

A hidden harm:

why healthcare professionals
want to stop unfair asthma
prescription charges



“

ASTHMA KILLS - FACT.

Patients with financial hardship make choices, often unwise ones, leading to exacerbations, emergency treatment and in many cases progression to airway remodelling and chronic lifelong crippling airways disease.

A key factor in compliance for many is cost.

In 2019 we are still fighting to improve asthma care; removing charges for this group of patients is the single biggest intervention we need.

”

Nurse, primary care, England

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Foreword



Asthma is a potentially life-threatening, life-long condition with a rising death rate in the UK. 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. Tragically, three people every day still die from an asthma attack and two in every three of these deaths could have been prevented by good basic care¹.

Good basic care can be as simple as taking the right medication at the right time. For example, taking a preventer inhaler daily to build resistance to the triggers of asthma attacks or using a reliever inhaler to provide fast-acting relief when asthma is getting out of control. However, the cost of these medicines are deterring people with asthma from getting the very medication that could one day save their life. Asthma UK has found that over three quarters of people with asthma in England struggle to afford their prescriptions and over half had cut back on their medication as a result².

Yet people with some other long-term conditions are exempt from paying for their medication. The prescription charges medical exemptions list was formulated over 50 years ago – before the asthma preventer inhaler was even available. So, half a century later, we have asked healthcare professionals their views on whether it is time to review the list and bring it into the 21st century.

Asthma UK, with the support of the Royal College of Nursing, Association of Respiratory Nurse Specialists and Primary Care Respiratory Society UK, conducted a survey of over 750 nurses, doctors and pharmacists who look after people with asthma on a daily basis. The results are shocking.

We have written this report to reflect the voices of these frontline staff. We invite doctors, nurses and other healthcare professionals to join the campaign, alongside people with asthma, by signing the [petition](#)¹. Together we call on the government to listen to those who are striving to improve the care of people with asthma, but who are frustrated and distressed by the needless suffering they are witnessing because their patients struggle to afford their medication.

Their views from the frontline of delivering care for people with asthma were overwhelming: prescription charges are having a detrimental impact on the health of people with asthma and are hindering the care healthcare professionals are trying to deliver for their patients. The prescription charges medical exemptions list is an outdated anomalous policy which must be reviewed. After 50 years, it is time to stop unfair asthma prescription charges so that no one has to pay to breathe.

Samantha Walker RGN PhD,

Director of Research & Policy and Deputy Chief Executive at Asthma UK



About this report

In 1968, the prescription charges medical exemptions list was drawn up, with the help of healthcare professionals, to identify the medical conditions which would exempt an individual from being charged for their prescriptions. Over 50 years later, this list still hasn't been substantially reformed, and it remains an historic anomaly within the NHS in Englandⁱⁱ.

We have previously asked people with asthma about their experience of [prescription charges](#)¹. This report presents findings from a survey of healthcare professionals, to understand their experience of the impact of prescription charges on their patients, and their professional opinion on the need for policy reform. The survey, promoted by the Royal College of Nursing (RCN), the Association of Respiratory Nurse Specialists (ARNS) and the Primary Care Respiratory Society (PCRS), as well as Asthma UK, received responses from 787 healthcare professionals, of whom 81% (636) were nurses, 7% (57) were doctors and 7% (56) were pharmacistsⁱⁱⁱ. 96% (693) of respondents treat people with asthma. Quotes and key themes discussed are not representative of all comments given, please see the Appendix for a full breakdown of the qualitative data gathered.

Key findings from the survey of healthcare professionals

98% think the current medical exemptions list should be reviewed.

87% say they have had patients skip their preventer inhaler because of the cost of their prescriptions.

57% say they have had patients who have had an asthma attack or needed emergency care after they skipped their medication because of the cost of their prescriptions.

87% say prescription charges should be stopped because they put people with asthma at risk of potentially life-threatening asthma attacks.

48% reported patients missing an asthma appointment because they were worried about the cost of the medicines they might be prescribed.

Main recommendations:

- Officially review the medical exemptions list, taking into account the expert opinion of healthcare professionals and the impact on patients
- Commit to making asthma prescriptions free of charge so that no one has to pay to breathe.

ii The only change to date has been the addition of cancer to the list, back in 2009. The government of the day had promised the list would be expanded to include all long-term conditions, including asthma, and commissioned the [Gilmore report](#), which drew up the implementation pathway for this policy. However, the policy was not pursued by the incoming coalition government.

iii Please see appendix for full breakdown of respondents.



What is the impact on the health and care of people with asthma?

