



# FALLING INTO ISOLATION

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LIVED EXPERIENCE OF PEOPLE  
WITH SEVERE ASTHMA



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## FOREWORD

Living with severe asthma is so much more than asthma attacks and occasional hospital admissions. It can have devastating consequences on every aspect of people's lives. They may feel isolated, lonely and scared, left without hope or the right support. Many people with severe asthma are forced (because there are no other options) to take long-term, high-dose oral steroids but these often cause toxic or debilitating side effects including mood-swings, anxiety, increased appetite, diabetes, cataracts and osteoporosis. Biologic treatments have started to transform the lives of many people with severe asthma, but more needs to be done to ensure all severe asthma centres provide the right support for each individual.

It is time that the needs of people with severe asthma are at the heart of designing specialised services and that commissioners and local service leaders take account of what people with severe asthma really need. Services need to understand the real lived experience of people with severe asthma and provide the right support to stop them falling into isolation or living a life of fear and anxiety.

We thank all the people with severe asthma who shared their experiences with us. We hope their stories are heard and inspire real change.

**Dr Samantha Walker**

Director of Research and Innovation, Asthma UK



*“Services need to understand the real lived experience of people with severe asthma and provide the right support to stop them falling into isolation or living a life of fear and anxiety.”*

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## EXECUTIVE SUMMARY

An estimated 200,000 people in the UK have asthma which is so severe that it does not respond to usual treatments putting them in a never-ending cycle of emergency trips to hospital. There are now four biologic treatments available for severe asthma which are having transformative effects. However, the way that the current NHS asthma care pathway is set up does not take into account the availability of these new treatments and there is considerable variation in severe asthma care across the UK. Our previous research has shown that as few as 18% of those who should be referred for a specialist opinion according to clinical guidelines are referred and there is variation in when clinicians will refer.<sup>iii</sup> We have also shown that as many as 48,000 people with severe asthma are missing out on potentially life-changing biologic treatment.<sup>iii</sup>

To gain a better understanding of how people with severe asthma live their lives and their experiences of the care they receive, we conducted semi-structured interviews with six people with severe asthma. We used thematic analysis to identify key themes related to the impact of severe asthma, experience of referral, care at the severe asthma centre, biologic treatment and most important outcomes. We also conducted a brief survey of 51 people with severe asthma, to understand what health outcomes are the most important to them.

From the interviews we found that the impact of severe asthma is so much more than dealing with individual asthma attacks and hospital admissions. It can have devastating consequences on general wellbeing with patients feeling isolated, lonely and scared. People with severe asthma stress this impact on quality of life as the most important to them. Experiences were often varied and individual, but there were indications of what is seen as 'good' care and what people with severe asthma would like to see from their severe asthma centre.

For people with severe asthma to get the care they so desperately need, severe asthma centres need to have the right infrastructure to allow data sharing across the network (to manage multiple emergency re-admissions to different healthcare settings) and provide a range of services, including psychological and nutritional support (to manage those with co-morbidities or with poor adherence). Commissioners, policymakers and severe asthma clinicians need to consider what it really means to live with severe asthma and take this into account when designing services.

This qualitative research highlights the terrible impact of delayed access, the frustrating process of referral and how people still feel like their asthma is not taken seriously enough. It has also raised many important issues about care at severe asthma centres, which need to be explored through further research with the wider severe asthma population.

We know from our previous reports, now reinforced by the voices of people with severe asthma, that for there to be real change the following must happen:

- The development of clinical guidelines for difficult/severe asthma, including when to refer to a specialist.
- A review of capacity in secondary and tertiary care based on the unmet need highlighted in our previous 'Living in Limbo' report and the commissioning of new asthma services as required.
- Appropriate access to biologic treatment to address the huge unmet need.
- Better data sharing between severe asthma centres and hospitals to ensure patients get the best level of care possible.

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## INTRODUCTION

NHS England are planning to optimise severe asthma services in England, with equivalent initiatives in devolved nations, to reduce unwarranted variation in the care of severe asthma patients. In order to make sure severe asthma services meet the needs of people with severe asthma, we need to ensure that they are central to this work. To inform this, we have carried out semi-structured interviews with six adults with severe asthma to give us a better understanding of their experiences.

Our previous report, 'Living in Limbo', showed that only 18% of those who should be referred according to clinical guidelines are, and only one fifth of those potentially eligible for biologic treatment are receiving it.<sup>iv</sup> The burden of severe asthma and its impact on people's everyday lives is well documented in the existing literature,<sup>vi</sup> however there is limited research into how people with severe asthma feel about services and their experience of care at NHS severe asthma centres. We show in this qualitative analysis, the real lived experience of people with severe asthma, the serious impact of delaying access to care can have on people's lives and explore ways in which severe asthma services can be improved.

## METHODOLOGY

We conducted six semi-structured interviews and a brief survey with people with severe asthma from England. For the interviews, we defined severe asthma as those who are receiving treatment at a specialist asthma centre. Participants (five women and one man) were aged between 21-65 and from different parts of the UK. All the participants were being treated with a biologic at the time of the interview.

