

# Paying to breathe:

Why unfair asthma  
prescription charges  
must be stopped



## Contents

- 3 Foreword**

---
- 4 Summary**

---
- 4 Background: the outdated and unfair system of prescription charges**

---
- 5 Asthma UK's Prescription Charges Survey: key findings**
  - 5** Affordability of asthma prescriptions
  - 6** Impact on everyday spending
  - 7** Impact on health
  - 8** Regional variations and health inequalities
  - 8** Ineffectiveness of Prescription Prepayment Certificates

---
- 10 Key recommendations**

---
- 11 References**

## Foreword



**Asthma is a lifelong, serious condition. The facts are stark – every 10 seconds someone has a potentially life-threatening asthma attack and three people die each day. Two out of three deaths from asthma are preventable with good basic care – in essence, being**

**supported to take the right medication at the right time<sup>1</sup>. This could be a preventer inhaler taken daily to reduce symptoms, or a reliever inhaler to give fast-acting relief when someone’s asthma is getting out of control or they are having an asthma attack.**

Asthma medication is prescribed by the NHS, but, unlike many other long-term conditions that rely on daily medication, asthma is not included on the prescription charges exemptions list. This list was created over 50 years ago, before effective treatments were widely available for asthma. This outdated policy means people with asthma of working age and in employment have to pay for their NHS prescriptions, while many others with a different long-term condition do not. We feel this is intrinsically unfair – in essence, people with asthma have to pay for the right to breathe.

We continually hear from people with asthma that this is another example of asthma not being taken seriously. In response, in November 2018, Asthma UK conducted the largest ever survey carried out on asthma prescription charges, engaging over 9,000 people. The results are staggering, revealing that many people are cutting back on their medication for financial reasons with a dramatic impact on their health. This survey paints the picture of an outdated policy potentially driving health inequalities. The NHS is focused on prevention and reducing avoidable hospital admissions. It is therefore illogical to retain an outdated policy that puts barriers in the way of people taking their preventative medicines as prescribed.

With the evidence we have gathered, we can confirm that prescription charges are an unfair ‘tax’ on people with asthma, a long-term condition that is not controllable without medication for life. Action must be taken now to stop the impact prescription charges are having on the health of people with asthma. Asthma UK is calling on the Secretary of State for Health and Social Care to stop unfair prescription charges, so that people with asthma no longer have to pay to breathe.

**Kay Boycott** *Chief Executive, Asthma UK*

### Key findings of Asthma UK’s Prescription Charges Survey



Three in four people with asthma who have to pay for their prescriptions struggle to afford them.



More than half of people who pay for their prescriptions have at some point cut back on their medication due to cost.



Cutting back on asthma medication is having a dramatic impact on people’s health.



Regional variations in the impact of prescription charges are potentially driving health inequalities.



Prescription Prepayment Certificates are still an unfair burden on people with asthma and not everyone can afford them.



People with asthma think prescription charges are unfair and should be stopped.

## Summary

### The results of Asthma UK's Prescription Charges Survey are clear and decisive:

- NHS prescription charges are unfair, outdated and exacerbate inequalities for people with asthma. 97% of people who took part in the survey said that they support our campaign to bring an end to prescription charges for people with asthma.
- Most people with asthma who have to pay for their prescriptions are spending more than £100 a year on their medication – just for the right to breathe.
- More than half of people with asthma have cut back on their medication at some point due to the cost of their prescriptions, which is often having a serious impact on their health and wellbeing.

Asthma is a potentially life-threatening, long-term condition, so it is essential that people take their medication as prescribed to prevent their condition from deteriorating and to avoid lung damage that can occur from repeated asthma attacks. It's not surprising, therefore, that 93% (8,359 people) of those who replied to Asthma UK's Prescription Charges Survey think that the current system is unfair.

This is why Asthma UK is campaigning to stop unfair prescription charges, so that people with asthma do not have to pay to breathe. Sign our petition at <https://www.asthma.org.uk/prescriptioncharges> and share it with your family and friends.

