chest clinic. For [redacted] this was the most difficult period of her life and due to the volatility of her asthma she was left feeling desperate, believing she would not see her fortieth birthday.

[redacted] asthma care was transferred to a Professor of Respiratory Medicine in 2010, shortly after her subcutaneous Terbutaline was discontinued and her asthma treatments reviewed and adjusted. She currently takes Ciclesonide 160mcg BD, Oxis 12 BD, Uniphyllin 300mg BD, Monteleukast OD, Azithromycin 3 x a week and Prednisolone 30mg – 50mg as a rescue course for a flare up of symptoms.

Since the change of care in 2010, [redacted] asthma has been better monitored and she has total confidence in the medical care she receives. Unfortunately despite this her asthma remains unpredictable and difficult to control and while her hospital admissions have been marginally reduced, she is still requiring emergency medical attention monthly. Despite this [redacted] has pursued a fitness regime and since adapting her lifestyle to include exercise, she has seen an improvement in both her peak flow and lung function by 70-80%. This has allowed herto get a job teaching young people outdoor pursuits.

While [redacted] thoroughly enjoys her job, her outdoor work does pose some asthma challenges; she still experiences asthma symptoms on a weekly basis, especially as her asthma can be triggered off by laughing. She has and often uses her portable nebuliser at work to help get her asthma symptoms under control. [redacted] is very well supported at work, she has educated her colleagues about asthma and they are very aware of her particular asthma symptoms.

Even though [redacted] asthma is not particularly 'allergic', her respiratory specialist suggested a trial of Omalizumab for four months, due to her ongoing asthma symptoms. [redacted] has secured funding for her trial and was well informed medically about what it involved. She hasn't got any expectations of Omalizumab, especially as she doesn't have allergic asthma.

So far [redacted] has had three Omalizumab injections and she has not noticed any difference to her asthma symptoms. Due to a change in weather she has had to increase her steroid dose and start taking antibiotics, with the Omalizumab making no improvement to her symptoms. [redacted] experienced a headache after having her first injection, though she put this down to being dehydrated, as she hasn't experienced this again.

While [redacted] suspects that Omalizumab probably won't work for her, she feels very strongly that everyone with severe and unpredictable asthma, regardless of age should have secure funding and the opportunity to try Omalizumab under the care of a specialist consultant.

[redacted]

[redacted] developed asthma aged 11. When she was first diagnosed, she was able to manage her asthma reasonably well with limited treatment, but her symptoms got much worse when she was aged 15-17.

During this period, she spent lots of time on the respiratory ward. She had numerous hospital admissions as a result of her asthma and spent time in intensive care. Her quality of life was extremely poor and she was afraid that she would eventually die from her asthma. It also had a severe impact on her friends and family because they had to see her when she was really ill. Her mum found it particularly stressful.

She had to take a lot of drugs for her asthma including Symbicort and Theophylline, and had to use a nebuliser at home. She was permanently on oral Prednisolone, but it wasn't working and she was still regularly being admitted to hospital for ten days at a time – she was also readmitted shortly after discharge on several occasions.

She suffered several side effects from the steroids, including weight gain, bone thinning and feelings of aggression.

[redacted] was prescribed Omalizumab in 2008 and had an injection every four weeks from June 2008 until July 2011. She was initially reluctant to try it because she was worried that it would make things worse for her. An initial trial period of Omalizumab for 16 weeks didn't show any impact, but a second trial seemed to work. She had fewer asthma symptoms and attacks and generally felt better and slept better. She was also able to reduce her dose of Prednisolone. She was admitted to hospital a couple of times shortly after she started to take Omalizumab, but had no further admissions during her last 18 months on the treatment.

[redacted] didn't have severe side effects from Omalizumab, though she did get a sore arm and a headache on the day of the injections. She is not especially worried about possible long-term effects but knows that these are still unknown.

After three years, [redacted] stopped taking Omalizumab on a trial basis. Although her symptoms are not as bad as they were before she started on the drug, she has seen a gradual decline in her asthma control since she stopped the injections. Her steroid dose has been increased again and she has had a severe asthma attack. She plans to see how it goes.

She says that her quality of life on Omalizumab improved a million times. She had been about to lose her job and her place at college, but now says that some people wouldn't know she has severe asthma. She is very much hoping that her symptoms don't get much worse again. She says: 'It changed my life; I would fight for others to get it.'

[redacted]

[redacted] has had asthma since he was nine months old. He has had several periods when his asthma has been very severe, particularly between 1993 and 2002. During this time, he was often going in and out of hospital because of his asthma, though it improved and after 2002, he managed to keep it relatively well under control with Singulair, Theophylline, Seretide and Salbutamol, as well as other medicines for allergic rhinitis.

In 2009, [redacted] was coping with his asthma and working as a teacher. However, that summer, his asthma worsened significantly. His peak flow dropped to about 20% of predicted levels and he struggled to walk around, go upstairs or pick up his baby daughter. He says: ‘The bottom fell out of my world.’ He had to increase the amount of medicines he was taking, doubling his doses of Theophylline and Singulair, using a nebuliser four times a day and adding a high dose of Prednisolone. Even this did not bring his symptoms under control – the asthma remained severe and he had to give up work. He also gained weight because of the steroids and became seriously depressed. He was struggling to cope but stubbornly tried to avoid going in to hospital.

[redacted] also has osteoporosis and degradation of his spine as a result of taking high doses of steroids for his asthma during the 1990s. In addition, he suffers from sleep apnoea, which is often worsened by being overweight.

[redacted] was referred to a specialist who recommended Omalizumab. He initially struggled to get it funded by the local PCT and had to make a case for it. Funding was eventually approved and he started taking Omalizumab in June 2010. During the first three months, his peak flow improved, but not by very much. It was not until [redacted] had been taking Omalizumab for nine months that he started to see really significant improvements, and at that stage his symptoms improved so much that he was able to walk and exercise again. He now rarely uses his reliever inhaler and has reduced his steroid dose from 50mg to 10mg, enabling him to lose 25kg between May and October 2011. He has been able to get a new job and can even walk to work, so his outlook and mental health have improved dramatically. He says one of the greatest benefits is that he can now play with his daughter and know she won’t have to grow up constantly worrying about him.

The main disadvantage of taking Omalizumab was that he initially had to travel once a month while struggling with symptoms in order to get it. The injections were also painful because the mixture was quite thick. However, [redacted] now has his injections closer to home and the drug is now available in a formulation which is much less painful.

[redacted] (and mum [redacted])

[redacted] has two children: [redacted] and another child aged four.

[redacted] experienced recurring chest infections and was diagnosed with asthma at age one and a half. He was prescribed inhaled steroids at three years of age and Atrovent at three and half years of age. When he was admitted as an emergency at three years of age, his hospital did not know how to deal with such an attack and they had to phone another hospital for advice. At four and a half years of age [redacted] was prescribed Seretide 125, two puffs twice a day. He was also prescribed Montelukast. He had received an IgE blood test but the paediatrician is still not sure what he is allergic to. He uses Cetirizine for allergic rhinitis seasonally. [redacted] has laminated all the floors of her home and buys new pillows and duvets every three months.

As [redacted] got older, his condition worsened. For the last three and a half years, he has received soluble Prednisolone tablets, 10mgs on alternate days. [redacted] states that he has not experienced side effects from his steroid medication. Prior to commencing Omalizumab, he was prescribed Slo-phyllin and is now on this twice per day.

When [redacted] was admitted to hospital aged five, he had to be transferred to another children's hospital ICU as there is no PICU where he lives. He then became under the care of another doctor who prescribed Omalizumab in April 2010.

From six years of age, [redacted] was having regular hospital admissions; he was in hospital for four to five days every fortnight up until he received Omalizumab. This meant [redacted] and her baby had to stay in hospital with him. [redacted] was rarely at school. Even when he was out of hospital he was often absent from school. They were visited by education welfare because of his absences and the school sent school work home but he still fell behind.