Our objective was to gather insights and experiences of having and managing severe asthma to inform and influence the development of the NHS severe asthma care pathway, and to improve Asthma UK's understanding of living with severe asthma.

This is building on our previous reports which have found that only 18% of adults with possible difficult and severe asthma are getting referred for specialist treatment in line with clinical guidelines and there is variation in when clinicians will refer.<sup>vii</sup> We have also estimated 48,000 people are currently missing out on life-changing biologic treatments. People with the most devastating form of the condition are not receiving the care they need and there needs to be a better understanding of the true impact of the condition and how the right care can transform people's lives.

The interview was based around three research questions:

1. What are the experiences of people with severe asthma of the process of getting a referral or getting prescribed a biologic?
2. What are the good and poor experiences of people with severe asthma of treatment in severe asthma centres?
3. What outcomes/ improvements and deterioration of symptoms or quality of life have people experienced since receiving specialist treatment, and what was most important for them?

We used thematic analysis to identify key themes related to the impact of severe asthma, experience of referral, care at the severe asthma centre, biologic treatment and most important outcomes.

We also conducted an online survey of people with difficult and severe asthma, promoted through our volunteers and Facebook, to find out what outcomes were most important to people with severe asthma. We received 255 responses for the survey, with 51 of those being people receiving biologic treatment for their severe asthma.

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# RESULTS

## I. THE IMPACT OF SEVERE ASTHMA

The qualitative analysis revealed there was variability and breadth in the way in which asthma has impacted on each of the participants, often depending on the individual's personal situation. However, isolation and loneliness, frequent hospital admissions and oral steroid use, fear/anxiety and not being able to work, were key themes across the interviews. The impact of severe asthma is not just about the frequent hospital admissions and time off work but the implications of this on quality of life. Not being able to see friends or work can be isolating and lonely and the terrifying experiences of many with severe asthma don't just go away, but may manifest in anxiety, fear and depression. This can impact asthma management and a person's wellbeing. For example:

*"It's really restricted me. I have suffered because there was a point where I refused to leave the house... So, it really affected my work, my lifestyle. Meet your friends, just even speaking to them, I would get really out of breath. I was trying to avoid all of that."*

**Participant 1**

Many of the participants have been in and out of hospital with their asthma and this has been very disruptive to their lives, often adding to the problems of isolation and not being able to work.

*"But, obviously, I spent all the time in hospital. The first few times you get admitted, everybody comes to see you. But then, it gets a little bit boring and out of the way. So, friendships drift off and fall into a bit of isolation, really."*

**Participant 2**

*"You know, don't get me wrong, I do have friends, I do socialise and that, but they all work or they go out in the evenings. With all the other issues I have with fatigue and my medication and all that sort of [thing], evenings are not a good time for me... And they'll say, oh come on, let's go out tonight. And I just go, you know what, I can't. I'm too tired, it's too cold."*

**Participant 6**

Two of the participants talked about 'not living any more' and the effect this had on their mental health was felt through the descriptions and the tone they used.

*"I just wish I had been put on this biologic a lot sooner. Because the period I was suffering, you can't explain it in words. It was really, really hard for me. It was just so depressing that sometimes you think your life is just not worth living anymore."*

**Participant 1**

*"Because, obviously, I wasn't living anymore. I was just existing. I had absolutely no control of my asthma."*

**Participant 2**

One of the participants is now responding well to biologic treatment and no longer having asthma attacks. However, their terrifying experience in the past is still with them. This is evident in the quote below:

*"They were just saying to my husband well, we've tried everything and she's not responding. And all I could remember was the clock on the wall and I was just staring at the clock, thinking that when am I going to stop breathing because it's getting too painful, I just can't carry on anymore. And that experience, I think, is still stuck with me every time I can't breathe. It just brings all that back to me. And I think that's part of my panic and I just start breathing, getting anxiety."*

**Participant 1**

The fear of the biologic no longer working was also explored in other interviews. For example:

*“But I’ve never had it refused [biologic treatment]. And I don’t know what would happen if I have it refused. Because they say to me that I can only go a week either side of my time that I’m supposed to have it. I’m scared to ask what would happen if I don’t do that.”*

**Participant 4**

For everyone, severe asthma had some impact on work or school, with many of them having to take prolonged periods off work or give up work altogether. There were many examples of this:

*“Yes, and the worst thing was trying to get used to it, from being such an active person and working fulltime, it was just trying to get used to it because I just couldn’t work. For quite a long time, I just couldn’t work”*

**Participant 1**

*“I’ve been off work, most of the time this year because of my asthma. I’ve literally had no life, really. And then when I was in Year 11, my school attendance was 43%.”*

**Participant 5**

*“And then I knew it was serious when I retired from my job at the age of 30, because I was spending more time as a patient than I was as a nurse.”*

**Participant 6**

The impact of severe asthma is therefore not just about the frequent hospital admissions and time off work but the implications of this on quality of life. Not being able to see friends or work can be isolating and lonely and the terrifying experiences of many with severe asthma don’t just go away, but may manifest in anxiety, fear and depression.