## Background: the outdated and unfair system of prescription charges

**The NHS is based on the principle of equal access to healthcare for all, free at the point of use according to need, not on ability to pay – a principle still upheld by the public<sup>2</sup>. Yet, quite in contrast to this principle, some people have to pay for their prescriptions, while others receive them free of charge.** The existing prescription charges exemption list\* was drawn up over 50 years ago; it set out the criteria and long-term conditions that exempted certain patients from having to pay for their prescriptions, but asthma was never included on this list. In 2006, a committee of MPs concluded that the system of prescription charges was “inconsistent and anomalous<sup>3</sup>.” The Government at the time promised to scrap charges for all people with long-term conditions<sup>4</sup>, but this commitment was later dropped. Unfortunately, little has changed since then, despite the efforts of the [Prescription Charges Coalition](#)<sup>5</sup>, a group of 46 organisations who have been calling on the Government to scrap prescription charges for people with long-term conditions in England for over 10 years. Therefore this historic inequality still stands: people with asthma have to pay for all of their medication, while people with some other long-term conditions<sup>6</sup> receive theirs free of charge.

People in the devolved nations already benefit from universally free prescriptions, so it's only fair that people with asthma in England have the right to free medication too, to help them stay well.

“It is totally unfair and discriminatory against asthmatics that we have to pay for our life-saving medication”

### Survey respondent

\* A list of criteria that qualify an individual for free prescriptions. These criteria are largely income-related, but they also include a list of various long-term conditions that exempt an individual with those conditions from having to pay any prescription charges. There is a link to the full list in Reference 6.

# Asthma UK's 2018 Prescription Charges Survey: key findings

In November 2018, Asthma UK launched a ground-breaking survey to discover the impact that paying for prescription charges was having on the lives of people with asthma. In just three weeks, the survey received over 9,000 responses, making it the largest ever patient survey on prescription charges. Full details of the survey methodology, questions and responses can be found in the appendices to this report, available to download at <https://www.asthma.org.uk/get-involved/campaigns/our-policy-work/prescription-charges/>.

The results provide overwhelming evidence that prescription charges are having serious consequences for the health and wellbeing of people with asthma.

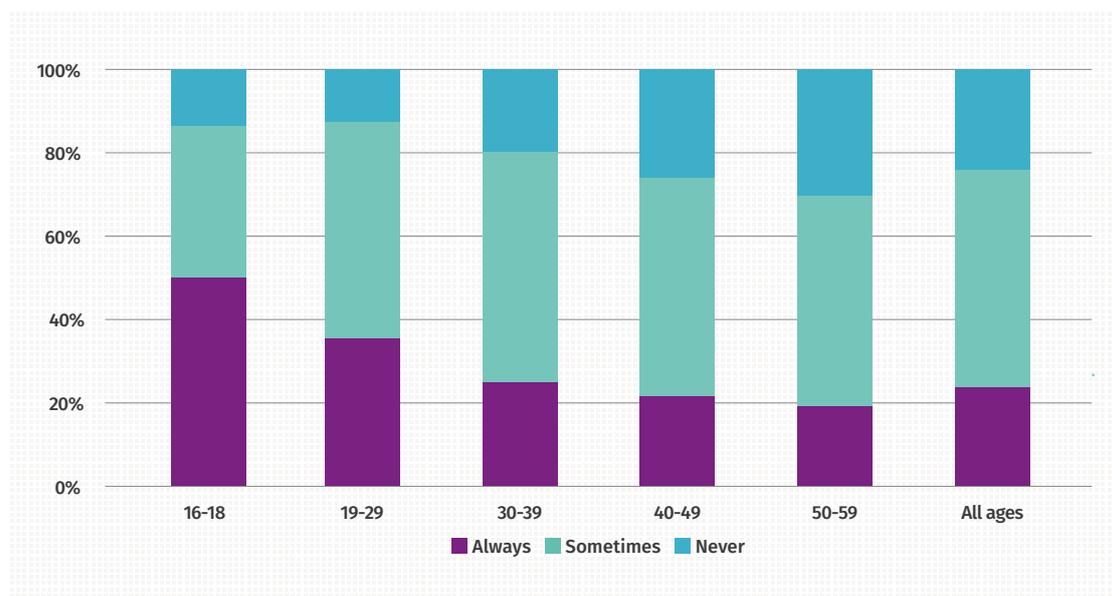
## Affordability of asthma prescriptions