Since commencing Omalizumab, he has not had any absences from school and is still attempting to catch up with his schooling. [redacted] feels that [redacted] asthma is not well understood by the school. She thinks asthma is not treated as seriously as diabetes and they do not understand the seriousness of [redacted]asthma. Prior to Omalizumab, he could not join in PE at school. Even though he is supposed to take his reliever inhaler four times a day, the school failed to do this, so [redacted] did not have confidence in sending him to school prior to Omalizumab. She said he was never at school and was more in hospital than at home. She always kept a bag packed for the hospital in case of emergency admissions. She was always very frightened at any admission in case this one was going to be his last and she would not be taking him home. She said [redacted] constantly took the hospital admissions in his stride; he did get scared when carried out by paramedics but knew what to expect and coped generally well.

Owing to the severity of [redacted] asthma, it has been a financial struggle for [redacted]. She has been refused disability living allowance. The family have never had a holiday. [redacted] has not been able to work because of [redacted] asthma. Since he has been prescribed Omalizumab, [redacted] has managed to secure a part-time job. Since commencing Omalizumab, [redacted] has only had three admissions over the last year. His consultant would like to reduce his Prednisolone but has not because of the hospital admissions. He will consider doing this next summer. [redacted] knows he can now do more and is able to do sports and play. [redacted] was proud that he was able to run all day at the local Tesco sports day recently. He did not need his reliever inhaler and he loved the experience. She said he knows not to overdo it and to take his inhaler when required. She thinks his quality of life has increased since commencing Omalizumab and if it continues, life can only get better.

The consultant had applied to the PCT for funding for Omalizumab for [redacted]. This was initially refused and [redacted] had to attend an appeal where the request was granted. At that meeting [redacted] answered questions about [redacted] quality of life at home and at school. They agreed to fund a trial of Omalizumab and if successful continue funding indefinitely. [redacted] said at that point she was prepared to try anything.

[redacted] feels that Omalizumab is amazing – it is not a miracle drug but does help enormously. She describes it as life-changing; she is concerned about parents whose children do not have access to Omalizumab.

She received written information when he was first prescribed Omalizumab. She thinks she was given enough information to make the decision for [redacted] to go on Omalizumab.

[redacted]

[redacted] was first diagnosed with asthma in 2006, but didn't really experience many symptoms until about a year later. At that point, her asthma worsened substantially and daily life became a real struggle. Breathlessness would keep her awake at night and she would usually be very tight-chested. The smallest thing would trigger an asthma attack – even a very short walk would leave her struggling to breathe. She would have to stop to rest between each stage of her morning routine and needed her young son's help with simple tasks like washing her hair and getting in and out of the bath. She would arrive at work already exhausted and would then struggle with further asthma attacks throughout the day.

[redacted] would often need to go to hospital because of her asthma, with admissions approximately every two months and stays of about a week. She says: 'I felt like I was losing control of my life, like things were being taken away from me. Being in hospital meant that I missed numerous special occasions and family events. We couldn't make any plans because everything felt like a gamble as to whether I would be well enough.' Every performance review she had at work would focus on her asthma and her employer (a Housing Association) was considering whether she was fit enough to keep working.

She was quickly referred to a specialist consultant as her symptoms worsened. She had to take high doses of Prednisolone as well as numerous inhalers and use a nebuliser at home. She also suffered from side effects such as headaches, hot flushes, stomach problems and palpitations. Her consultant explained about Omalizumab relatively early on and she was receiving the injections from May 2008 to August 2011.

Taking Omalizumab made a very significant difference, though it took a little time to become noticeable. Symptoms improved and hospital admissions reduced. [redacted] has only been in hospital twice in 2011 (due to flu on both occasions) and has not needed to take any other unplanned time off work. She wrote a set of goals for her treatment at the outset and has now met all of them – meaning she can now do things like fly a kite with her son, rather than only watching from the sidelines. She feels much more positive and that she can plan for her future again. Family members no longer need to spend all their time caring for her and she has some colleagues who don't even know that she has asthma. She says: 'I used to feel that I had to fit my life around my asthma, but now I can fit my asthma into my life. It has given me my life back.'

[redacted] is currently trialling a break in her Omalizumab treatment. It's too early for her to tell what the impact of this will be on her asthma, though her allergy symptoms have become noticeably worse.

The disadvantages of taking Omalizumab for [redacted] have been inconvenience and side effects. Her nearest hospital is 25 miles away, so she had to take an afternoon off work every four weeks to go for the injection, which she found quite intrusive in her daily routine. She would also get headaches and feel sleepy after the injections, but this did not last for very long. She put on weight and developed problems with her bones while on Omalizumab and her consultant is considering whether taking the drug may have been the underlying cause of the bone problem.

Her outlook now is to accept that she will probably always have severe asthma, but she now feels much more positive than she did in the past. She has more control and no longer feels as though she has to sit by and watch everyone else live their lives. She is also interested to find out the difference that will be made over the next few months by coming off Omalizumab.

[redacted]

[redacted] has been taking Omalizumab for just over eight years.

She was diagnosed with asthma after a chest infection when she was 21. Although she had been healthy before that, her asthma deteriorated very rapidly and her quality of life became very poor. Her breathlessness was so bad that she couldn't walk or even speak very well. She lost her social life and her job and needed her family to care for her. She and her family found this very difficult, and were often also frustrated by the benefits system. She says that life was 'dreary' and that she was 'just existing rather than living', finding it difficult to even get up in the morning. She was also visiting her GP several times a week, and her consultant once a week, and would very often (every ten days) have asthma attacks that put her in hospital for days at a time.

She was prescribed a long list of medicines. She took Prednislone, Salbutamol nebules, Atrovent nebules, Intel inhaler, Salbutamol tablets, Singulair and Seretide for her asthma. These drugs had such severe side effects, including migraine and osteoporosis, that she also had to take a number of other drugs to treat those. Her list of medicines included 46 items in total.

[redacted] was on a trial for Omalizumab. She started seeing a big difference in her asthma after about eight months of using the drug. She had been using a nebuliser every two hours, day and night, but she stopped feeling that she needed them so often. She has also been able to reduce the doses of her other medicines and no longer needs to be admitted to hospital very often – it's now only about once a year.

She gradually became able to look after herself and had more 'better' days when she was able to get out. She went to college and got a degree, then a part time job two years later. Her mental health also improved and her family have also felt benefits as they no longer need to care for her – she says: 'I've been given my life back'.

The injections are painful and she gets some bruising on the injection site. She has had so many injections in her arms that scar tissue has now developed, so the drug now has to be injected into her legs. She also had to travel once every twelve days for seven years, which took out a whole day each trip, though she can now get the injections locally. She says that benefits of Omalizumab far outweigh either the inconvenience of travelling or the painful injections.

[redacted] was given lots of information before the trial and knows how Omalizumab works to target IgE.

[redacted]

[redacted] developed asthma aged 16 and it became severe when she was 18.

Before developing asthma, she had a very active lifestyle and used to play many sports competitively, including entering her horses to competitions at a national level. However, once she developed severe asthma and went away to university, she wasn't able to live the student lifestyle. Damp student accommodation and attempting to keep up with her fellow students caused problems for her and she missed the majority of first term in her second year because of her asthma. She was asked to take a year out by the university and was contemplating this, but started taking Omalizumab at around the same time and recovered enough to complete the rest of her degree.

Before receiving Omalizumab, [redacted] was taking maintenance oral Prednisolone at high doses as well as inhaled steroids, a long acting beta 2 agonist, using a nebuliser at home, Montelukast, antihistamines and Theophylline. She developed joint pain and stomach problems (reflux) as side effects of these drugs, as well as putting on weight. This resulted in her taking more drugs to counteract the side effects of her asthma medication.

[redacted] has been on Omalizumab for three years. She was seeing a consultant and initially applied for funding for it where she was at university. However, funding was denied because she had not had a hospital admission and therefore did not meet NICE's criteria. She moved home during the summer and applied to her PCT for exceptional funding, which was declined. However, after an eight-day hospital admission and transfer to a new consultant, it was decided that she did meet the criteria, so funding would be made available. In the delay between being told she could trial Omalizumab and being able to begin treatment, [redacted] had two further hospital admissions. [redacted] feels that as a result of the delay in accessing Omalizumab, she ended up taking high doses of a lot of other medication she wouldn't otherwise have needed.

After starting on Omalizumab, [redacted] was able to reduce her use of home nebuliser and her oral steroid dose. She lost weight and did not experience any other asthma attacks as a result of allergic triggers (though her asthma is also triggered by viral infections and she has continued to have problems with this). Her eczema also disappeared.