The devastating effects of oral steroids are well known and the impact they can have is felt strongly in the interviews. Some were suffering from the long-term consequences such as diabetes and osteoporosis and others were on dangerously high doses.

## **2. EXPERIENCES OF REFERRAL**

The interviews revealed both negative and positive experiences of referral. Negative experiences centred around long waiting times and GPs reluctant to refer them, usually, they thought, because asthma is not taken seriously enough or because they lacked knowledge about severe asthma and the biologic treatments available. Positive experiences of care were streamlined, quick and well informed. Most of the participants spoke about the need for more awareness of severe asthma within primary care and greater knowledge and information.

Two participants discuss how their GP didn’t take asthma seriously enough to know why referring was important. For example:

*“No, I do remember quite clearly because it was a battle. So, my GP was quite an old GP, and basically said this is life, this is how it is. You’re just one of those unfortunate people who’ve got this. Pull your socks up and off we go. My local hospital consultant wasn’t much help either.”*

**Participant 2**

*“My own GP here, who has been no different. She has been marginally better, to be honest, than a lot of ones I’ve had over the years, will always say we can get on top of this, which was doing me no good at all. Because in the time before I was referred to [the specialist asthma centre], I had something like four years continuously on antibiotics and oral steroids.”*

**Participant 1**



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Similarly, another participant was put on a long waiting list and they felt their condition was not taken seriously enough. For example:

*“All I got was well, we’ve got a big waiting list, you’re just going to have to wait. And it doesn’t matter what I’d got, how severe it is, in and out of hospital, how many steroids I’ve been on. Every month I was on steroids and antibiotics, but it didn’t really matter, I was just put on a waiting list.”*

**Participant 1**

One participant had a much more positive experience, it was a streamlined process from the GP referring when the condition deteriorated to being seen at the severe asthma centre. Since this was around ten years ago, it is likely that this was down to luck rather than because of recent improvements with the service. For example:

*“It didn’t actually take that long, to be quite honest. They were quite quick. I can’t fault my doctors at all. I feel like I’m a guinea pig sometimes, because I only mention something and suddenly I’ve got a letter or something.”*

**Participant 4**

Most of the participants spoke about the need for more awareness of severe asthma within primary care and greater knowledge and information for both GPs and people with asthma to ensure referrals happen when they’re needed.

### **3. EXPERIENCES OF CARE AT THE SEVERE ASTHMA CENTRE**

Responses from the interviews about the care received at the severe asthma centre revealed five key themes: communication, attitude of staff, convenience, multidisciplinary team (MDT) support and continuity of care.

#### **a. Communication**

There was variability in the experiences of care received at the severe asthma centres but communication, whether good or bad, was a theme in each of the interviews. People said that they wanted to feel informed about their treatment, included in the decisions and have regular contact with their consultant. Different ways of communicating with the consultant or specialist asthma nurses outside of their usual appointments was central to good communication.

Two of the interviews flagged how communication was a problem and this appears to be down to a lack of time. For example, one interview explains:

*“I think he tried to do so many things at once, even [while] he’s seeing you, his mind is with every other patient in the other rooms as well. . . you need that bespoke service. . . even ten minutes, you need his attention and his care, but I don’t think I was getting that.”*

**Participant 1**

Both participants explained how they didn’t see their consultant as regularly as they liked or when their asthma was uncontrolled, and they needed support. For example:

*“Especially when I don’t see him regularly and he doesn’t even give you that time, he’s rushing you, yes”*

**Participant 1**

*“Well, the problem is you go to see your consultant. And say, you’re having a good time. Then, they’re like, oh, we’ll see you in six months. But this condition deteriorates so quickly, I think it should be regular. But, with the amount [of] patients that are on the books it’s not possible”*

**Participant 5**

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Asthma is a very variable condition and so six-monthly appointments may not be appropriate for those who have not been able to fully control their symptoms. Better digital solutions and real-time remote monitoring would allow people with asthma to be seen when their condition deteriorates and when they need the extra support.

Whilst some people feel informed and included in the decisions about their care, others feel quite the opposite. For example:

*“Every time there is something on the market that they do feel that I would benefit, because they have a multidisciplinary team meeting. And I get a letter saying that I have been discussed in the meeting. If there’s anything I’d like to ask or ring up. So, I do feel quite included in my treatment at the severe asthma centre.”*

**Participant 2**

In contrast, on two separate occasions one participant was caught by surprise about decisions that had been made about their care.

*“And then in the end, I don’t know what happened, because I just got this strange message. But I think they decided that my life is more important than [that]”*

**Participant 5**

*“And then I got a strange text message, saying your appointment’s been booked on so-and-so for a [a biologic] or something”*

**Participant 5**

What seems to work very well for the people we interviewed was being able to contact their consultant or specialist asthma nurses outside of their appointments using email, text or phone calls. This is particularly important because asthma is a variable condition which can be unpredictable.

