



# Still Paying the Price

## Prescription Charges and People with Long-Term Conditions

A report by the Prescription Charges Coalition

June 2017

[www.prescriptionchargescoalition.org.uk](http://www.prescriptionchargescoalition.org.uk)

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**“I balance food, prescription costs and energy. No point eating on a day when I don’t have the medication to stop me being sick.”**

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## **THE PRESCRIPTION CHARGES COALITION**

The Prescription Charges Coalition brings together more than 40 organisations<sup>1</sup> concerned with the impact that prescription charges are having on working-age people with long-term conditions in England.

Previous research undertaken by the Coalition demonstrated that prescription charges have a significant negative impact on medicine adherence, self-management, quality of life and health outcomes for people with long-term conditions<sup>2</sup>, with knock-on effects on their ability to secure and retain suitable employment<sup>3</sup>. Our latest research builds on this evidence and shows that working-age people with long-term conditions in England continue to suffer as a result of an outdated system that urgently needs reform. Our recommendations for the Government are set out in Section 9.

### **KEY FINDINGS:**

Among those living in England with long-term conditions paying for their prescriptions:

- 88% require on average two or more prescription items per month.
- 33% have not collected a prescription due to the cost.
- 30% sometimes or often skip or reduce their recommended doses of medication. Of these, 43% cite the cost of their prescription as a reason for doing so.
- 59% of those who skip or reduce their doses have experienced negative health outcomes as a result. Of these, 50% report having to take time off work as a result.
- 34% of those who skip or reduce their doses have required additional medical treatment (such as GP or hospital appointments) as a result of doing so.
- The Prescription Prepayment Certificate remains under-publicised, with 40% of those who are aware of it having waited more than a year after diagnosis to be told and only 8% learning about it from their GP or consultant.
- Qualitative responses reveal that prescription charges are having a detrimental impact on respondents’ health, finances and quality of life and inspire a strong sense of injustice in light of the exemptions that are available for other conditions and in other parts of the UK.

## 1. INTRODUCTION AND CONTEXT

England is now the only part of the UK that charges for prescriptions, with charges 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 persists in modified form today. The charge itself has risen every year but one since 1979, increasing from 20p to the current level of £8.60 per item during that time.

Around 90% of prescriptions in England are currently dispensed without charge, but the majority of the remainder are paid for by working-age people with long-term conditions. While certain medical 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<sup>4</sup> has not changed since 1968, despite the lack of any clear underlying rationale. As a result, most people with a long-term condition who are diagnosed at a young age can expect to pay for their prescription medications throughout their entire working lives.

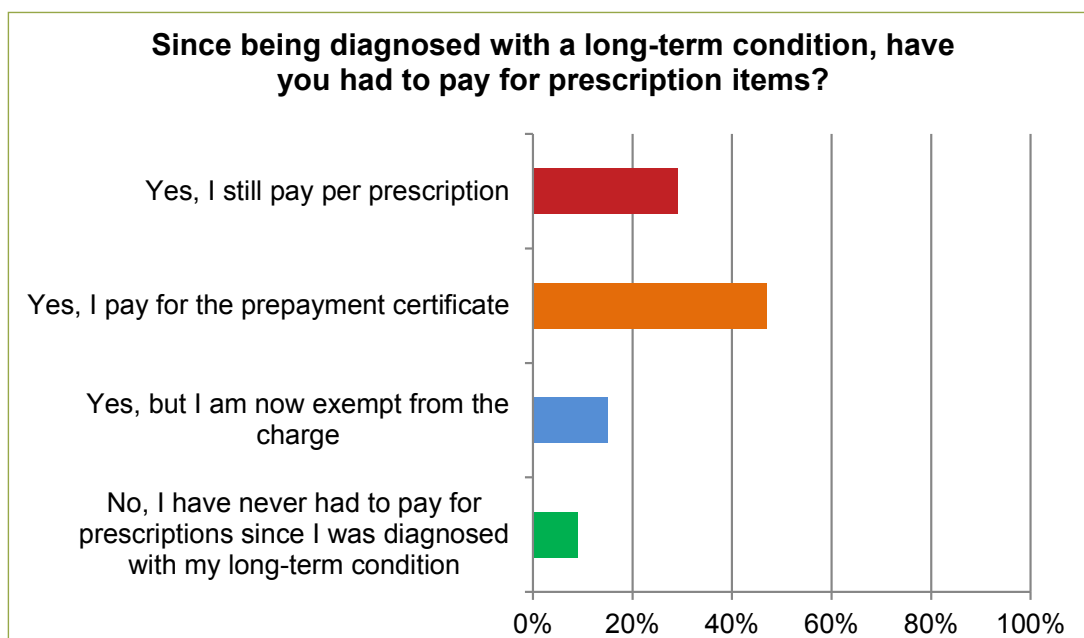
## 2. METHODOLOGY

The survey ran online for nine weeks from 3 March to 7 May 2017. It was advertised through the website, email list and Twitter account of the Prescription Charges Coalition, as well as the websites, Facebook pages, Twitter accounts and newsletters of member organisations.