Patients are skipping asthma medication

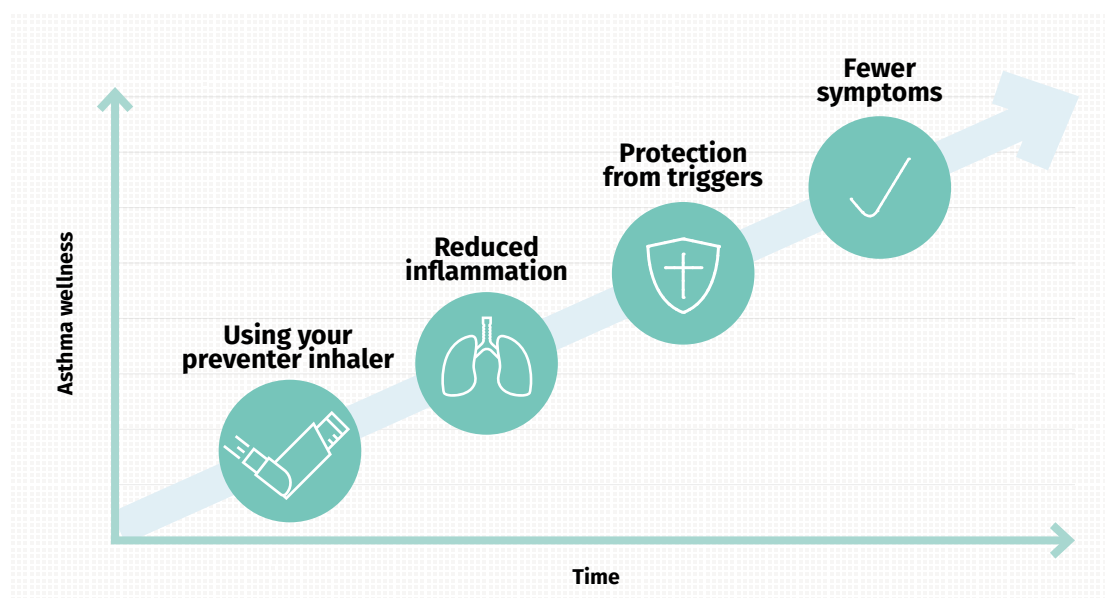
87% (559/645) of healthcare professionals reported patients skipping their preventer medication because of the cost of their prescriptions.

“I have had patients tell me they have halved their dose of preventer inhaler so it will last until pay day.”

Nurse, hospital/specialist, England

Preventer inhalers are designed to reduce inflammation and swelling in the airways which decreases sensitivity to asthma triggers and helps prevent asthma attacks. However, preventer inhalers are only effective when people with asthma take them every day as prescribed. If this regime is not continually adhered to, the benefit of the medication reduces, increasing the individual's vulnerability to a potentially life-threatening asthma attack³.

Preventer inhalers build up asthma protection over time



This finding starkly illustrates the barrier prescription charges are placing on good asthma management, putting lives at risk. It also aligns with our previous survey¹, where 57% of people with asthma reported skipping their medication because of the cost, of whom 73% were skipping their preventer inhaler.



Of the other prescribed items healthcare professionals reported their patients omitting:

45% (293/645) have had patients skip reliever medication because of the cost of their prescriptions.

22% (144/645) have had patients who have not collected steroid tablets because of the cost of their prescriptions.

It is startling that almost half of healthcare professionals have seen patients skip the medication that could save their life during an asthma attack. Reliever inhalers deliver fast-acting relief when an individual's asthma is getting out of control or they are having an asthma attack. Whilst it is crucial that people with asthma have this medication to hand at all times in case of such an emergency, reliever inhalers are only a temporary fix, and do not reduce the swelling and inflammation in the airways that will ultimately prevent future asthma attacks. Over-reliance on reliever inhalers can also reduce their effectiveness, putting patients at risk in the event of a severe asthma attack, and new international clinical guidelines recommend against reliever-only asthma management even for mild asthma⁴.

People with asthma should not be forced to choose between these medications - this evidence suggests they are.

“People will often choose their reliever over the preventer as [they] see that as the most important, leading to untreated inflammation and risk of [an] asthma attack”

Nurse, third sector, England

Moreover, one in five healthcare professionals reported patients not collecting the steroid tablets they had been prescribed because of the cost. Steroid tablets are only prescribed as a last resort when asthma symptoms are really bad and need aggressive treatment. They reduce inflammation and widen the airways of people who are experiencing a worsening in their asthma or have had an asthma attack⁵. This finding further emphasises the problematic nature of prescription charges for healthcare professionals trying to deliver care, as well as the worrying risk at which they place the health of people with asthma.

