



Continuing to pay the price

The impact of prescription charges on people living with long term conditions

The Prescription Charges Coalition

The Prescription Charges Coalition brings around 50 organisations and professional bodies together to campaign to scrap prescription charges in England for people with long term conditions who are not currently on the exemption list.

Research undertaken by the coalition in 2014 and 2017 found that the charge is having a significant impact on the ability of people with long term conditions in England to stay well. It is also impacting medicine adherence, quality of life, employment opportunities and their health outcomes.

Our latest research demonstrates the impact of the charge on people with long term conditions, who have also faced:

- the NHS England decision to move many over the counter medicines off prescription and make people buy them
- Coronavirus - due to long waits to see health professionals and also for treatment; and
- the current cost of living crisis.

It is clear the prescription charge exemption system needs urgent reform, as it is not meeting the needs of people with long term conditions, and is putting their health at risk.

Our recommendations for the UK Government are set out in section four.

We would like to thank all those who participated in the survey, the organisations that promoted the survey and those that contributed to the report. Also, a particular thanks to Ben Wilkins at Parkinson's UK who analysed the findings of the survey that this report is based on.

Key findings

- Nearly 1 in 10 people have skipped medication in the past year due to the cost of prescription(s). Of this group:
 - 30% now have other physical health problems in addition to their original health condition.
 - 37% now have other mental health problems in addition to their original health condition.
 - And over half (53%) have had to take time off work as a result of worsening health.
- Additionally 1 in 10 (9%) report being unable to collect their prescription due to the cost in the last 12 months.
- 38% of respondents became aware of the Prescription Prepayment Certificate more than a year after their diagnosis with a long term condition.
- Around a third (35%) have had the duration of their prescription changed, meaning they're paying more frequently for their medicines.

“I find it frustrating that I have to pay despite having a lifelong health condition that is not caused by lifestyle choices. If I don't take the meds, I will end up very poorly and cost the NHS a hell of a lot more in consultant, tests and investigation fees. It's more prudent to give people free prescriptions to keep them healthy and hopefully they will need less costly treatments.”

Recommendations

The Prescription Charges Coalition recommends the UK Government takes the actions below to enable people with long term health conditions in England to collect the vital medication they need to stay well:

- Commit to freezing the charge for 2024.
- Recommend that prescribers stop reducing the duration of prescriptions - as this prices people out of affording their vital medicines.
- Conducts an independent review of the prescription charge exemption list urgently. The review should examine the benefits to the health of the citizens in Northern Ireland, Scotland and Wales of scrapping the charge, and also take into account health inequalities.
- Scrap their plans to align prescription charges with the state pension age.
- Ensure information about prescription charge entitlements (including the low income scheme and PPCs) are provided to all those with long term conditions when they are diagnosed with their condition. This information should also be given out when medicines are dispensed and reviewed. Materials covering these topics should also be displayed at all GP surgeries and pharmacies.

1. Introduction and context

England is the only UK country where prescription charges still exist, having been abolished in Wales in 2007, Northern Ireland in 2010 and Scotland in 2011.

Controversial from the outset, prescription charges were introduced in 1952, abolished in 1965 and reintroduced in 1968 with a system of exemptions that continues today. The charge itself has risen almost every year since 1979, although the charges were frozen last year by the Health Secretary¹, to recognise the impact of the cost of living.

At the time the survey was conducted a single item on prescription was £9.35 and a Prescription Prepayment Certificate (PPC), which spreads the cost of medicines was £30.25 for three months and £108.10 for 12 months.

However, on 9 March 2023 the health minister Neil O'Brien announced that prescription charges would rise from 1 April 2023 to £9.60 for a single item and a three month PPC will be £31.25 and a 12 month PPC will be £111.60².

The UK Government states that 89% of prescriptions in England are currently dispensed without charge, but most of the income to the NHS from prescription charges comes from working-age people with long term conditions.

While certain health conditions entitle people to a medical exemption certificate and therefore free prescriptions, only a handful of conditions qualify.