Those who are more positive about the communication from the specialist centre also have these options. For example:

*“We’ve got the agreement that whenever I start to get a chest infection or anything, the first thing I do is ring... our research nurses. They said don’t go to the GP, come out here and we’ll assess you first. I find the communication between them is speedy. If for some reason I can’t get to the phone, I email, they will always come back very quickly.”*

**Participant 3**

*“My symptoms came back within three weeks, quite severe. But they were very supportive. And if I needed to speak to them, I had a telephone to speak to an asthma nurse. And I also had an email for my consultant if I had any questions. But I managed to scrape through”*

**Participant 2**

*“He’s not on the ward as much, so I don’t see him as much. I mean, I’m lucky with him that we email. If I’ve got a problem, I’ll email him [and ask]”*

**Participant 6**

However, this didn’t seem to be an option for everyone, suggesting variability in the way people can communicate with their clinicians across different centres.

## **b. Attitude of staff**

Most interviewees were positive about the attitude of staff at the severe asthma centre and this was important to them. Key attributes they were looking for were reassurance, knowledge and having dedicated time.

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*“As soon as I described my symptoms and showed my inhaler and techniques and everything, it was very reassuring. Don’t worry. We’re going to do this and we’re going to do that. We’re going to have some tests. We’re going to have an X ray and a CT scan.”*

Participant 2

*“I can’t fault either, really. They’re very attentive and very on the ball.”*

Participant 4

*“He’s also a great enthusiast. He genuinely believes that there can come a time when asthma is a curable disease.”*

Participant 3

*“The experience of working with the consultant and the team up there was a genuine revelation. For the first time I had the feeling I was in the care of people, A, who cared about what they were doing. B, who had the scientific knowledge to try and get to the bottom of things”*

Participant 3

### **c. Convenience**

Currently, there are 15 centres covering the whole of England and so where you live may mean you have to travel great distances to your nearest severe asthma centre. This has been reinforced in our interviews, with some participants having to take a whole day out for an appointment. However, other ways of making the experience more convenient were discussed. This included having everything in one place, being flexible about appointments, not having to wait too long and having everything done in one appointment. For example:

*“It’s about an hour both ways. So they will coordinate my appointments... if I’m there all day I can take a bag of stuff and leave [it at] the hospital. So they’re really good with ensuring, they take into consideration [where] you’re coming from, [if] you’re not local”*

Participant 2

*“And I already pre plan my booking with them for the next week, when I go to the first visit. And then, I’ve got the next visit already planned. I find the staff extremely good and very efficient”*

Participant 4

*“And sometimes it’d be a two and a half hour journey, just for somebody to take blood, which was less than five minutes. To go back for two and a half hours. So, the fact that I can get everything done at once is not only helpful for me, but it’s helpful for my family as well, and my carers. That they’re not losing a full day just for a ten minute blood test. We can do everything all at once.”*

Participant 6

For our participants, being able to access care more locally, especially for simple tests such as bloods, would improve how they feel about the care they receive. The interviews demonstrate for some people it is important to have a one stop clinic where everything is done in one day. There may also be an opportunity for more digital care, such as video consultations.

### **d. Continuity of care**

Continuity of care was a theme across all the interviews. Some of this related directly to the care at the severe asthma centre (such as seeing different clinicians who weren’t sharing or reading notes, requiring patients to repeat their history) and other times it was about the severe asthma centre not being joined up with the local hospital or other departments. A lack of continuity of care and a lack of shared records between hospitals was shown to have a direct impact on how people feel about the care at their severe asthma centre.

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Examples of disrupted continuity of care within the severe asthma centre were found in two of the interviews. This included changing of doctors, lack of shared notes and the patient having to repeat their history with anyone new. For example:

*“Because he’s a different consultant, I was back to square one again. We were going through the questionnaires, and then calling me back and then putting me on treatment, and leaving it for a few months, then calling me back again.”*

Participant 1

*“To be honest with you, I wasn’t always seeing the consultant there, I was seeing other people under the consultant. There would be junior doctors or the other registrars. So, I think, for me, it was just repetitive and going around and around in a circle with them... I would have just preferred if the consultant had always seen me.”*

Participant 1

However, one interview explained how good continuity of care made the experience easier. With better shared records, quality of care can be vastly improved, for example:

*“Yes, they seem to be able to manage it quite well, irrespective of who it is they have to talk to make it work. Everyone seems to know what they’re talking about. All the different people. So, you don’t have to reexplain yourself”*

Participant 4

The disruption of continuity of care due to a lack of shared records between hospitals and departments was found in three of the interviews. Due to the lack of shared records, patients had to have repeated tests and investigations, which they find frustrating, a waste of time and an added burden of having to remember everything they are told at each appointment.