“I have felt for a long time that it is wrong asthmatics pay for inhalers, especially preventers. It is mainly students and sometimes working adults who let their health suffer, they know they are at risk but make the choice anyway. I find it ridiculous that the rule was made in 1968 and not reviewed.”

Nurse, primary care, England



Patients are missing out on care

Our healthcare professionals survey also revealed insight into the impact prescription charges are having on patient care, highlighting how damaging prescription charges are to the delivery of care and to keeping patients well.

48% (307/645) of healthcare professionals reported patients missing an asthma appointment because they were worried about the cost of the medicines they might be prescribed.

Any asthma appointment is vital to keeping track of an individual's asthma, especially as it is a variable condition which fluctuates over time. Asthma reviews are recognised as a key element of basic asthma care as stated in the National Institute for Health and Care Excellence (NICE) guidelines⁶.

The importance of asthma reviews cannot be overstated, as the findings in the National Review of Asthma Deaths (NRAD) highlight; 43% of those who died from an asthma attack had had no asthma review in general practice in the year preceding the attack².

By charging patients for their medication, it is creating a disincentive for people with asthma to attend medical appointments and receive the care they need. This ultimately means prescription charges are driving people with asthma to neglect their condition and put their health at risk.

As part of the survey, we asked healthcare professionals to provide any further comments they had on prescription charges in a free form text box. One of the themes to emerge from this qualitative data collection (19%; 31/164) were accounts of parents and siblings using a child's inhaler because children receive prescriptions free of charge. Healthcare professionals noted how this also had very worrying implications for the child, as it flagged an alert on their prescribing record. This made it appear as though the child was taking more medication than they had been prescribed, suggesting their condition was deteriorating. This could also result in the child running out of medication before they were due to receive more, putting their health at risk.

Using a child's inhaler is also dangerous for the person borrowing the inhaler; not only do they have limited access to potentially lifesaving medication, but it also makes monitoring their medication use a lot more difficult at an asthma review. This also aligns with the findings from our recent prescription charges survey of people with asthma, in which 29% of those who cut back on their prescriptions because of the cost had to borrow an inhaler¹.

“I see parents using their children's inhalers to avoid paying prescription charges, leading to more frequent repeat requests for children's medications and causing alerts on the child's prescribing [record] when it is actually the parent or a paying age sibling that has been using them.”

Nurse, primary care, England

These findings have uncovered the damaging impact prescription charges have on patient care and how this is ultimately placing the health of people, including children, with asthma at greater risk.



CASE STUDY



Bonnie Beard is a lead respiratory nurse who works in two surgeries in Essex and sees around 20 patients with asthma every week. She has been a nurse for 30 years and is a Queen's Nurse.

"I know first-hand that the cost of asthma prescriptions can be harmful to patients as it can prevent them from managing their asthma and in some cases, this can put lives at risk. Most weeks, I speak to patients whose asthma has worsened or who have had asthma attacks, sometimes requiring emergency care because they have been unable to afford to take the medication that keeps them well.

"I want the best for my patients so it is frustrating that some of them become unwell because they can't afford to pay for their prescriptions. It seems unfair they have to pay when those with other long-term life-threatening conditions such as diabetes are exempt. Some of my patients might need as many as five prescription items but they have to wait until they get paid before they can afford to get their medicine. Others are borrowing their child's inhaler or one from a relative or friend which means they are taking medication which may not be right for them. This can put them at risk of having poorly controlled asthma.

The government needs to urgently review prescription charges for asthma patients – before more suffer or lives are lost by those who can't afford to pay for medicine."



Patients' asthma is getting worse

Prescription charges are driving unsafe choices by people with asthma, undermining healthcare professionals' efforts to improve asthma management. This is having a direct impact on clinical outcomes.

85% (546/645) of healthcare professionals were aware of their patients' asthma symptoms getting worse because they had skipped their medication.

57% (368/645) of healthcare professionals have had patients who have had an asthma attack or needed emergency care because their patient skipped their medication.

These findings correlate with our previous survey where 82% of people with asthma who said they were cutting back on their medication as a result of the charge reported that this had made their asthma symptoms worse.

The importance of these findings cannot be understated. Asthma is a long-term condition and can be life-threatening. On average, three people every day die from an asthma attack. To charge people for the medication that keeps them well and out of hospital is harmful. Moreover, asthma accounts for 65,802 hospital admissions a year in England^{iv}, this evidence suggests that many of these are avoidable admissions caused needlessly by prescription charges, placing unnecessary strain on the NHS.