Aside from the addition of cancer in 2009 the list of exempt conditions has not changed since 1968, even though there have been significant medical advances. For instance people with childhood conditions like cystic fibrosis who were not expected to survive, or conditions that didn't even exist at the time like HIV.

Other changes that impact prescription charges

Since the last report there have been some changes that may affect people with long term conditions around prescription charges.

In 2018, NHS England brought in new guidance for Clinical Commissioning Groups³ that meant thousands of items people had previously received on prescription would now have to be bought over the counter, like antibiotic eye drops and eye ointments, vitamins, creams for mild dermatological conditions and medicine for constipation. This has meant that individuals' medication related costs have increased each month, on top of their prescription charge.

From 1 April 2023 anyone will be able to apply for the hormone therapy treatment (HRT) prepayment certificate which will cover all HRT items licensed to treat the menopause in England⁴. This certificate costs £19.30 per year and could save people almost £90 per year. This is a welcome step forward to reduce costs, however the Coalition believes these charges should be scrapped altogether.

¹ Department of Health and Social Care. New prescription charge freeze to help with the cost of living - <https://www.gov.uk/government/news/new-prescription-charge-freeze-to-help-ease-cost-of-living>; May 2022

² Hansard - <https://questions-statements.parliament.uk/written-statements/detail/2023-03-09/hcws624>; May 2022

³ NHS England. Guidance on conditions for which over the counter items should not routinely be prescribed in primary care - <https://www.england.nhs.uk/medicines-2/conditions-for-which-over-the-counter-items-should-not-routinely-be-prescribed/>; 2018

⁴ Pharmaceutical Journal. HRT prepayment certificates <https://pharmaceutical-journal.com/article/news/hrt-prepayment-certificate-to-cover-all-hrt-items-licensed-to-treat-the-menopause>; 31 January 2023

Finally in summer 2021, the Government consulted on aligning prescription charges with the state pension age in England⁵. If introduced this would mean those with long term conditions would have to pay for their prescriptions for at least another six years.

In addition, the over 60s would be expected to pay for their medication until they reach state pension age, unless they have an exemption based on the condition they live with. The UK Government is yet to publish its response following the consultation.

⁵ Department of Health and Social Care. Aligning the upper age for NHS prescription charge exemptions with the State Pension age

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<https://www.gov.uk/government/consultations/aligning-the-upper-age-for-nhs-prescription-charge-exemptions-with-the-state-pension-age>; 2021

2. Methodology and demographics of respondents

This survey ran online for five weeks from 16 January to 26 February 2023. It was advertised through the website of the Prescription Charges Coalition, as well as the websites, Facebook pages, Twitter accounts and newsletters of member organisations.

4,014 people living with long term condition(s) completed the survey.

59% of survey respondents indicated they are living with Crohn's or Colitis. Research conducted in 2022 suggests there are nearly half a million people in the UK living with either Crohn's or Colitis⁶.

Where relevant we have shared notable differences between those living with Crohn's or Colitis and the total sample size.

Condition breakdown

Respondents were asked which long term conditions they are living with. Outside of the already mentioned frequency of Crohn's or Colitis, only four other conditions were indicated by more than 10% of respondents:

Condition		Condition	
Allergies	10%	Migraine	8%
Asthma	15%	Multiple Sclerosis	1%
Behçet's	4%	Multiple System Atrophy	<1%
Cystic fibrosis	1%	Muscular Dystrophy	<1%
Fibromyalgia	7%	Parkinson's	6%
Genetic condition	1%	Rheumatoid arthritis	13%
Heart disease	2%	Rare disease	2%
Crohn's disease or Colitis	59%	Sickle Cell/Thalassemia	<1%
Kidney disease	6%	Scleroderma & Raynaud's	1%
Lung disease	2%	Spinal injury	2%
Lupus	4%	Stroke	1%
Mental ill health	13%	Other	24%