Omalizumab has made a big difference to what [redacted] can do day-to-day. It has enabled her to start running again, to look after her horse and to go out riding. It has made life much more consistent in that it is now easier for her to predict what will lead to an asthma attack. Her parents are now much less concerned about her than they were. She is also able to go out with friends without them having to make special allowances, because she can now walk much further and doesn't have to plan her social life depending on how well she is.

[redacted] had to look up a lot of information about Omalizumab for herself before getting it. She hasn't had major side effects from it, though she occasionally gets tired after her monthly injection. She had been led to expect more from it (she hoped to be able to cut down doses of steroids even more and for all asthma attacks to be avoided), but it has done what it needed to do for her quality of life. However, she is anxious about the possibility of having children in future and what would happen if she had to stop taking Omalizumab while pregnant.

[redacted]

[redacted] has had asthma since she was born but it started to take over her life when she was 12. At this age she had a severe asthma attack and was admitted to intensive care. Over the next five years she was regularly in and out of hospital and suffered from asthma attacks several times a week. Doctors put her onto Slo-phyllin tablets, Prednisolone 40mg daily and she used a nebuliser frequently to help her breathlessness.

The steroids gave her unbearable side effects. She suffered from depression, was constantly tired, felt dizzy, sick and achy and was unable to attend most of her school lessons. She also gained six stone in weight, taking her from eight stone to 14 stone when she was 16 and 5'4''. The change in her appearance affected her confidence greatly and made her feel that she had to tell everyone she met that it wasn't her fault she was overweight and it was down to her medication.

She was given counselling sessions by the NHS Trust but became disheartened with them when her third session wasn't followed up and then relied on her mother and partner for support. Her condition worsened and by the time she was 17 she was barely able to move without becoming breathless. She was confined to her bed in her home and was restricted to a wheelchair when she went out. [redacted] was also mocked by other students at her college when she attended her classes in a wheelchair.

In June 2007, doctors phoned [redacted] mother and told her there was nothing more they could do to help her. The medics warned her that [redacted] body was shutting down and she was going to die. But a month later they heard about Omalizumab and told [redacted] about it. Her mother, Asthma UK, local MP and doctors had to lobby for funding to obtain the drug for her. [redacted] says: 'Doctors had said nothing else would work so Omalizumab felt like a lifeline.'

She started having monthly injections of Omalizumab in December, 2007. At first she felt worried about taking it because it was a new drug that hadn't been widely used before, but she was willing to try anything which could help her condition. She wasn't expecting it to work, but three months after starting the treatment [redacted] started noticing the differences it was making to her life. She could walk more easily, didn't need to use her inhalers as much and barely needed her nebulisers. Doctors were also able to dramatically reduce the dosage of her steroids, down from 40mg a day to 7mg, relieving their side effects. She hasn't had any asthma attacks since starting Omalizumab and hasn't needed to use nebulisers for two years.

The improvements to her health meant she was able to complete a degree in social work, where she made friends, and she is currently looking for a job. She has lost two stone and her fitness levels have improved; she regularly goes jogging and rides her bike. [redacted] is getting married next year and has been able to plan it with her fiancé by visiting different venues – something she says she wouldn't have been able to do without Omalizumab.

She says she now has a positive outlook on life and feels like a different person compared with how she felt before taking Omalizumab. She says: 'Omalizumab has given me my life back. I can do what everyone else can do now. It's helped me to think positive now and think I'm lucky to be here. I just get on with things now. If I got a phone call saying I couldn't have it any more I don't know what I'd do.'

[redacted] has been warned that she can't fall pregnant while taking Omalizumab because doctors do not yet know if the drug would harm a baby. While having children isn't on her agenda yet, she says it would be a concern for other people taking the treatment.

She is also having tests on her adrenal glands, as her doctors are worried she has developed Addison's disease. She says they think her adrenal glands have failed as a result of the high dosage of steroids she had to take for so many years. If the tests find that she does have Addison's disease, she will have to take another type of steroid for the rest of her life.

[redacted]

[redacted] was medically retired from the offshore oil industry in 1993 at the age of 51. This followed confirmation that he had been diagnosed with severe asthma. At no time prior to this had he experienced any form of asthma related symptoms. His initial asthma attack was in response to the aroma of perfume whilst sitting in an airport lounge. This led xxx to be hospitalised. He was discharged on a Bricanyl inhaler and prophylactic antibiotics. During the next 12 months he experienced a further two admissions and was then commenced on low dose inhaled steroids. As time moved on it became necessary to take ever increasing levels of inhaled steroids and regular courses of Prednisolone tablets.

From 2003, [redacted] asthma continued to worsen to the point when few months passed without a hospital admission. In that year he was admitted seven times. He has also been ventilated twice and experienced a number of HDU admissions for additional support. These types of admissions compounded his fear of the 'final attack'. [redacted] wife was now also experiencing the worry associated with serious life threatening admissions.

In 2006, [redacted] was randomised for a controlled drug trial of Omalizumab. Within two months it became apparent that his asthma was under better control and by the end of the trial [redacted] had not required a hospital admission. To confirm such an improved control of his asthma, [redacted] underwent a further trial. The conclusions were the same. When the second trial was over further treatment was not automatically available within the NHS. [redacted] could not bear the thought of his wife experiencing such extreme stress or worry again nor a restricted and disabling lifestyle but also the appalling side effects of high dose steroids.

To remain alive and return to some form of normality he felt that if the PCT was not prepared to fund such treatment, he and his wife would have no choice but to sell their home to fund the medication themselves. [redacted] had already established that the medication was available over the counter in Spain. He felt very bitter having worked all his life without claiming any social benefits and felt if this was the only other option to keep him out of hospital and keep him alive, then it would be very difficult to fund the drug as a pensioner.

[redacted] worked with his Respiratory Consultant, colleagues, GP and the media to persuade his PCT to fund Omalizumab on a quality of life and economic case for multiple hospital admissions. He was successful and the PCT funded him within three weeks after the Omalizumab trial ended. He did not receive any written information about Omalizumab but had a full understanding about the properties of Omalizumab which were discussed in detail with his consultant.

[redacted] present medication is 150mg cc Omalizumab every 28 days. This is further supported with inhaled steroids and relievers. During the last year he required four intensive courses of Prednisolone and the use of nebulised medication but he has only had one hospital admission in the last three and a half years.

Omalizumab has had the similar effect of an antihistamine to [redacted] in that it has stopped all allergic trigger points that induced his asthma. These included smoke, pollens, perfume, certain types of red wine and flowers.

[redacted] does experience side effects from Omalizumab in that he some times develops urticaria of varying intensity a week later after the injection and always experiences severe fatigue up to 48 hours after receiving the injection. During this time he does not drive.

[redacted] quality of life has remained good since being on Omalizumab again. He now keeps himself fit by attending a gym four times per week. Prior to Omalizumab he would ask his friends not to bring around flowers or wear perfume when they came to visit, the only restriction he now puts on his friends is not to car share if they have a cold or signs of a cold coming on. In terms of mental health, [redacted] believes there has been a complete 'turnaround' for the better with Omalizumab. He believes he would have died by now, owing to the severity of his asthma attacks, if he were not receiving Omalizumab.
[redacted] however is still at risk during severe thunderstorms when barometric pressure falls suddenly and also of chest infection.

After so many years disabled with asthma, life has undergone a big change bringing a sense of normality back to day to day living. What frustrates [redacted] more than anything is Omalizumab is now proven to be a life saver for patients with moderate to severe allergic asthma. The cost to the Government is a fraction of the cost of ITU admissions or the cost of four to six ward admissions per year.

[redacted] feels that the NICE criteria for prescribing Omalizumab are too tight and inflexible. He says that FEV1 must improve by 10% thirty minutes after a reliever is used. 'For me as a brittle asthmatic, my FEV1 does not vary and remains unchanged if I am well, irrespective of how many doses I take.'

NICE further requires hospital admissions in the previous two years. [redacted] considers that there are patients who are so ill that they require hospital admission during an attack but they themselves refuse, risking loss of life. These patients could also benefit but are not entitled because they refused admission when advised.