It is estimated that 52% of people with asthma in England are paying for their prescriptions, which equates to 2.34 million people<sup>7</sup>. 48% of people are exempt as they are either children, over 60 or they meet other criteria.

The 2018 Asthma UK Prescription Charges Survey found that those people in England paying for their asthma prescriptions (84% of our survey respondents) are spending, on average, over £100 a year on their asthma medication. Each item on a prescription costs an individual in England £8.80<sup>8</sup>. A small minority of people (around 2%) told us that they were spending more than £400 a year on their medication.

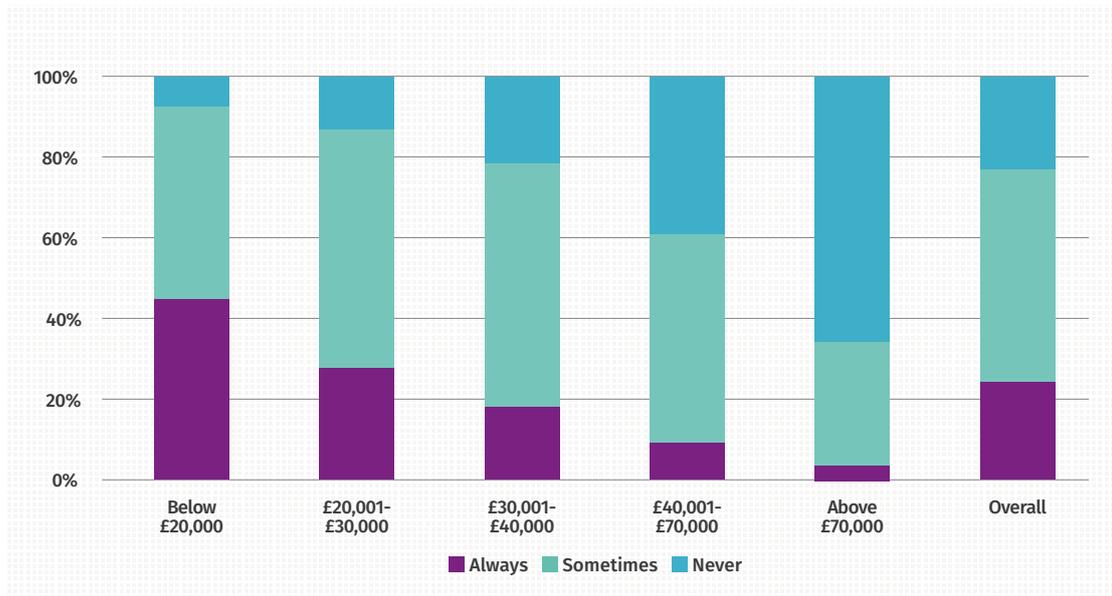
As Figure 1 shows, of those that have to pay for their asthma prescriptions, 76% (5,661/7,465) of people reported that they found it sometimes, or always, difficult to afford their asthma medication. Young people struggle the most to afford their prescriptions, with 86% (1,115/1,283) of 16-29 year olds sometimes, or always, finding it hard to afford their asthma medication (Figure 1).

**Figure 1:** Struggling to afford asthma prescriptions, by age group



Not surprisingly, people in the lowest income groups are struggling the most with the cost of their asthma medication (Figure 2). More than nine in ten (92%) of those on an income below £20,000, said they found it hard to afford their asthma prescriptions. The inequality and unfairness created by prescription charges is stark.