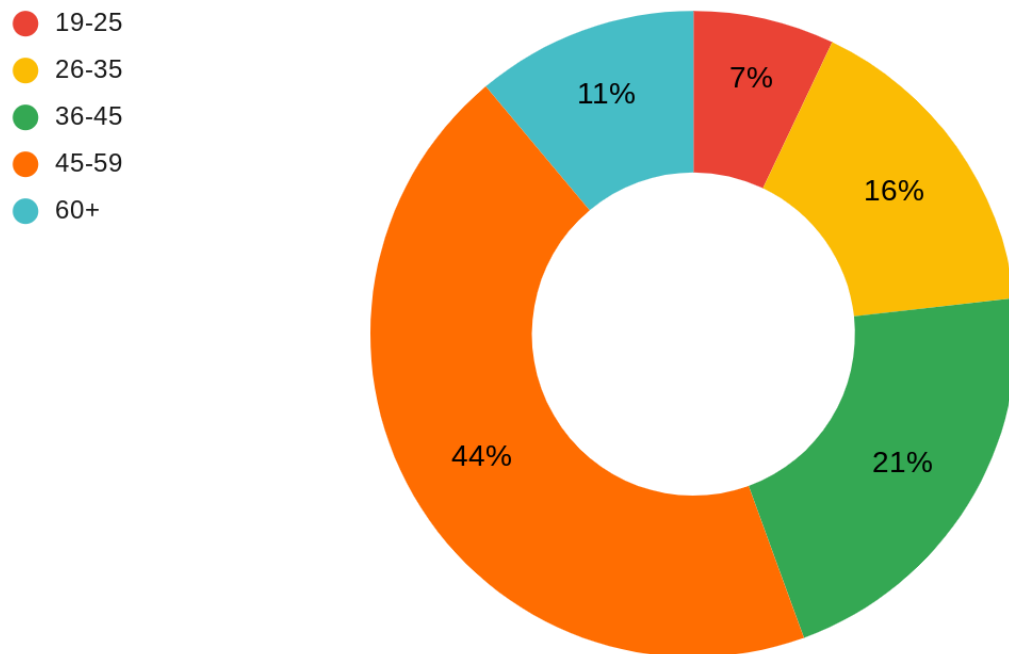
Some of the conditions respondents listed as 'other' include osteoarthritis, vasculitis, high blood pressure, spondylitis, osteoporosis, arthritis, antiphospholipid syndrome, endometriosis, coeliac disease, ME/chronic fatigue, Pernicious Anaemia, chronic pain, Common Variable Immunodeficiency and Grave's disease.

Gender

74% of respondents were female and 25% were male. The breakdown of survey respondents' age can be found in the chart below.

⁶ Crohn's & Colitis UK. Research shows over 1 in 123 people in UK living with Crohn's or Colitis - <https://crohnsandcolitis.org.uk/news-stories/news-items/new-research-shows-over-1-in-123-people-in-uk-living-with-crohn-s-or-colitis>; March 2022

Age of respondents



Employment

43% of respondents were in full-time employment but when looking only at those with Crohn's or Colitis, this increases to 50%. 20% of respondents were employed part-time and 9% of respondents were retired. 8% of respondents were unable to work because of sickness or disability and 3% of respondents were receiving benefits due to illness, being a carer or being unable to work. 4% of respondents were in full or part-time education.

Demographic and condition specific data indicates that those living with Crohn's or Colitis are more likely to be working full-time, would miss work if unable to take their medication, and they are also ineligible to receive benefits.

These attributes could suggest that those living with Crohn's or Colitis may skew younger, however, their distribution across the ages is comparable to those who live with other long term conditions.

3. Key findings

Prescription medicines

78% of respondents stated they are prescribed between 0-6 items per month. 87% of respondents are prescribed 2 or more items per month, which is slightly lower than the 88% recorded last time this research was conducted in 2017.

Prescription Prepayment Certificate (PPC)

Over half of all respondents to this survey are paying for their prescriptions by using the PPC.