[redacted] (and mum [redacted])

[redacted] noticed there was something wrong with [redacted] from six months old; he was diagnosed with severe bronchial asthma and severe allergies at the age of two. He was under a paediatrician and immunologist at their local hospital. He received skin prick tests and dietary intervention. When he was in hospital for a week under his immunologist, [redacted] was taken under the care of another consultant. The consultant diagnosed Bronchiectasis and Primary Eosinphilic Oesophagitis. He discontinued the inhalers prescribed by the paediatrician and prescribed a new combination of inhalers and started him on oral steroids. He also encouraged Joseph to be as physically active as possible. [redacted] was a very active child and responded well to these new treatments. Between the ages of four and six, [redacted] levels of oral steroids were reduced and on two occasions they were withdrawn altogether, but each time he became unwell again. [redacted] health was stable until he was seven and over the next 12 months he deteriorated rapidly, with his steroid dosage increasingly significantly.

Even though [redacted] was extremely sporty, by the age of eight he could not train, play football or do sport at school, and his Prednisolone dose increased to 40mgs per day. Any reduction in dose led to a hospital admission. The consultant feared that [redacted] would not live past 12 owing to the high levels of steroids and side effects. He had developed brittle bones, Cushing's syndrome, rounded chest, increased blood pressure and increased appetite.

[redacted] is an incredibly strong, courageous and pragmatic boy. When faced with the news that he may die, and at the stage that he had developed brittle bones, he was quick to reassure his mum and believed that a positive outcome would be reached. [redacted] stated that his episodes of self pity are short-lived.

The consultant and the family initially discussed prescribing Omalizumab in December 2006 when [redacted] was seriously ill and his quality of life was reduced considerably. Initially [redacted] GP would not prescribe Omalizumab even though the consultant recommended it and the NHS was paying for it. Andrea had to plead to the GP and be very assertive to get him to change his mind.

After 12 months of trying to obtain the drug [redacted] received his first dose of Omalizumab in December 2007, when he was nine years old. He has now been on it for nearly four years. Prior to Omalizumab, [redacted] was admitted to an open access ward in emergencies approximately ten times per year. He has not been admitted to hospital since commencing Omalizumab treatment.

Within four weeks of taking Omalizumab, [redacted] lung function and peak flow improved and he began to reduce his Prednisolone and was completely off it within three months. The consultant encouraged [redacted] to exercise and strengthen his lungs. His lung function and peak flow are now above average. He is only prescribed a short course of Prednisolone tablets twice a year usually associated with catching a cough or cold. He is currently prescribed Seretide and takes an antihistamine seasonally. He never requires his Ventolin inhaler. His lung function results are above those of a typical child his age in contrast to being very poor prior to receiving Omalizumab. [redacted] was being given Omalizumab every four weeks but now it is every five weeks – the consultant has suggested he reduces it to every six weeks but [redacted] is too frightened to adjust the dose as things are going so well at the moment. [redacted] loves sport, football, and hockey and is now very fit since commencing Omalizumab. He is now playing at a high level: for Amateur Football Club 13s, Hockey Club 13s. He also attends a boxing club once per week and has joined a trail cycling club. He also plays on the school football and rugby teams.

It is now easier for the family to go on holiday without the numerous medications prior to Omalizumab. The whole family gets more sleep and has greater peace of mind. It is less stressful as [redacted] does not need to constantly assess [redacted] symptoms. The symptoms are not typical asthma symptoms: [redacted] does not wheeze; instead he gets dark shadows, cyanosed lips, poor appetite and lethargy. He can now do late nights with friends without putting his health at risk. He can run about as normal. Prior to Omalizumab, [redacted] had severe food allergies including milk, egg, nut, maize, corn, citrus fruit and bananas. [redacted] was completely dairy free and had therefore never eaten a cake apart from dairy-free products. The additional benefit of Omalizumab is that it has reduced his allergies to intolerances and he can now have small amounts of the foods he previously could not risk ingesting. However, this is also a negative as without Omalizumab he would revert back to the allergy.

[redacted] does not think there are any downsides to [redacted] taking Omalizumab except the uncertainty/underlying fear of 'where we go in the future', that he might be taken off it or left on it for life. [redacted] thinks it is life changing and it must not be taken away.

[redacted] and [redacted] have never been given written information about Omalizumab. They received in-depth information about how the drug works and discussion from the consultant. They did not receive information about possible side effects or potential problems with injecting sites. [redacted] struggled at first when getting the injections but he has since overcome his fear of needles and attends for the injection by himself.

[redacted]

[redacted] was born with asthma but it was kept reasonably under control until she was 17, when she moved to Australia. The combination of the change in climate and emotional problems she experienced when she was there led her to have her first major asthma attack and she was rushed to hospital. During the two years she lived there she was in hospital every few months, and was prescribed Aminophylline and took Prednisolone tablets after each attack.

In 1987, a few years after she returned to the UK, she became pregnant with her first daughter and found that her asthma improved while she was pregnant and for a year afterwards, with her barely needing her inhalers and coming off her steroids. After this [redacted] asthma worsened but improved again when she was pregnant with her second child.

[redacted] health took a turn for the worse when she moved to Hong Kong. She was in an abusive relationship which took its toll on her asthma. She returned to Britain four months later and by this time her children, then aged four and seven, had become used to phoning 999 each time she had an asthma attack. By 1995 she was having major attacks four or five times a year and doctors put her on 40mg of steroids for a short period after each attack.

In 2000, [redacted] had a severe attack and was intubated for the first time in intensive care for eight days. Her asthma went downhill and doctors put her on her steroids permanently, and a magnesium drip and Aminophylline intravenously each time she was admitted to hospital. From then on her asthma got progressively worse. She was constantly in and out of intensive care and dependent on her steroids, which caused her to gain eight stone in weight. As well as her weight gain, she became very depressed and was prescribed Prozac. She was always tired and developed sleep apnoea, so she was put on a CPAP machine at night to aide her breathing. She found that her asthma greatly limited her in life – she was frequently too ill to work in her job as an accounts deputy manager and she had to use a wheelchair because she became too breathless to walk for any length of time. [redacted] was later given a Terbutaline pump to inject Bricanyl into her stomach subcutaneously, which she had to have with her at all times. This helped her for a couple years but by 2007 it had become less effective.

At this point she was told about Omalizumab. After having tests, doctors found she was within the correct guidelines for it. She didn’t know anything about the properties of the drug but she had high hopes that it would improve her quality of life, even though her doctor warned her not to expect too much from it. [redacted] noticed she was feeling better after ten weeks on the drug. She says: ‘By 16 weeks it was like I didn’t even have asthma.’ She started swimming again and was even able to complete a 200-length swim to raise money for the hospital.

She was on Omalizumab for 18 months and in the first year of taking it she hardly had any asthma attacks, although they increased in the last few months she was on the treatment. Doctors reduced her steroids dosage down to 7.5mg, she didn’t need her nebuliser anymore and her Aminophylline was reduced. [redacted] also lost three stone in weight and said she felt a ‘whole new lease of life’. Her family stopped worrying about her health as much and she was finally able to plan holidays with her husband because she knew she’d be well enough to go on them.

At the beginning of 2009, when [redacted] had been taking Omalizumab for 18 months, its effectiveness decreased and her asthma worsened again. Her doctor took her off the drug and after that she started needing to use her inhalers and nebulisers more, the dosage of her medication increased and she became depressed once more. She says: ‘It was just awful. I was thinking, “This is my life, is this going to be it now?” My Prozac dose went up, I felt tearful all of the time and was in a terrible slump. To me that was the last thing that was left to try.’ Since stopping Omalizumab she has been intubated six times and her life is still restricted by her condition, as she is unable to work and still needs to use a wheelchair.

[redacted] recently had a gastric band fitted and has since lost five stone, which she says has helped her asthma. She currently takes 10mg of steroids a day, still uses nebulisers and says her major asthma attacks are becoming less frequent. She is hoping to ask her consultant about going back on Omalizumab as she thinks it may work better now considering her weight loss. She says: ‘My outlook is quite depressing. I just want to be well, go back to work and do what normal people do but I don’t see that happening at the moment.’