Some of the participants were being treated for multiple conditions under different services and waiting lists, this is difficult for patients

to navigate and prioritise and should not be up to the patient to organise. For example:

*“The difficulties are that I’m under six different hospitals. Four of them are in different hospital trusts, so therefore nobody can access my notes from one appointment to another. So, if I go and have a blood test on a Monday at one hospital, I go on Tuesday to another hospital, which is in a different area, run by a different authority.”*

Participant 2

*“Nobody seems to share. I seem to go between. And if I’ve missed something out, then I’m the one who’s in trouble... I have to prioritise which one I can cancel and which one I can miss to get the other one, so I don’t have to get referred back to get back on the waiting list, to get back again. Because there’s just no negotiation with hospital appointments.”*

Participant 2

*“Because my local hospital and the specialist asthma centre, they don’t have the same system, do they? Which I think is ridiculous... That was another thing. So, when I went from my local hospital to the severe asthma centre, I had to repeat all the tests that I’ve had done, because they didn’t have it on their records... Well that was a lousy waste of time”.*

Participant 5

*“And there’s all these different consultants. My bones, the max-fac is saying, you need to come off the steroids because your jaw’s breaking down. I’m like, great, I can have a jaw but I’ll be dead, you know. Endocrinology are saying, well we want you on hydrocortisone not prednisolone. And in the end I said to my main consultant, will you please just have a conference or something and decide what I’m doing, because I’m stuck in the middle here.”*

Participant 6

There is clear frustration about the lack of joined up care from all three of the interviews and this is directly impacting the care they receive and subsequent management of their asthma. Within centres, seeing the same clinicians as much as possible and having patient records shared between clinicians are important factors in how people feel about the care they receive. MDTs need to look at all the patient's morbidities and coordinate a plan with the other specialities, not just for their asthma. Further research is needed to see if this is an issue for the wider population, however we know that for other conditions such as rheumatoid arthritis, National Institute of Health and Care Excellence (NICE) guidelines state that patients should have access to a named member of the multidisciplinary team (for example, the specialist nurse) who is responsible for coordinating their care .

#### **e. Variation in access to multidisciplinary care**

Given that all the participants had at some point been assessed by an MDT, there was wide variation in the support offered from other disciplines. This is particularly important as some of the impacts of asthma discussed earlier require a more holistic approach for the person to manage their asthma effectively.

Five of the interviews mentioned physiotherapy and three were offered a psychologist. However, one participant who spoke the most about depression and anxiety appeared to have not been offered any kind of psychological support and others had not been offered any extra support.

*“But they just don’t want to look outside the box... But my consultant, no, he’s just, oh, you’re on the biologic and that’s... Full stop. There’s nothing else I can offer you.”*

**Participant 1**

*“But just the support side, to be honest with you, I would have just liked there to have been more support. And help with managing my asthma, especially when I’m at home... I’m on my own, especially, because I think when you’re on your own, you panic.”*

**Participant 1**

*“Asthma’s one thing, isn’t it? But then there’s no support that way [referring to psychologist and dietician]. There are no support groups. It’s a different condition, but diabetes. There are all these support groups. But I just feel with asthma you’re just left”*

**Participant 5**

One participant was offered a range of extra support in the form of weekly courses including: diet/nutrition, physio exercises, finance and entitlements and one with a psychologist.

*“Excellent, because they also have a bit of a holistic approach. So, when you go, there was a dietician there, which I didn’t really expect. A physiotherapist. They offered me a course on ...managing asthma symptoms, but there was a course with different weeks”*

**Participant 2**

*“Yes, I was a bit sceptical, to be honest [about the dietician and psychologist]. I’m a bit of a northerner, so we don’t really do those things. But I went anyway, and I was really glad that I did, because there were things that I never thought of. Especially from the dietician, tips about how to prepare food in stages”*

**Participant 2**

Scepticism about psychologists was also present in some of the interviews, but for those that did utilise the extra support they found it helped with their asthma management.

*“I haven’t been offered a psychologist, but I probably wouldn’t have taken advantage of that”*

**Participant 3**

*“That was quite an eye-opener... I saw physios, psychologists, cardiotherapy technicians, nurses, the whole lot, and the professor, all in one day. I mean, that was interesting. It was helpful.”*

**Participant 6**

Not all extra support will be necessary for every patient, however an initial assessment and offer of nutritional and psychological support should be part of normal care. Some participants explicitly asked for more support, whether that be about missing work and the financial implications, psychological support or just having more options to help them manage their asthma. The severe asthma centre should also explain what the extra support is for and why it will be helpful. This would help overcome some of the scepticism and stigmatisation about the care.

#### **4. EXPERIENCES OF BIOLOGIC TREATMENT**

The interviews covered the impact of biologic treatment, the expectations before starting treatment, the process before receiving treatment and home administration. Although we asked about the process before receiving treatment, such as adherence checks and eligibility criteria, this didn't seem an area that was particularly important to the participants. Most understood it as necessary and were so relieved that there were more options available to them that they were willing to undergo all the tests and investigations. For example:

*“I find they do a lot of tests. But they don't do them just for the sake of them. I assume there's a reason for it.”*

**Participant 4**

*“So it was a massive weight off my shoulders. That I felt, wow, it's not just me. There is something wrong. It's not just me doing things wrong. That we were actually getting somewhere after all those years. And there was a list of treatment options available.”*

**Participant 2**

For three participants stopping and switching biologic treatment was also explored.