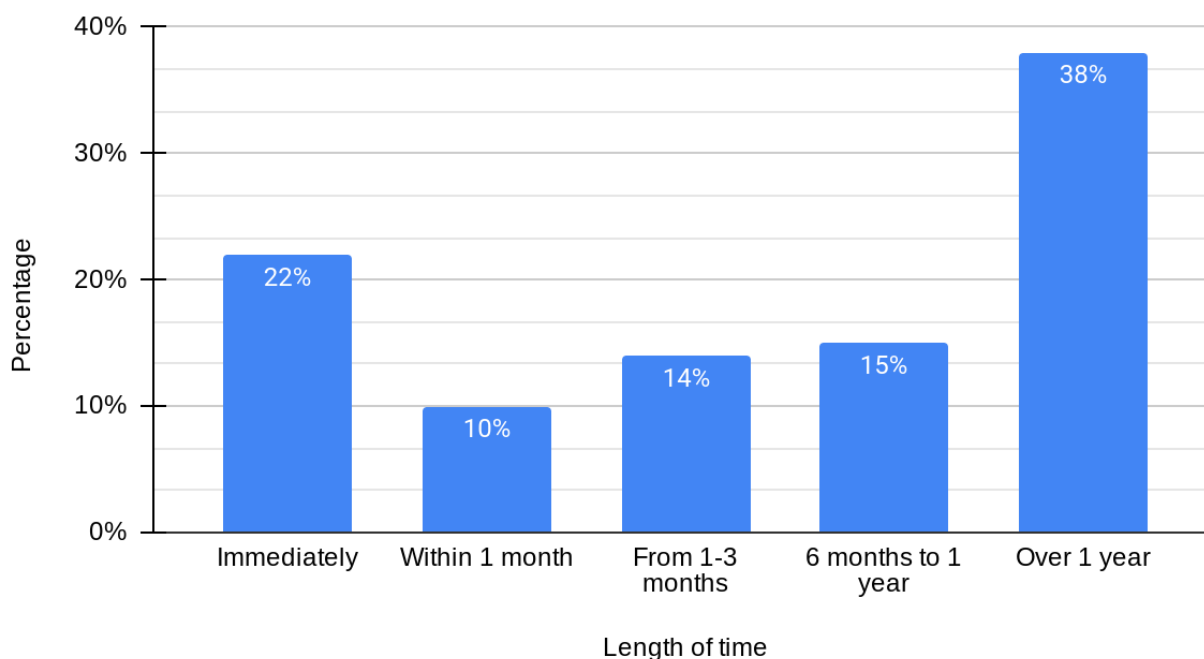
- Around a quarter (24%) pay for their medicines per item but when looking only at those with Crohn's or Colitis, this increases to 30%.
- 17% are either now exempt or have always been exempt from prescription charges.

Figures from a Freedom of Information request show that in 2021/22 there were over 867,000 3-month PPCs purchased and over 1.7 million 12-month PPCs purchased⁷.

Awareness

The vast majority (94%) of respondents are aware of the PPC. However, respondents report they typically only become aware of PPCs over a year after their diagnosis, which we feel needs to be addressed. We believe that as soon as someone is diagnosed with a long term condition and prescribed medication on a regular basis they should be informed about the PPC.