[redacted]

[redacted], now 37 years of age, has had asthma since early childhood. Her asthma has always been of an allergic nature but it worsened as she hit puberty and since then it has been very severe and difficult to control. [redacted] started training to be a nurse after leaving school, but after eight months of training she had to leave nursing college as she was so susceptible to viral infections and colds that her asthma became even more difficult to manage.

Asthma dictates every aspect of [redacted] life, she is pretty much housebound and she only makes ‘provisional plans’. With her asthma as severe as it is, [redacted] is usually admitted to hospital every four to eight weeks to the Intensive Care Unit.

Despite this [redacted] has a positive state of mind. She has a small but good support network of friends and carer. She uses the internet to stay in touch with other people who have severe asthma and finds the Asthma UK blog pages really useful. [redacted] has recently completed and been awarded a BA (Hons) in Literature and Creative Writing, with First Class Honours from the Open University. She is currently studying for an MA in Creative Writing at Newcastle University. [redacted] is also writing a book on living with severe asthma, filled with lots of personal anecdotes.

[redacted] medication regime is extensive and complex. She currently takes Prednisolone 60 - 120mg mane, Salbutamol nebuliser 2.5-5mg qds + PRN, Ipratropium Bromide nebuliser 500μg qds, Saline nebuliser 5-10mg qds, Seretide 500 Accuhaler 2 puffs bd, Theophylline S.R. (Uniphyllin) 400 mg bd, Bambuterol 10mg nocté, Fexofenadine 180 mg mane, Fluticasone nasal spray 100μg each nostril bd, Pyridoxine 50 mg mane, Fluoxetine 20 mg mane, Ivabradine 7.5 mg bd, Domperidone 10 mg qds, Omeprazole 20mg bd, Ondansetron 4mg qds, Furosemide 40mg bd, Orlistat 120 mg tds (only with meals), Risedronate 35 mg once a week (Monday), Codeine Phosphate 30-60 mg PRN, Cetirizine 20mg PRN, Chlorphenamine 4-8mg PRN and Adrenaline EpiPen 0.3mg PRN. [redacted] also uses a Bipap, a portable ventilator to help her breathe more easily.

The unwanted and difficult side effects from the steadily increasing dose of Prednisolone include weight gain, disturbed sleep, mood swings and cataracts (which [redacted] has had removed under a local anaesthetic). Her consultant has considered trialing Kenalog injections, so they could attempt to reduce the dose of prednisolone. [redacted] is becoming resistant to absorbing the prednisolone and has developed some problems with her liver as a result of the long-term, high-dose prednisolone use. She has recently been diagnosed with Non-Alcoholic Steatohepatitis and is waiting for a referral to a Hepatologist. This recent diagnosis has been very difficult for [redacted]. She has also had surgery for Carpal Tunnel Syndrome which has probably been caused by Prednisolone.

[redacted] has extensive allergies to: Sulphates, sulphites, nitrates, nitrites, benzoates, benzoic acid, sodium benzoate, sulphur dioxide, preservative E numbers between E210 - 227 and E249-252 and food colourings except for Turmeric (the only ground spice allowed), Annatto (E160) and Caramel (E150). She also has to avoid mint/menthol and banana derivatives in medications.

[redacted] is known to be allergic to: magnesium sulphate (the sulphate component being the aspect she is allergic to, meaning that she cannot be given magnesium when having an asthma attack); Nystatin, Morphine, Lophepramine, Duraphat dental suspension (contains flavouring derived from bananas), Erythromycin, Azithromycin capsules (the capsules contain SO2, but she can take the tablets). Other non-anaphylactic allergies include: ECG electrode ‘dots’, Transpore/Claripore tape, dogs, horses, house dust mites and many pollens.

Due to the severity of [redacted] asthma she was offered a securely funded trial of Omalizumab. Her first and only dose was given on the 14 February 2001, after which [redacted] had such a severe reaction to the Omalizumab that she ended up in Intensive Care and on life support within 24 hours of having the injection.

Despite the fact that Omalizumab is not suitable for [redacted], she firmly believes that anything with the potential to be life changing for people with severe asthma, must be made available to all, especially as there are so few treatments out there.

‘People with asthma should be given every opportunity they can have, to lead a life with better controlled asthma’.

[redacted] (and mum [redacted])

[redacted] was diagnosed when he was about 11 months old. He received inhaled steroids and was under a paediatrician. He had several hospital admissions as a baby. [redacted] was later told that [redacted] has ‘chest infection variant’ asthma by another paediatrician.

[redacted] had many allergies as a young child (food, dust mite, grass and peanuts) but at the age of seven these became more severe and there was a noticeably faster onset of attacks, and in particular he was now also sensitised to tree pollen. After a very severe attack (just walking out the door of his home), the doctor referred [redacted] to another paediatrician. He was prescribed Omalizumab and has been on it for 18 months. He is under review every 16 weeks; now the paediatrician has arranged for [redacted] to have injections at the local hospital, which is 15 minutes away so less disruption for school and family. [redacted] has been told that [redacted] will continue to receive Omalizumab in the medium term but fears the hospital may close down. Since commencing on Omalizumab, [redacted] has not had any hospital admissions for 12 months. He did not have frequent hospital admissions prior to Omalizumab as maintained on so much medication and using a nebuliser at home.

Prior to Omalizumab, [redacted] was on a high dose of steroids daily (Prednisolone tablets, Triamcinolone and Seretide) causing Cushing’s Syndrome and adrenal failure. He was also on Montelukast. Since commencing Omalizumab he is now on Symbicort Smart, prophylactic antibiotics, and a decreasing does of hydrocortisone tablets for the adrenal failure. Owing to his allergy to tree pollen, it was very difficult for Scott to go out or for him to control his symptoms.

The advantages of being on Omalizumab have been huge. [redacted] has reduced absences from school from 20% to 12%, he is now two years ahead in schooling for his class, he can play sports again and he does not just get education but also interaction with friends which [redacted] feels is equally important. His school has been very understanding and flexible. Being on Omalizumab has taken away the extreme anxiety shared by the family and attacks do not come on as quickly or suddenly in response to triggers. [redacted], who does not like receiving injections, feels that the benefits from being on Omalizumab are so huge that he is willing to put up with the discomfort of the four weekly injections. [redacted] now has the quality of life that he had lost and can take part in the sports he loves.

[redacted] says that she has learnt about Omalizumab through the Novartis Omalizumab pack/treatment folder written for children: [redacted] finds this very helpful and has even taken it to school. [redacted] said that he did not have any quality of life while stuck on steroids and he has gone back to looking like he did when he was five. The only side effect of Omalizumab has been severe irritation and swelling of injection sites, so he now has to rotate injecting into his leg.

[redacted]

[redacted] was first diagnosed with asthma at three years of age. She has many allergies including walnuts, grass, horses, cats, dogs and dust. She was very poorly with her asthma during childhood and had multiple admissions to hospital. During her teenage years, her asthma appeared to stabilise until she was 22 years of age. She began to require constant visits to A&E and required a nebuliser at home that she used frequently. During her university years she worked in a pub but had to leave this because of the smoky environment. From the ages of 22-27, she had approximately ten visits to A&E per year and was admitted to hospital approximately five times per year. Her consultant prescribed Ventolin, Seretide 250 mcg four puffs twice per day, and Prednisolone up to 40 mgs daily. [redacted] attempted to reduce the dose of Prednisolone but found this very difficult to sustain. After attending university and studying sociology, [redacted] wanted to become a social worker but was unable to do this owing to the severity of her asthma. Instead she worked for a charity helpline. Unfortunately, owing to so much absence, [redacted] took the decision to leave her employment. She was then unemployed for four months until after she was prescribed Omalizumab in February 2008.

During those five years, [redacted] quality of life suffered owing to being unable to socialise with all her friends. Sometimes she felt isolated and lost some friendships as she had to frequently cancel engagements owing to her asthma attacks. Due to allergies she had to avoid some social situations, such as house parties and visiting friends and family with pets. Since starting Omalizumab, cats are still an issue, however [redacted] has been able to visit her sister and see her new dog without having an attack, which is a real improvement. She used to spend hours trawling the internet looking for alternative asthma drugs to steroids.