##### **a. Impact**

The positive impact biologic treatment has had was reported across all the interviews, even for those where the treatment has not worked so well. Most talked about improvements to quality of life for some that meant they were 'Absolutely life changing' (Participant 1) or have 'totally transformed my quality of life' (Participant 3). Others have had more modest but still important improvements. For example:

*‘I can't run or anything still, but I can do little walks around the supermarket, which is just something I couldn't do. I've got a little part time job, which is only two hours a week. But it's a start. And it's something I've got.’*

**Participant 2**

*“And I'll tell you, the difference I had with it was amazing. I didn't end up not taking certain drugs at that point, but I don't know, I wasn't ill so often. I didn't get so many colds, or feel chesty. I still have the same symptoms in some respects as asthma, but they're nothing like I did have”*

**Participant 4**



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The interviews illustrate the significant impact that biologic treatment can have on the lives of people with severe asthma. They reinforce the idea that judging the success of biologic treatment should be based on wider morbidities and patient aims rather than just asthma symptoms and exacerbations.

### **b. Expectations**

Most of the participants had very low or no expectations of the biologic treatment. For example:

*“I didn’t have any expectations, because I didn’t actually realise that it would work... I had no expectations, so I just thought I hope it works. And I was pleasantly surprised”*

Participant 4

*“My expectations were zero. When [the biologic] became such a good friend, it was just astonishing, really.”*

Participant 3

*“I think I was a bit cautious. I didn’t want to get too excited, in case it all came crashing down, with the [the biologic] not starting to work and my symptoms starting to come back again. I was feeling a little bit twitchy I think. But since they started the other biologics, I felt a much better improvement than I did than when I started the [first biologic].”*

Participant 2

However, one participant had expected the treatment to work more quickly, suggesting their expectations were different.

*“So, I was a bit delusional, because I’d been so poorly. And I don’t really know why I thought this. But I just expected everything to get better. But it did take a long four months.”*

Participant 5

A discussion about patient and clinician expectations of treatment are important for both the patient to feel informed about their treatment and empowered to make choices about their own care,

and for the clinician to be able to judge success against individual needs. For this to happen, the right information needs to be provided.

### **c. Information**

Information is a cross-cutting theme that emerged from the interviews. Having the right information is important during referral, at the severe asthma centre and when initiating biologic treatment. There were varying levels of information given to the participants at each stage and this is closely connected to the communication at the severe asthma centre discussed earlier. Most relevant was the information provided with biologic treatment, which included information about what to expect, side effects and benefits. Many participants did feel well informed, but others had concerns. For example:

*“I was really reluctant to actually go onto the biologic because I just feel I wasn’t given enough information. It does scare you when they tell you it’s a new drug and we don’t know what all the side effects are, we’re not fully aware of them... Because all I was getting was it’s a good drug, it’s new on the market... but it has benefited a lot of people... But then, I’m saying how has it benefited them?”*

Participant 1

### **In contrast:**

*“Rather than being told this is this, this is that, I do get asked what I think, and these are the advantages. Actually, these are the side effects. We think this might work for you because... And then, I do get a say whether I want to give it a try or not”*

Participant 2

Being provided the right information isn't just reassuring for patients but important in keeping them informed and part of the decision-making process. It may not change the decision made, but the confidence provided by being part of that decision can have positive consequences on their overall asthma management and sense of self-efficacy.

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#### **d. Switching biologic treatment**

Three of the participants had experience of switching biologics or the biologic no longer working as it did. For two of them, a lack of shared decision making about when to stop treatment is noticeable. There are obvious concerns from the participant that the biologic is not working, and they think they should try something else. They have interpreted their uncontrolled asthma as the reason why they can't switch, which seems counter-intuitive.

*“No one knows what doesn't [work], but they don't take anything out, just in case. They say because my asthma is unstable, then we'll leave it as it is. [But] if [the biologic] isn't working, then [they should] take it out. But they're saying they can't take it out because it might be doing something with something else.”*

**Participant 4**

However, we also see a very similar story with another participant. They want to switch to another biologic (which they are eligible for) because the current treatment is not reducing oral steroids as they had hoped it would. For example:

*“Yes. I'm, currently on 20mg...And I can't reduce them. I've tried. So, now we're going to try 2½mg every month. But this is my point to everyone. Yes, [the biologic's] working for me. And keeping me out of hospital, touch wood. But, the point of it is to get down on steroids, isn't it?”*

**Participant 5**

They are concerned that the biologic is not reducing oral steroids, which is important to them as they are on such high doses. They also interpret that “because of the year I've had, they're leaving me at the moment” (Participant 5). There is either misinformation about why they will not switch, a lack of shared decision making or a reluctance to switch from the clinician.