Length of time from diagnosis to finding out about the PPC



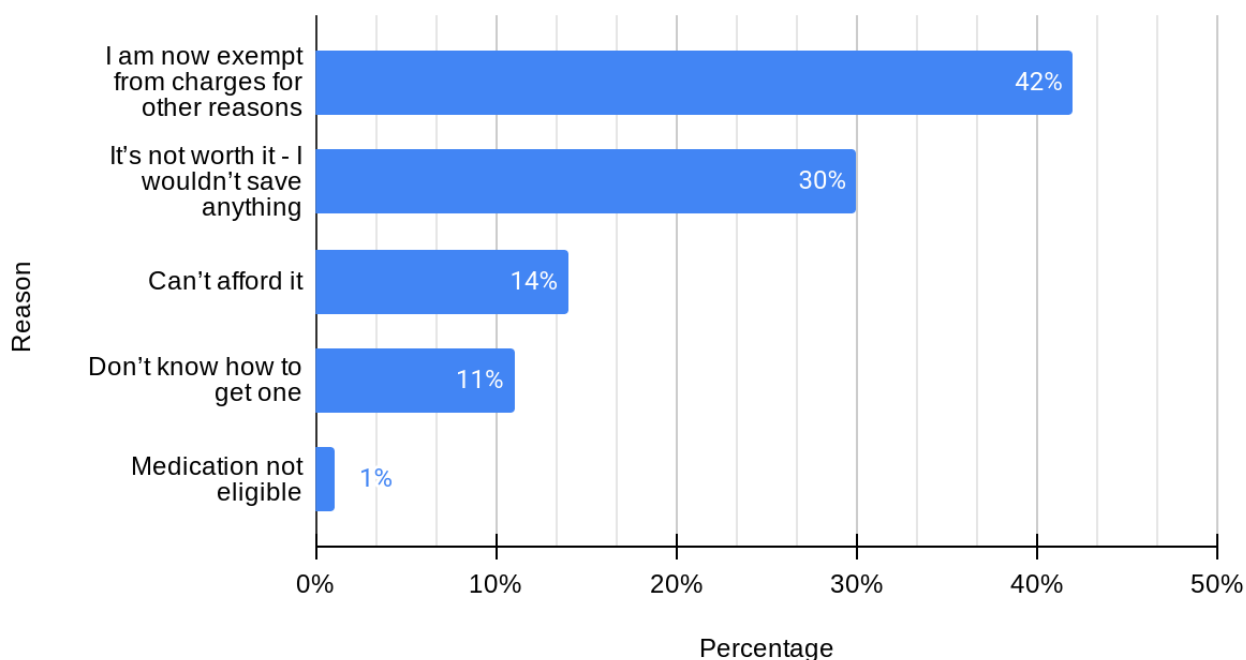
Furthermore, the most commonly cited source of learning about the PPC is from 'friends/family' (31%), slightly ahead of 'pharmacist' (29%).

Just over half (58%) of respondents currently have a PPC. The vast majority of those that do (90%) have the certificate valid for 12 months.

Of the respondents without a PPC (42%), the most commonly cited reason for not having one is that they are now exempt.

⁷ NHS Business Services Authority. Freedom of Information request 28843 - <https://opendata.nhsbsa.net/dataset/foi-28843>; December 2022

Reason for not having a PPC



It is worth noting that 30% of respondents state that they don't think they'd save anything with a PPC, but when looking only at those with Crohn's or Colitis, this increases to 36%.

NHS Low Income Scheme

The NHS Low Income Scheme offers support with prescription costs and other NHS services to some people on low incomes. Anyone can apply as long as they do not have savings or investments over a certain limit. Our survey found that 83% of respondents knew nothing about the scheme.

Of the 17% of respondents who are aware of the scheme, only 14% of them have applied. 85% say they aren't eligible, so wouldn't apply anyway.

However, 15% of people either do not know how to apply or are unsure about whether they are eligible or not.

The awareness of and/or lack of eligibility of the scheme may be explained by the benefit status of respondents to the survey, as 74% don't receive any benefits. The most frequently claimed benefit by respondents of the survey was Personal Independence Payment at 15%.

Cost of living

9% of survey respondents shared they weren't able to collect their prescriptions in the last 12 months due to cost. This equates to hundreds of thousands of individuals in England who live with a long term condition^{8 9}.

⁸ NHS England blog. Making the case for a personalised approach - <https://www.england.nhs.uk/blog/making-the-case-for-the-personalised-approach/>; 2018

⁹ The King's Fund. long term conditions and multi-morbidity - <https://www.kingsfund.org.uk/projects/time-think-differently/trends-disease-and-disability-long-term-conditions-multi-morbidity>

This figure is in line with research undertaken by Healthwatch England¹⁰ who conducted a tracker poll with 2000 adults in England between October and December 2022. They assessed the impact of the cost of living on their health and wellbeing and whether it has affected how respondents have used health and social care services.

They found that more people avoided getting prescription medicines, and booking NHS appointments, including dental treatment, due to the fear of extra costs in December than in October.

- And one in ten (10%) people have also avoided taking up one or more NHS prescriptions because of the cost, up from 6% in October;
- One in ten (10%) avoided buying over the counter medication they normally rely on, up from 7% in October.