Her consultant prescribed Omalizumab when she was in hospital in December 2007. Her PCT had previously refused to fund Omalizumab twice for [redacted] and her hopes had been dashed. She now feels that Omalizumab has completely changed her life. She has the freedom to do things she enjoys. It has allowed her to regain her health, social life, happiness and employment. [redacted] thinks that funders and clinicians should consider the vast increase in quality of life that Omalizumab can offer people with asthma. She believes it affects one’s physical, mental and social health, and therefore all aspects of health ought to be considered when assessing the benefits of Omalizumab. [redacted] felt that her asthma left her stuck in the house for days on end and made her feel low and despondent. Since receiving Omalizumab, [redacted] has gained freedom and real hope when no other clinical alternatives could be found.

She now works in customer services. Her current employers are extremely considerate and understanding of [redacted] need for time off to get her injection, which is administered every four weeks. She experiences lethargy after receiving the Omalizumab injection. Her employers have agreed for her to work extra hours during the week in order to take the afternoon off work when she receives the injection.

Since receiving Omalizumab she has had less absences from work – she has not been absent between May 2011 and November 2011, and she has gained some level of normality in her life. Over the last three years, she has had four hospital admissions and six or seven A&E visits. She is still on the same dose of Seretide but is completely off the daily dose of Prednisolone, and only requires approximately three courses per year. [redacted] experienced weight gain whilst on her previous steroid dose but now she has been able to experience a better level of control over her weight and has lost two stone since receiving Omalizumab.

[redacted]

[redacted] is 44 and has had asthma since she was 22. The severity of her condition has worsened as she has gotten older though her asthma has always been difficult or brittle. Her asthma has a major allergic component. It is also affected by colds and viruses. Over the years, [redacted] has had numerous life threatening hospital admissions.

[redacted] has had two separate experiences of Omalizumab. She was part of the initial clinical trial for Omalizumab in the late 90s. During the trial she developed pneumonia and had to be taken off of the drug after eight months. Her experience of Omalizumab at this time was not a positive one, however it has since been suggested that she may in fact have been on the placebo during this trial.

After the failed trial,[redacted] was on a variety of medication including Singulair, Phyllocontin, Aminophylline, Prednisolone, Pulmicort and Ventolin. At this stage [redacted] describes herself as ‘not really having a life’ and being mainly confined to her downstairs living room unable even to walk up the stairs unaided.

[redacted] asthma continued to be difficult and after a particularly poorly period at the end of 2005 her consultant suggested she try Omalizumab. Her expectations at this stage were quite low after her experience on the trial but she agreed to give it a try. [redacted] describes that first time she attended the hospital to have Omalizumab administered: she was unable to walk the 24 paces down the corridor to receive the injection. [redacted] receives the injection every two weeks and while travelling for this can at times be ‘a pain’, the benefits outweigh the problems this can sometimes cause and her situation has improved dramatically.

[redacted]feels that being on Omalizumab has been life changing – she says: ‘I do have a life now’. The number of emergency admissions she has required has fallen by about 50% and she is now able to worry less about being exposed to allergens such as pet dander. While these will still trigger her asthma, it is to a much lesser extent, and as a result she can manage her asthma when this happens. Her asthma still worsens when she has a cold or virus but she is very aware that Omalizumab is not designed to have an effect in this situation. [redacted] still has to take a variety of medications for her asthma including Singulair, Phyllocontin, Symbicort and Ventolin.

[redacted] is concerned for the future: she worries that if NICE changes its guidance she and other people may no longer benefit from Omalizumab and she does not want to give up the life she now has as a result of the treatment. She is also concerned for her 18-year-old daughter, whose asthma has grown worse since puberty. [redacted] worries that if it continues to get worse, as [redacted] did at this age, she may require Omalizumab and if NICE changes its guidelines she will not be able to receive it, meaning another life severely affected by asthma.

An interesting thing to note about [redacted] experience with Omalizumab is that she did have a strange side effect. The first time it was administered in late 2005 she became very giggly and felt drunk; there was also a smell of alcohol coming from her. She had a similar though more mild effect on subsequent administrations but this stopped after the first few.

Fighting for breath

The hidden lives of people with severe asthma

asthma UK

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**

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 symptoms[1].

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.

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 people[2]. 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 people[3] – 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 asthma[5]. 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 centre[6]. Those who joined our discussions shared personal information about living with severe asthma. Their words, views, opinions and experiences appear anonymously in this report.

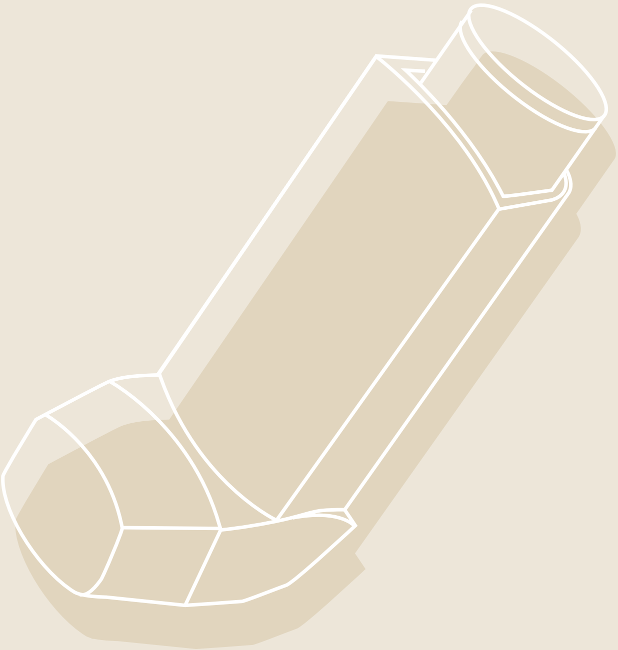
We also interviewed individuals from across the UK whose lives are affected by severe asthma who agreed to share their stories with us and be photographed for this report.