A perceived lack of reasoning for the choice of biologic and the problems with switching is also present in one of the interviews. They described the experience:

*“I'll find more on Monday, it's more of a case of, once you've been on one and you can't have a blood test, it's a bit like the tombola. They just put their hand in, pick one out and say, you can have that one, because they can't do any blood tests to go with it.”*

**Participant 6**

Two of the participants have switched between biologics. For one of them there was a two-year gap between the treatments, but this seems to have coincided with moving from child to adult services. For the other participant, the process of switching was a difficult time as it required a three-month gap between treatments. However, it is evident that they were well informed, felt supported and could speak to their severe asthma team whenever they needed to.



*“So, my symptoms came back within three weeks, quite severe. But they were very supportive. And if I needed to speak to them, I had a telephone to speak to an asthma nurse. And I also had an email for my consultant if I had any questions. But I managed to scrape through.”*

**Participant 2**

It is evident from these participants' accounts that information about switching and stopping biologics is important for the patient to feel informed and reassured. It appears there may also be a reluctance to switch biologics and a lack of shared decision making. This indicates that we need better guidelines about switching and stopping biologics for the clinicians, but also for the patients to be able to understand the choices being made and feel empowered to be part of that decision-making process.

### **e. Home administration**

All the participants were optimistic about the option of home administration, however a couple had concerns about how their asthma would be monitored and checked.

*“I'd be very keen on that. Extremely keen on that. But I don't know what they'd do about the respiratory thing. I don't know how they'd check out my respiratory bits”.*

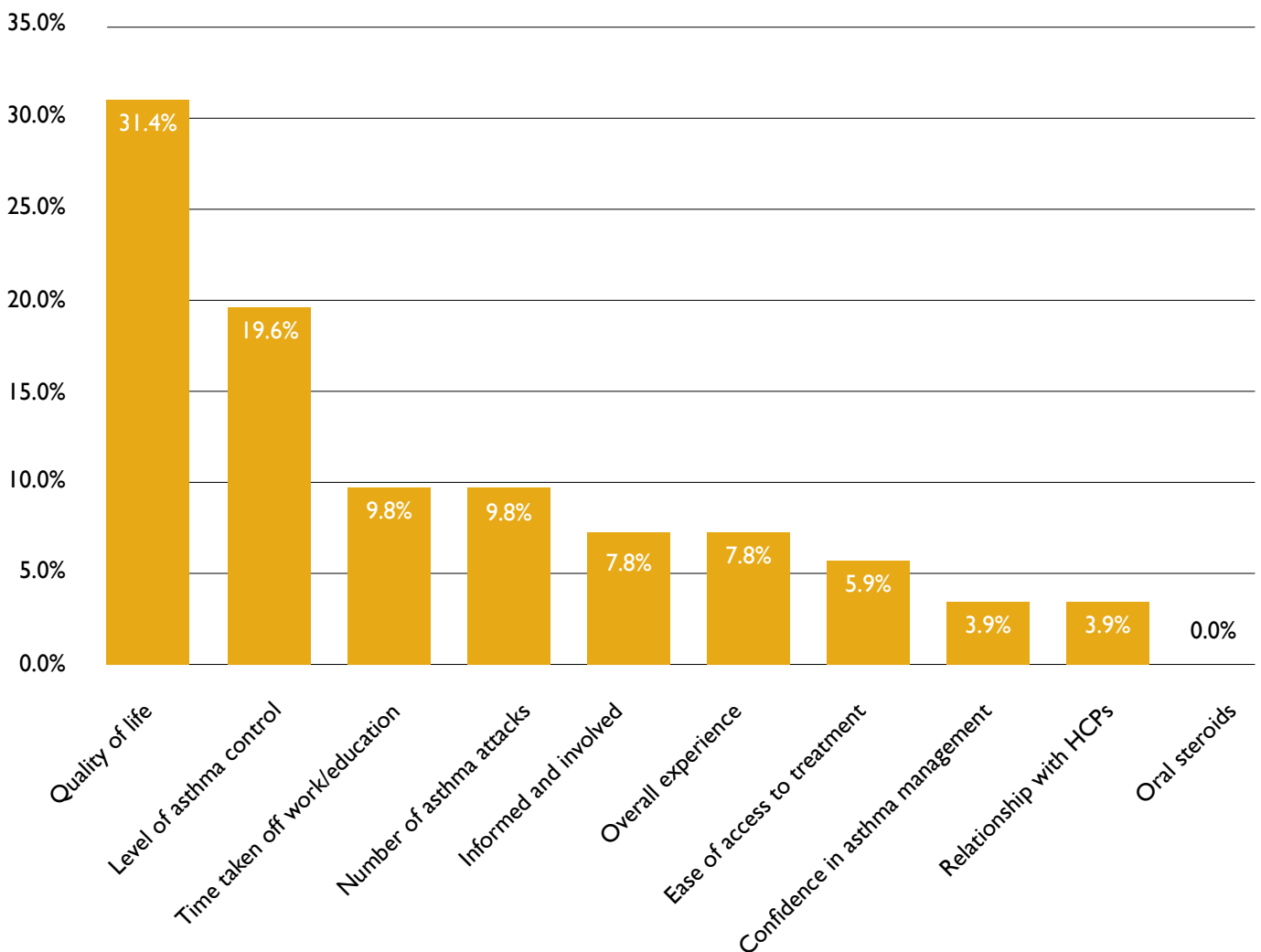
**Participant 4**

This suggests that home administration needs to be supported with regular communication through means other than standard appointments and asthma monitoring at a local hospital or through their GP.