Our survey also found that:

- 1 in 5 respondents have skipped a dose of medicine in the last 12 months.
- 12% of people who pay for their NHS prescription have cut medication in half to make it last longer.
- 7% of respondents have not picked up medication in the last 12 months, again this rises to 12% for those who pay per NHS prescription.

Additionally, nearly a quarter (23%) have struggled to keep up with bills due to the cost of living crisis.

Other organisations cost of living data

As respondents to this survey are disproportionately living with Crohn's or Colitis and have purchased a PPC, data from other member organisations of the Coalition may give a wider picture on the impact of the cost of living on people with other long term conditions. Their reports found:

- 1 in 6 people with asthma and lung disease¹¹ surveyed had cut back on using their potentially life saving inhalers as they were worried about the cost.
- 29% of respondents with cystic fibrosis¹² had skipped their medication due to prescription charges.
- 1 in 5 people with MS¹³ say they don't have enough money to pay for the medication or treatment they need.

We also hear from organisations representing pharmacists¹⁴ who are members of the coalition that as community based professionals they are frequently asked by their patients to advise which essential medication they can leave behind, as they can't afford it.

A YouGov poll conducted in October 2022¹⁵ showed that 90% of the British population support scrapping prescription charges for those with long term health conditions. The YouGov poll also showed that a quarter of respondents (27%) shared that they had either delayed collecting their prescription or not picked it up because of cost. And two-thirds of respondents (68%) shared that not collecting or delaying their medication had affected their physical health.

¹⁰ Healthwatch England. Cost of living research - <https://www.healthwatch.co.uk/news/2023-01-09/cost-living-people-are-increasingly-avoiding-nhs-appointments-and-prescriptions>; January 2023

¹¹ Asthma and Lung UK. Cost of living research - <https://www.asthmaandlung.org.uk/cost-of-living-crisis-1-in-5-people-with-asthma-surveyed-say-price-hikes-causing-asthma-attacks-as-they-cut-back-on-life-saving-medicine-food-and-electricity/>; September 2022

¹² Cystic Fibrosis Trust.. The Cost of cystic fibrosis 2022 - <https://www.cysticfibrosis.org.uk/news/1-in-3-people-with-cystic-fibrosis-miss-critical-hospital-appointments-due-to-cost-says-cystic>; June 2022

¹³ MS Society. Reduced to breaking point - <https://www.mssociety.org.uk/get-involved/campaign-us/ms-enough/breakingpoint>; September 2022

¹⁴ Royal Pharmaceutical Society.. Cost of living impacts access to prescription medicines - <https://www.rpharms.com/about-us/news/details/the-cost-of-living-impacts-access-to-prescription-medicines-says-rps>; February 2023

¹⁵ YouGov prescription charges poll, October 2022

“I take a lot of different medications at the moment, and have not had to factor this into my weekly budget at all. It’s unbelievable to me that there are people in the UK who need to pay for their essential prescriptions.”

Survey respondent from Scotland

Medicine adherence

30% of respondents report either occasionally or often missing, or taking a lower dose of their medication. Of this group, 37% state they forget to take their medicine, while 32% say the ‘cost of prescription’ is why they don’t take their medicine as prescribed.

64% state that they would either be more likely to or almost always take medicine as prescribed if prescriptions were free.

“I got used to spacing them out to save money and now I struggle to take them every day.”

“Sometimes I skip meals which is currently why I sometimes skip medication but for many, many years (i.e. when I wasn’t exempt) I would purposely skip taking my medication to save money.”

The effects of non-adherence

Almost a third (30%) of those who have missed medication now have other physical health problems in addition to their original health condition.

35% have had to visit their GP as a result of worsening physical health and 26% had to seek treatment either via a visit to Accident & Emergency or a longer term hospital visit.

37% of those who have been unable to collect prescriptions due to cost, report having other mental health problems in the last year. And as a result 23% have had to see their GP due to their worsening mental health in this period.