**Figure 2:** Struggling to afford asthma prescriptions, by annual income



“Asthma is life-threatening and very scary to live with. If people can’t afford medication they will die – fact.”

### Survey respondent

#### Impact on everyday spending

The number of respondents who reported having to find savings in other areas of their lives because of the need to pay for their asthma medication is an even greater cause for concern, uncovering the real, personal impact that prescription charges are having on many people with asthma:

- 35% (2,577/7,465) of respondents said that they had, at times, needed to cut back on food to be able to pay for their asthma medication.
- 21% (1,577/7,465) of people said that they had cut back on bills.
- 8% (587/7,465) of people said that they had cut back on their children’s school trips and 5% (329/7,465) of respondents on their children’s school uniform to afford their asthma medication.

Even more shocking, however, is the disproportionate impact that this is having on the lives of those on the lowest incomes (those earning under £20,000 a year):

- 54% (903/1,681) of respondents said they had cut back on food to afford their prescriptions.
- 33% (561/1,681) of people had cut back on bills to afford their medication.

It is clear from these responses that NHS prescription charges mean some people with asthma are facing an impossible choice between paying for their asthma medication or paying for other essential items like food.

“There are times when I have had to go without food or cut back on other things just to afford what I need to breathe every day.”

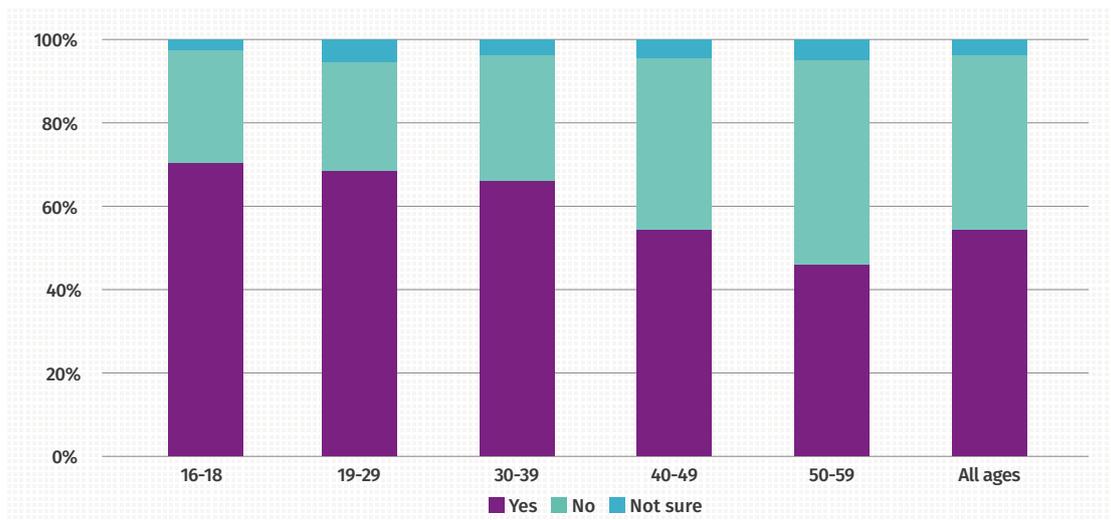
Survey respondent

### Impact on health

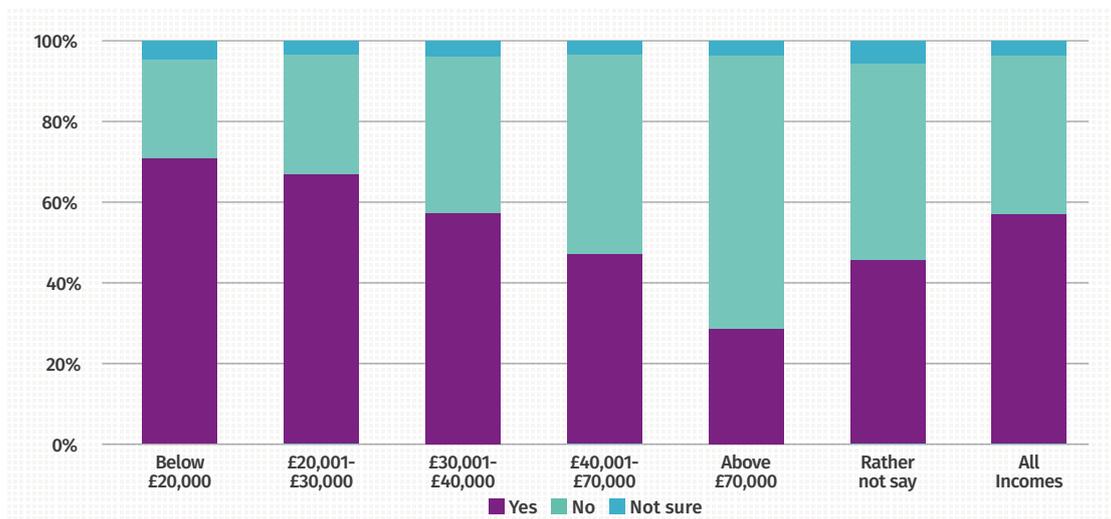
Good adherence to medication leads to better health outcomes for people with asthma<sup>9</sup>. For example, preventer inhalers help to stop symptoms from developing – they are key to preventing potentially life-threatening asthma attacks. To get the full benefits of preventer inhalers, people with asthma need to take them every day as prescribed.

However, Asthma UK’s Prescription Charges Survey revealed that 57% of all respondents affected by prescription charges felt that they had to skimp on their asthma medication because of the cost. Even more disturbingly, 69% (881/1,283) of those aged between 16 and 29 (Figure 3) and 70% (1,185/1,681) of those in the lowest income bracket (Figure 4) admitted to skipping their medication because of the cost, indicating poor adherence to their medication and thus increased vulnerability to an exacerbation in their condition.