## 5. Important outcomes

For our qualitative research, we asked all participants what their most important change from receiving biologic treatment has been or would be. As with most themes discussed, this depended on a person's situation and experiences before biologic treatment. Participants tended to emphasise the impact on quality of life rather than their symptoms/exacerbations or other clinical measures. To complement the individual interviews, we also conducted a survey with 255 people with difficult and severe asthma, including 51 people on biologic treatment, asking them to rank the most important outcome that they would like to see measured at the severe asthma centre. The survey found quality of life to be the highest ranking outcome for people on biologics, above asthma attacks and oral steroids (Figure 1).

Figure 1: Most important outcome for people with severe asthma (1st preferences only)



The most important outcome to someone is highly individual, however being able to do more, see friends, exercise and work as well as reduce oral steroid use and hospital admissions were all mentioned in the interviews. As discussed earlier these are important because they impact quality of life and not being able to do them negatively impacts wellbeing and the person's ability to self-manage.

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### **A few examples:**

*“The best thing is that I’m not getting that heaviness and pain in my left lung...So, the best thing is the pain has gone and I can do a lot more”*

Participant 1

*“What [the biologic] has also done is give me a sense of confidence...It has just provided that extra dimension of freedom, a psychological freedom, really. That’s an invaluable thing. It’s a really basic thing, not being sick all the time”.*

Participant 3

*“Well, I actually have a life now, because before I was on a mobility scooter. I was unable to do anything. I wasn’t able to leave the house without the scooter. I just had no life. So, yes, it’s come back now”.*

Participant 5

The variability of the condition is something that comes up frequently and for one participant just having a sense of stability is important to them. For example:

*“One is reduction in hospital admissions, because I want my life back. Well that’s three, yes. reduction in hospital admissions, a bit more stability generally, because at the minute I feel like the first wave. I’m up and down and up and down. Even if my good isn’t as good as it is now, if it’s a more stable good...When I’m bad, I can’t get to the bathroom. It’s ridiculous. And I don’t know when it’s going to go from one to the other. So some sort of stability. And of course the other [is] reduction of steroids, horrible stuff”.*

Participant 6

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## DISCUSSION

Since the qualitative research only used the experiences of six adults with severe asthma, we cannot make firm conclusions or recommendations. However, the interviews have highlighted some important discussion points about care within severe asthma services and shown a need for further research. For example:

- Good communication from the specialist centre was vital to our participants. For them, this meant being given the time, the right attitude and an offer of communication outside of usual appointments (such as by email or phone).
  - For our participants, convenience was also important and having 'one stop clinics' appeared to be a good solution to counteract long travel distances.
  - The interviews suggested that there may be issues with access to centres due to travel distances and more effort should be put into making care (such as simple blood tests) available more locally.
  - There was a need for a case manager to coordinate care between different specialities for most of our participants and is recommended by NICE guidelines for other specialties, such as rheumatoid arthritis.
  - We already know the benefits of services such as psychology and nutrition for people with severe asthma. These interviews demonstrated not everyone is being offered the same level of care and that stigma surrounding these services may be a barrier to access.
  - There was variation in the level of information people received about biologic treatment and this may be important for empowering patients to feel part of the decision-making process.
- Similarly, it seems more information about what to expect from biologic treatment, how to know it is working and when to switch between treatments should be provided to patients through a patient decision aid. However, more research is needed to know how useful this would be to the wider population.
  - Our participants were very positive about home administration of biologic treatment, but further research should be done with the wider severe asthma population to confirm this.

## CONCLUSION

We have found the experiences of those with severe asthma to be varied and individual. However, there were clear indications of what is seen as 'good' care and what people with severe asthma would like to see from their severe asthma centre. Through a better understanding of the experiences of those with severe asthma, we can ensure the right support is given to those who need it. From both our qualitative research and survey we have found that quality of life is the most important outcome to people with severe asthma and so should be considered an important factor when deciding treatment effectiveness.

Our previous research has shown not enough people with suspected severe asthma are being referred and access to biologic treatment is poor. This qualitative research has shown the terrible impact delayed access to the right care and treatment can have and the frustrating and often slow process of referral. It is unacceptable that people still feel like their asthma is not taken seriously enough and they must suffer because of it. However, it has also shown how there is hope for those who have not yet been referred or found the right treatment, as demonstrated by the truly life-changing impact biologic treatment can have. ■

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