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

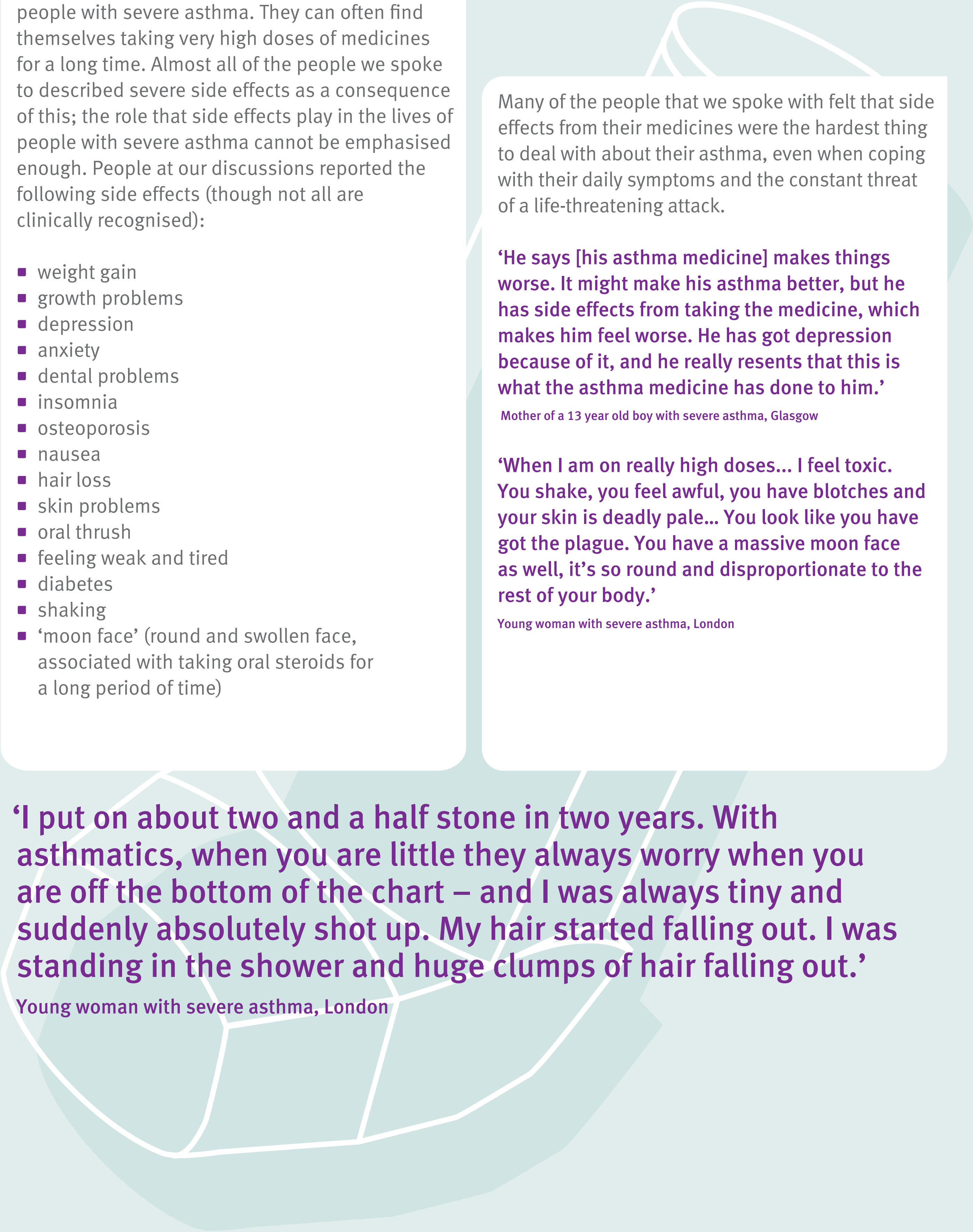
Treatment regimes

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 asthma[7] and confidential inquiries have found that psychosocial factors are a common risk factor for asthma deaths[8].

'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 severity[9]. 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 reversed[10]. 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 elsewhere[11]. 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 attack[12]. 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 staff[13]. 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

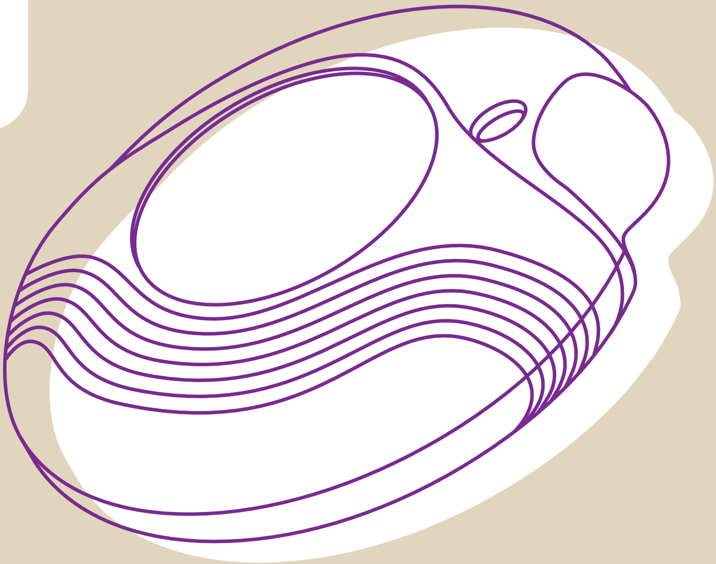
A fully effective severe asthma service needs access to multidisciplinary support, including consultants, asthma nurses, physiotherapy, dietary support, psychological support, pharmacy services, lung function testing, speech therapy, smoking cessation and allergy specialists, as well as social services. 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&E[18]. 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.’

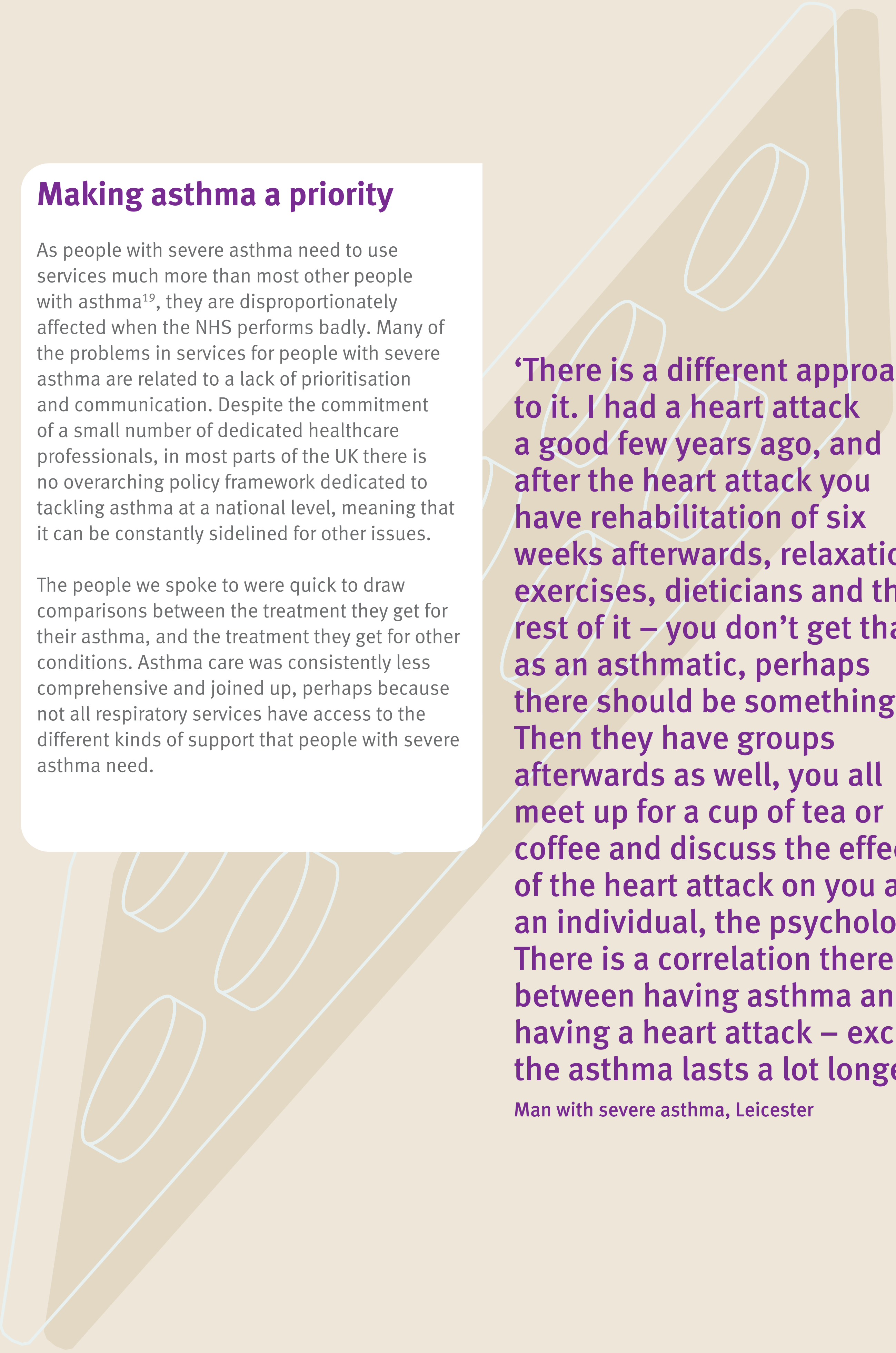
Jason Gray, Advanced Paediatric Emergency Nurse Practitioner, Royal Alexandra Children’s Hospital

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.

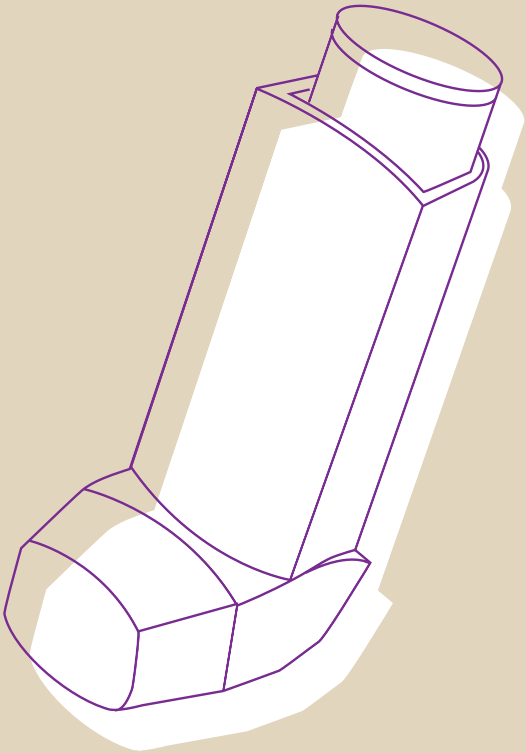


Making asthma a priority

As people with severe asthma need to use services much more than most other people with asthma[19], 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 Health[20]. 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.