**Figure 3:** Have cut back on asthma medication due to cost, by age



**Figure 4:** Have cut back on asthma medication due to cost, by income



In fact, the reported impact on people's health was staggering:

- 82% (3,482/4,259) of those who said they were cutting back on their medication due to the cost reported that this had made their asthma symptoms worse.
- 24% (1,025/4,259) of people reported actually having had an asthma attack as a result of skipping their medication, with 13% (561/4,259) of people requiring hospital treatment.
- Of those who reported skipping their medication because of the cost, 73% (3,124/4,259) of people were skipping their preventer inhaler – the very medication that could have prevented their symptoms from worsening.

These are overwhelming results that indicate the very real, negative impact prescription charges are having on the health of people with asthma. Poor adherence to taking prescribed asthma medication can cause exacerbations in people's asthma, potentially leading them to have life-threatening asthma attacks. People with asthma should not be forced to neglect their health and put themselves at risk of a life-threatening asthma attack just to make ends meet.

“When I was a student, when it was really difficult to afford [my inhalers], I ended up in A&E as a result.”

## Survey respondent

### Regional variations and health inequalities

The survey results also highlight distinct regional inequality in the ability to pay for prescriptions. In the North East of England, 81% (332/413) of people reported that they were struggling to afford their asthma medication, compared with 70% (397/561) of people in London. Likewise, 64% of respondents (264/413) in the North East reported that they were being sparing with their medication, compared with 49% (274/561) of people in London.

In November 2018, Asthma UK published a report, [On the edge: how inequality affects people with asthma](#)<sup>10</sup>, which revealed that asthma disproportionately affects people in less well-off socio-economic groups. The findings of our 2018 Prescription Charges Survey could, at least in part, explain why some people with asthma living in less well-off areas are more likely to end up in hospital, or even die, as a result of their asthma.