53% of this group have had to take time off work due to missing some medication and this has slightly increased (50%) since our 2017 survey. However when looking at only those respondents who live with Crohn’s or Colitis, this increases to 57%.

The reasons for requiring hospital treatment vary due to the respondents’ health conditions, but many had to stay in hospital for a week or more and in some instances, five or six weeks’ stay were required.

Not enabling people to access prescription medication could be costing the NHS and our economy more. The average cost to a NHS surgery for a 9 minute GP appointment is £42. While an outpatient appointment costs the NHS around £235¹⁶.

The average cost of to the NHS of a person attending A&E in 2021/22 can range from £77 to £359

¹⁶ University of Kent, Personal Social Services Unit. Unit Costs of Health and Social Care 2022 - <https://www.pssru.ac.uk/unitcostsreport/>; 2022

depending on the type of service they attend and investigations that are required¹⁷.

Data from Age UK¹⁸ shows the average excess bed day in the NHS costs between £2,089 and £2,532 a week for non-elective and elective inpatients. While these costs may not all be current, they clearly outweigh the burden of prescription charges.

For instance, taking the example of the individual who had to stay in hospital for five weeks - this admission would have cost the NHS over £10,000 in bed costs alone, without even adding any further costs for investigations or tests. In contrast, the cost of prescriptions is tiny and could keep more people well and out of hospital.

Some respondents directly attributed the need for hospital treatment to missed medication, which led to worsening symptoms or an “escalation of the condition” as one respondent shared.

“I was spending up to £70 per month on medication as they were being prescribed individually... it got to the point I simply couldn't afford it and that resulted in a 7 day hospital admission.”

“I couldn't afford to pay for my iron chelation tablets as it's really expensive to pay for it every month. I was ashamed to admit this to my thalassaemia team because I don't want them to know I couldn't afford it.”

Prescription charges costing the NHS

Research published in 2018 by York Health Economic Consortium¹⁹ highlighted how ending prescription charges for long term conditions could save money and reduce pressure on the NHS. This comes from preventing avoidable health complications that occur when people do not take their medication.

The research identified net savings of more than £20m per year if the NHS scrapped prescription charges for people with Parkinson's and inflammatory bowel disease (IBD) alone. Savings arise from:

- 9% fewer A&E visits for people with Parkinson's
- 11.4% less hospital admissions for people with Parkinson's
- 7,149 less flares for IBD
- 3,887 fewer GP visits for people with Crohn's.

While prescription charges generate around £650m a year in 2021/22, this research indicates that greater savings would be gained from removing the significant financial disincentives to taking prescribed medication.

¹⁷ The King's Fund, Key facts and figures about the NHS -

<https://www.kingsfund.org.uk/audio-video/key-facts-figures-nhs>; January 2022

¹⁸ Age UK. Four million hospital bed days lost since 2011 due to problems securing social care -

<https://www.ageuk.org.uk/latest-press/articles/2017/october/four-million-hospital-bed-days-lost-since-2011-due-to-problems-securing-social-care/>; 2017

¹⁹ York Health Economics Consortium. Economic evaluation of the benefits of extending free prescriptions to people with long term conditions -

https://www.parkinsons.org.uk/sites/default/files/2018-05/York%20report%20May%202018%20-%20final_0.pdf; 2018

Case study

Taking medication as prescribed is also associated with cost-savings for the NHS. For example, Atrial Fibrillation (AF) increases your risk of stroke by around 5 times and affects around 1.2 million people in the UK. Once AF is detected, the risk of stroke can be reduced by two-thirds with anticoagulation medication. Moreover, evidence suggests that *'for every 25 people diagnosed with AF and appropriately treated with anticoagulation, one stroke is prevented, saving an average of £46,039 per stroke in health and social care costs over 5 years'*.²⁰

Duration of prescriptions

Around a third (35%) of survey respondents have had the duration of their prescription changed.

The most common adjustment is reducing prescriptions that cover two or three months down to one month. Respondents were concerned that these changes have increased their medication costs, as they are purchasing smaller amounts more often, and/or the indirect costs associated with travelling to a pharmacy more frequently.