“If we want to cut the number of people attending A&E and the number being admitted into hospitals due to their asthma, then we need to help them in every way and one significant way would be with their prescription charges. It is unacceptable that we help others with long term conditions and not those with asthma. It makes no sense what so ever and it is not just!”

Nurse, primary care, England



What should be done to tackle the issue of prescription charges?

As people on the frontline of delivering asthma care, it is crucial to understand what healthcare professionals think of the current medical exemptions list and whether it was a policy which helped or hindered patients and the NHS.

98% (698/715) of healthcare professionals stated that the current medical exemptions list should be reviewed.

Given there has been no substantial reform of the list since its inception over 50 years ago, this evidence underlines the need for this issue to be addressed.

88% (695/787) of healthcare professionals went further and stated that prescription charges for people with asthma in England should be stopped.

“My patients are often low earners so they can’t afford to buy any inhaler. They then don’t take their preventative inhaler daily, only as and when they feel their symptoms returning. This is then crisis management of their chronic condition. This leads to lots of hospitalisations and many avoidable deaths.

These patients need inhalers to breathe, just like a diabetic patient that needs insulin! Free prescriptions for asthma patients is a must.”

Nurse, primary care, England

When asked why they thought prescription charges should be scrapped:

87% of healthcare professionals said prescription charges put people at risk of life-threatening asthma attacks.

83% of healthcare professionals said prescription charges were a barrier to people with asthma taking their medication.

79% of healthcare professionals said it was unfair that some other long-term conditions were exempt from prescription charges when asthma was not.

“It seems very unfair that e.g. thyroid patients get all medicines free but asthmatic patients don’t. In a way, in my opinion, it trivialises asthma. Patients struggle in some cases to afford all their asthma medicines so will just use a reliever [inhaler].”

Nurse, primary care, England



Conclusion and recommendations

The prescription charges medical exemptions list must be reviewed and cannot continue to be ignored. With such strong evidence from both people with asthma and healthcare professionals that the current system is causing a spectrum of harmful issues for people with asthma, it must be concluded that the medical exemptions list should now finally be reviewed as a matter of urgency.

Asthma UK, together with the RCN, ARNS and PCRS, are calling on the Secretary of State for Health and Social Care to stop unfair asthma prescription charges by conducting a review of the prescription charges medical exemptions list.

“People with asthma bear a heavy burden of prescription costs. This survey starkly shows how these costs interfere with people getting the treatment they need. This is a cause of unnecessary suffering and risk, suffering which disproportionately affects people on low incomes. This should not happen in a caring society.”

Duncan Keeley

Policy Lead on the Executive Committee of the Primary Care Respiratory Society – UK

“These new findings are damning; asthma is a case study that sheds light on the experiences of people with many other long-term conditions. These patient groups continue to miss out on vital medication due to cost. The government must listen to the expertise of health professionals, patients and charities and immediately review the prescription charges exemptions list.”

Lloyd Tingley

**Chair of the Prescription Charges Coalition &
Senior Policy and Campaigns Adviser at Parkinson’s UK**

“This report makes for a sobering read. It is unthinkable that people in England are risking their health and potentially their lives because they cannot afford their medication. There is absolutely no justification for the current prescription charges system to continue as it is; people with asthma are being discriminated against, which is a blatant breach of ethical principles.

This report conveys a powerful message which should act as a call to action for those who can make change happen. We now need politicians and policy makers to step up to the mark and address our findings as a matter of urgency.”

Beverley Bostock

Nurse Practitioner who sat on the National Review of Asthma Deaths, and Asthma Lead for the Association of Respiratory Nurse Specialists



“It cannot be acceptable that some people with long-term conditions are missing out on their vital medication because they cannot afford it. Nurses see the impact of this every day of the week and know what happens when people do not take their vital medication. This will only make their condition worse and they will end up needing further treatment adding additional pressure the health and care system.

It is time that there is equity with other long-term conditions such as diabetes where prescription charges are exempt.”

Wendy Preston

Head of Nursing Practice at the Royal College of Nursing

Recommendations:

We are calling on the government to:

- Officially review the medical exemptions list, taking into account the opinion of healthcare professionals and the impact on patients
- Commit to making asthma prescriptions free of charge so that no one has to pay to breathe.

Call to action:

- We are calling on politicians to commit to ending unfair prescription charges for people with asthma by including a pledge in their party's manifesto
- We are calling on people with asthma, healthcare professionals and the public to join our campaign to fight unfair asthma prescription charges, so people with asthma can lead healthier lives. [Sign the petition today](#)

Acknowledgements

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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



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