### Ineffectiveness of Prescription Prepayment Certificates

[Prescription Prepayment Certificates](#) (PPCs) allow people to purchase all their prescriptions up front, at a cost of £104 a year (or £29.10 quarterly)<sup>11</sup>. Asthma UK believes that no one with asthma should have to pay for their prescriptions, whether monthly or annually, but our survey also uncovered problems with PPCs, especially for those on low incomes (earning £20,000 or less a year):

- Over a third of people (37%) affected by asthma prescription charges don't buy a PPC.
- 24% (557/2,543) of people who didn't buy a PPC said it was because they couldn't afford it; of those on low incomes, 42% (218/518) admitted that cost was the reason they didn't purchase a PPC.
- 27% (628/2,543) of people said they were reluctant to buy an annual PPC as they didn't know how much medication they would need over the course of a whole year because their condition was variable.

If people are already struggling to pay for their prescriptions, paying up-front for a PPC will be even harder.

Asthma UK believes that, even if the PPC scheme was working effectively, people with asthma should not have to pay over £100 a year just to breathe. This represents an unfair burden on ill health which deters some people – generally the less well-off – from taking the medicines they need. This is not fair when medication for those with some other long-term conditions is available completely free of charge on the NHS in England, as it is for everyone in the devolved nations. For people with asthma, it’s a matter of fairness.

## What people in our survey told us about how prescription charges make them feel

Our survey also asked respondents if they had any further comments on prescription charges. To capture their comments, the word cloud below highlights the words and phrases respondents used most commonly. The larger the word or phrase, the more times it was mentioned by respondents. The cloud visually summarises the responses we received to the quantitative questions. Many people returned to the unfairness and severity of the consequences prescription charges were having on their lives.

**Figure 5:** Word cloud representing respondents’ comments on prescription charges and their effects on people with asthma



\* This word cloud represents a summary of the comments provided by participants at the end of the survey. After cleaning and passing through <https://databasic.io/en/wordcounter/>, those words used more than twenty times were then cleaned, with similar words or phrases and spelling errors removed. Phrases that stood alone and conveyed opinion or feeling were then selected. This process was repeated for two words and three words.

## Holly's story



19 year old Holly had a fatal asthma attack in January 2016. Her mum says Holly would still be alive today if prescription charges hadn't put her off regularly taking her asthma medication.

"Holly worked as a waitress and was on a low income. She found it difficult to pay for her asthma medicine, so me and her boyfriend helped where we could. She had mild asthma, but one day she had a terrible asthma attack out of the blue.

"As Holly only had one dose of medicine left in her inhaler, even as she struggled to breathe she didn't want to take it, saying she'd save it for when she really needed it. The horrific irony was that was the moment Holly really did need it. Within minutes of having her asthma attack, Holly fell unconscious, and died before she got to hospital.

"It is grossly unfair that people with asthma have to pay for the medication they need for their entire life – and to stay alive. I don't want anyone else to go through what we have. If the cost of asthma medicine is preventing people from taking it, the Government should do everything it can to help people stay well."

## Key recommendations

**Asthma UK is calling on the Secretary of State for Health and Social Care to stop unfair prescription charges for people with asthma by adding asthma to the prescription charges exemptions list.** This would give people with asthma the chance to self-manage their condition more effectively, with no financial barriers to helping them stay well.

**We are calling on MPs** to use their influence to urge the Secretary of State for Health and Social Care to review the current outdated prescription charges system, to make this change come about.

**We are calling on people with asthma, clinicians and the public** to join our campaign to fight these unfair charges for people with asthma, so they can lead healthier lives. Sign our petition at <https://www.asthma.org.uk/prescriptioncharges> and share it with your family and friends.

In the 50 years that the NHS prescription charges exemptions list has existed, it has only been amended once. It is time for this to change. It is time that people with asthma in England enjoyed the benefits of free NHS prescriptions, just like those with some other long-term conditions and those who live in the devolved nations.