We understand that medicine supply issues can impact more regular prescribing, so rather than give one person three month's worth of their medicines, prescribers give three people one month's supply of medicine. Sadly that unfairly punishes people who need their medicine, by tripling the cost, while also increasing revenue to the NHS.

"Initially, I think we were able to collect medication for two months at a time but now have to collect it monthly. This of course has further financial impact due to petrol costs."

"For one medication, I originally received three months at a time but it's now down to 28 days per prescription which has obviously trebled the cost for just one medication."

Over the counter medications

A minority (4%) of respondents also receive over-the-counter medications in their prescriptions, but for the vast majority (91%) these are paid for separately when needed.

²⁰ Xu XM, Vestesson E, Paley L, et al. The economic burden of stroke care in England, Wales and Northern Ireland: Using a national stroke register to estimate and report patient-level health economic outcomes in stroke. *Eur Stroke J* - <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5992739/>; 2018;3:82–91

4. Conclusions and recommendations

The findings of this latest survey demonstrate that charging working-age people with long term conditions for prescriptions is leading to self-rationing of medications. This, in turn, is leading to increased pressure on the NHS and poorer health outcomes for people whose ability to access health and care services has been detrimentally impacted because of the pandemic and the increased need to purchase other medicines over the counter to stay well.

The survey shows a slight increase in the number of people who have taken time off work due to being unable to afford to collect their medicine. This seems to be at odds with the UK Government's intention to make work more inclusive and accessible through the implementation of the National Disability Strategy²¹ and is particularly concerning.

Therefore the Prescription Charges Coalition recommends the UK Government takes the actions below to enable people with long term health conditions in England to collect the vital medication they need to stay well:

- Commit to freezing the charge for 2024.
- Recommend that prescribers stop reducing the duration of prescriptions - as this prices people out of affording their vital medicines.
- Conducts an independent review of the prescription charge exemption list urgently. The review should examine the benefits to the health of the citizens in Northern Ireland, Scotland and Wales of scrapping the charge, and also take into account health inequalities.
- Scrap their plans to align prescription charges with the state pension age.
- Ensure information about prescription charge entitlements (including the low income scheme and PPCs) are provided to all those with long term conditions when they are diagnosed with their condition. This information should also be given out when medicines are dispensed and reviewed. Materials covering these topics should also be displayed at all GP surgeries and pharmacies.

Prescription Charge Coalition member organisations:

Allergy UK, Anaphylaxis Campaign, Antiphospholipid Syndrome support, Asthma and Lung UK, Behcets UK, British Liver Trust, Children's Liver Disease Foundation, Chronic Granulomatous Disorder (CGD) Society, Crohn's and Colitis UK, Cystic Fibrosis Trust, Daisy Network, Disability Rights UK, Drug and Therapeutics Bulletin, Fibromyalgia Action UK, Genetic Alliance UK, Gene People, Hibbs Lupus Trust, Hypermobility Syndromes Association, Immunodeficiency UK, Kidney Care UK, Klinefelter's Syndrome Association, Lupus Trust, Lupus UK, Migraine Trust, Motor Neurone Disease Association, MS Society, Multiple System Atrophy Trust, Muscular Dystrophy UK, Myositis UK, National Axial Spondyloarthritis Society, National Pharmacy Association, National Rheumatoid Arthritis Society, Parkinson's UK, Patient Association, Pernicious Anaemia Society, The Pharmacists' Defence Association, PSC Support (Primary sclerosing cholangitis), Rethink Mental Illness, Royal Pharmaceutical Society, Royal College of General Practitioners, Scleroderma & Raynaud's UK (SRUK), SHINE, Shwachman Diamond Syndrome UK, Sickle Cell Intervention, Sickle Cell Society, Spinal Injuries Association (SIA), Spotlight YOPD, Stroke Association, Turner Syndrome Support Society, UK Thalassaemia Society

The Coalition is currently chaired by Parkinson's UK.

²¹ UK Government. National Disability Strategy - <https://www.gov.uk/government/publications/national-disability-strategy>; 2022