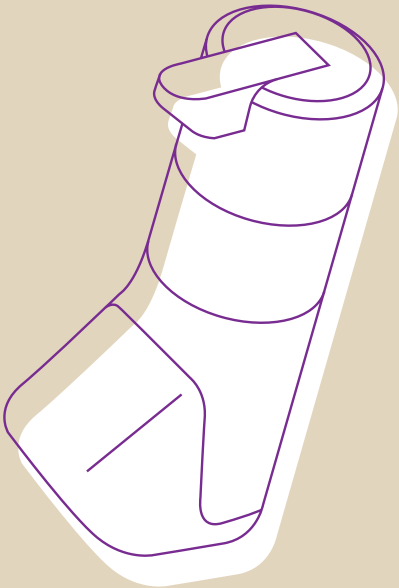
In 2007, NHS Quality Improvement Scotland (NHS QIS) developed seven clinical standards for asthma services for children and young people. Health boards are now expected to implement these standards and multi-disciplinary groups within each health board have been set up for this purpose. The Scottish 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 year[21].

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.

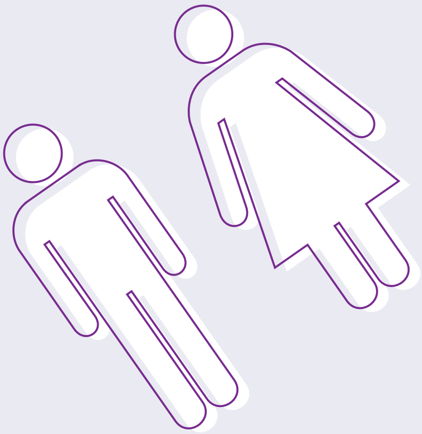
Equality for people with severe asthma

> ‘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.

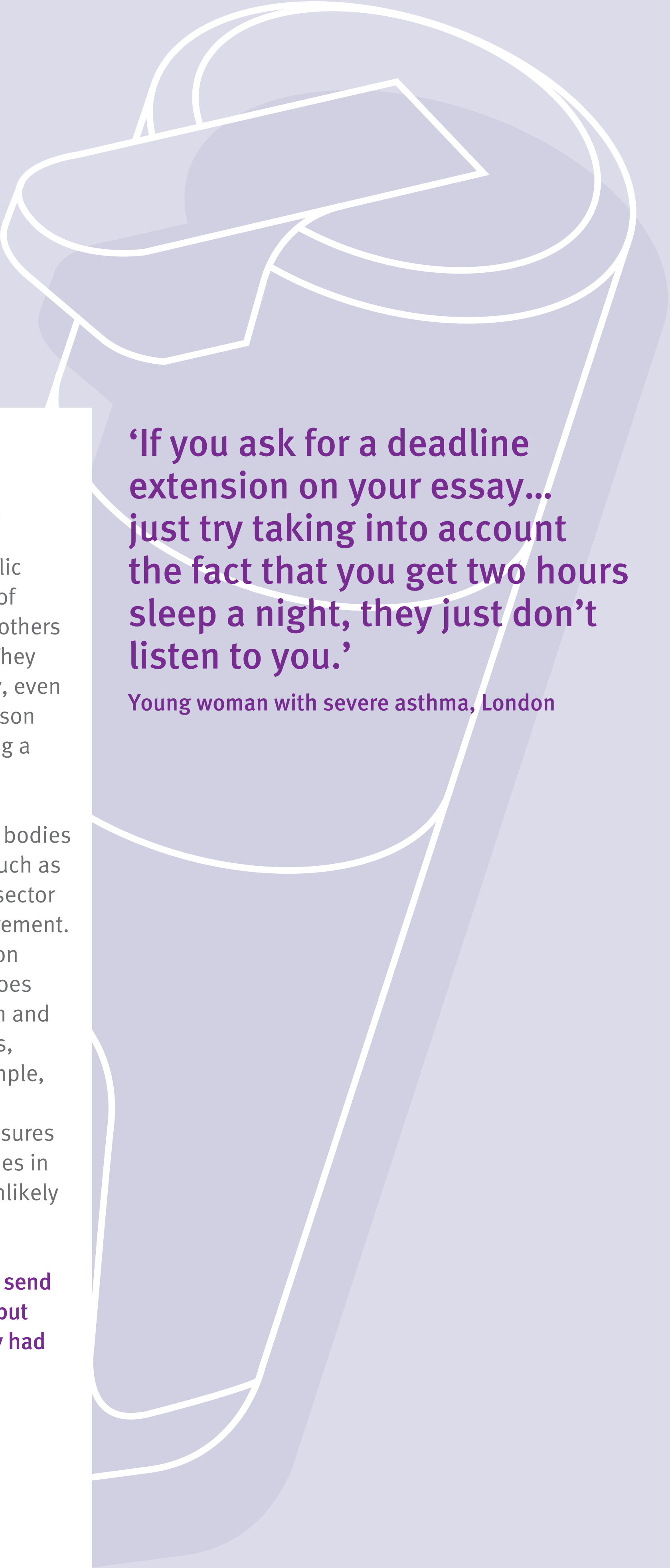
Equality duties

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

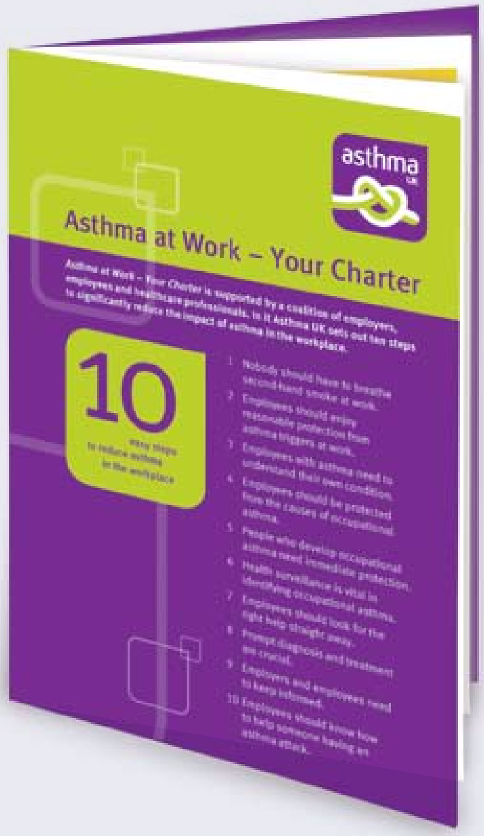
> **‘When they first start secondary school they went on a bonding week and [my son] wasn’t allowed to go. He was excluded straight away.’**
>
> Mother of a 13 year old boy with severe asthma, London

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.



asthma UK

Asthma at Work – Your Charter

Asthma at Work – Your Charter is supported by a coalition of employers, employees and healthcare professionals. In it Asthma UK sets out ten steps to significantly reduce the impact of asthma in the workplace.

10 easy steps to reduce asthma in the workplace

1 Nobody should have to breathe second-hand smoke at work.
2 Employees should enjoy reasonable protection from asthma triggers at work.
3 Employees with asthma need to understand their own condition.
4 Employees should be protected from the causes of occupational asthma.
5 People who develop occupational asthma need immediate protection.
6 Health surveillance is vital in identifying occupational asthma.
7 Employees should look for the right help straight away.
8 Prompt diagnosis and treatment are crucial.
9 Employers and employees need to keep informed.
10 Employees should know how to help someone having an asthma attack.

‘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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5. The people who joined our discussions were patients at one of the following hospitals:

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- Gartnavel General Hospital, Glasgow
- Glenfield Hospital, Leicester
- Leicester Royal Infirmary
- Royal Brompton Hospital, London
- Royal Hospital for Sick Children (Yorkhill), Glasgow

Because 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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