**It's time to stop unfair asthma prescription charges. No more #payingtobreathe.**

## Acknowledgements

Written by **Katie Stokes** and **Judith Abel**, Asthma UK

Asthma UK would like to thank all those who responded to our 2018 Prescription Charges Survey. Thank you also to **Andrew Cumella** and **Lottie Renwick** at Asthma UK for their analysis of the survey data.

## References

- 1 Royal College of Physicians, 2014, 'Why asthma still kills: the National Review of Asthma Deaths (NRAD)', accessed at <https://www.rcplondon.ac.uk/file/868/download?token=IQzyNWUs>, accessed January 2019
- 2 King's Fund, 2018, 'Public satisfaction with the NHS and social care in 2017: Results and trends from the British Social Attitudes survey', accessed at: [https://www.kingsfund.org.uk/sites/default/files/2018-06/Public\\_satisfaction\\_with\\_nhs\\_social\\_care\\_2017.pdf](https://www.kingsfund.org.uk/sites/default/files/2018-06/Public_satisfaction_with_nhs_social_care_2017.pdf), accessed January 2019
- 3 House of Commons Health Committee, 2006, 'NHS Charges', accessed at: <https://publications.parliament.uk/pa/cm200506/cmselect/cmhealth/815/815-i.pdf>, accessed January 2019
- 4 Hansard, vol. 482, 5th Nov 2008, accessed at: <https://hansard.parliament.uk/Commons/2008-11-05/debates/08110554000020/Engagements?highlight=prescription%20charges#contribution-08110554000157>, accessed January 2019
- 5 Prescription Charges Coalition, <http://www.prescriptionchargescoalition.org.uk>, accessed January 2019
- 6 NHS Business Services Authority, 'Free NHS prescriptions', accessed at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/free-nhs-prescriptions>, accessed January 2019
- 7 Asthma UK, 2016, 'Annual Asthma Survey 2016 report', <https://www.asthma.org.uk/share/?rid=6770>, accessed January 2019
- 8 NHS Business Services Authority, 'Prescription Prepayment Certificates', accessed at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates>, accessed January 2019
- 9 Asthma UK, 2018, 'Preventer inhalers', accessed at: <https://www.asthma.org.uk/advice/inhalers-medicines-treatments/inhalers-and-spacers/preventer/>, accessed January 2019
- 10 Asthma UK, 2018, 'On the Edge: How inequality affects people with asthma', accessed at: <https://www.asthma.org.uk/globalassets/get-involved/external-affairs-campaigns/publications/health-inequality/auk-health-inequalities-paper.pdf>, accessed January 2019
- 11 NHS Business Services Authority, 'Prescription Prepayment Certificates', accessed at: <https://www.nhsbsa.nhs.uk/help-nhs-prescription-costs/prescription-prepayment-certificates>, accessed January 2019. Prices correct at this time.

## Appendices and text:

The methodology and full survey results are available in the Appendices at <https://www.asthma.org.uk/get-involved/campaigns/our-policy-work/prescription-charges/>.

Every ten seconds someone in the UK has a potentially life-threatening asthma attack and three people die every day. Tragically two thirds of these deaths could be prevented, whilst others still suffer with asthma so severe current treatments don't work.

This has to change. That's why Asthma UK exists. We work to stop asthma attacks and, ultimately, cure asthma by funding world leading research and scientists, campaigning for change and supporting people with asthma to reduce their risk of a potentially life-threatening asthma attack.

### **We fight asthma in three ways:**

- We fund world class asthma research.
- We campaign to improve the quality of care received by people with asthma.
- We help hundreds of thousands of people a year with our expert advice and support.

### **To find out more about Asthma UK's work:**



**Asthma UK Helpline:**  
0300 222 5800



**Email us:**  
[info@asthma.org.uk](mailto:info@asthma.org.uk)



**Visit our website:**  
[www.asthma.org.uk](http://www.asthma.org.uk)



**Find us on facebook:**  
[www.facebook.com/asthmauk](http://www.facebook.com/asthmauk)



**Follow us:**  
@asthmauk  
@AUKResearch