6,196 individuals completed the survey. Of these, 584 were excluded on the basis that they either (a) lived outside England, (b) did not have (or did not know whether they had) a long-term condition or (c) had never been prescribed medication for their long-term condition. That left a sample size of 5,612 people living in England with long-term conditions requiring medication, which was used as the basis for Section 3 below. For the purposes of Sections 4 to 8, a further 1,348 people were excluded on the basis of being exempt from prescription charges, leaving a sample size of 4,264 people living in England with a long-term condition and paying for prescribed medications.

## 3. PAYING FOR PRESCRIPTIONS

Out of 5,612 respondents living in England with a long-term condition requiring medication, 76% (4,264) are currently paying for their prescriptions, with 29% doing so on a per-item basis.

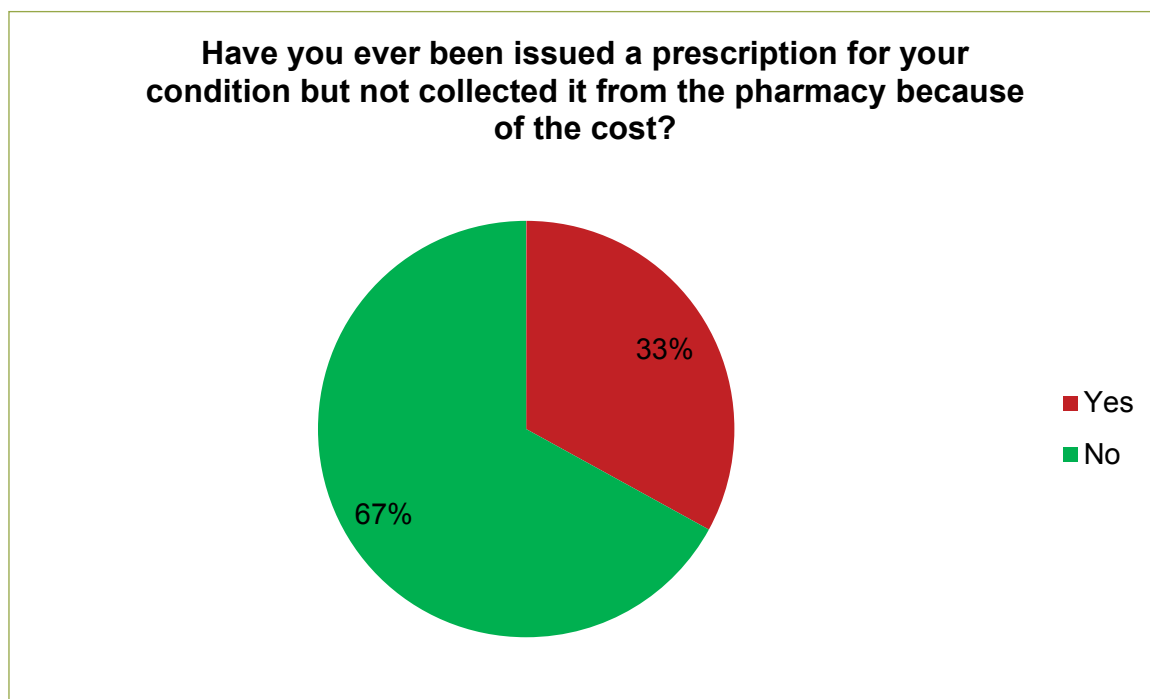


Among the 5,081 respondents aged 16 to 59, the percentage paying for medication rises to 84% (4,245). Only 7% (390) of this group currently hold a medical exemption certificate.

## 4. MEDICINE ADHERENCE

### A. RATES OF NON-ADHERENCE

33% (1,386) of people with long-term conditions who pay for their prescriptions stated that they had previously not collected a prescription from the pharmacy due to the cost.



Asked about their current habits relating to taking medication as prescribed, 30% (1,290) of those who pay admitted to sometimes, or often, missing or reducing their dose.

*"If I'm running low and can't afford to renew my prescription before pay day I'll take a lowered dose until I can pick up my prescription."*

Among those who missed or reduced their doses, 43% (551) gave "the cost of the prescription" as a reason for doing this. 44% (567) stated that not paying for prescriptions "would definitely make a difference" in encouraging them to take their medications as prescribed, while a further 31% (400) stated that it "might make a difference".

*"I am stressed all the time about not having enough money and regularly have to make choices about whether I eat, heat my home or fill my prescriptions as well as all the other costs involved in just living."*

49% (631) of those who reported rationing their medication in this way were working full-time and 68% (865) were not in receipt of any state benefits. This indicates that prescription costs can easily become unaffordable for those with long-term conditions, even when their condition does not prevent them from working.

One reason for this is that medication is just one of a range of additional costs that those with long-term conditions are likely to face, on top of adjustments to their home, physical aids, changes to diet and additional over-the-counter treatments.

“I find that I struggle to buy food that week if I have to buy a prescription... I follow a gluten free diet due to my condition and the GF food is so expensive.”

“I also have to pay for my own high factor suncream, eye tests for retinal damage, frequent dental appointments and hygienists, makeup to cover up rashes on my face...”

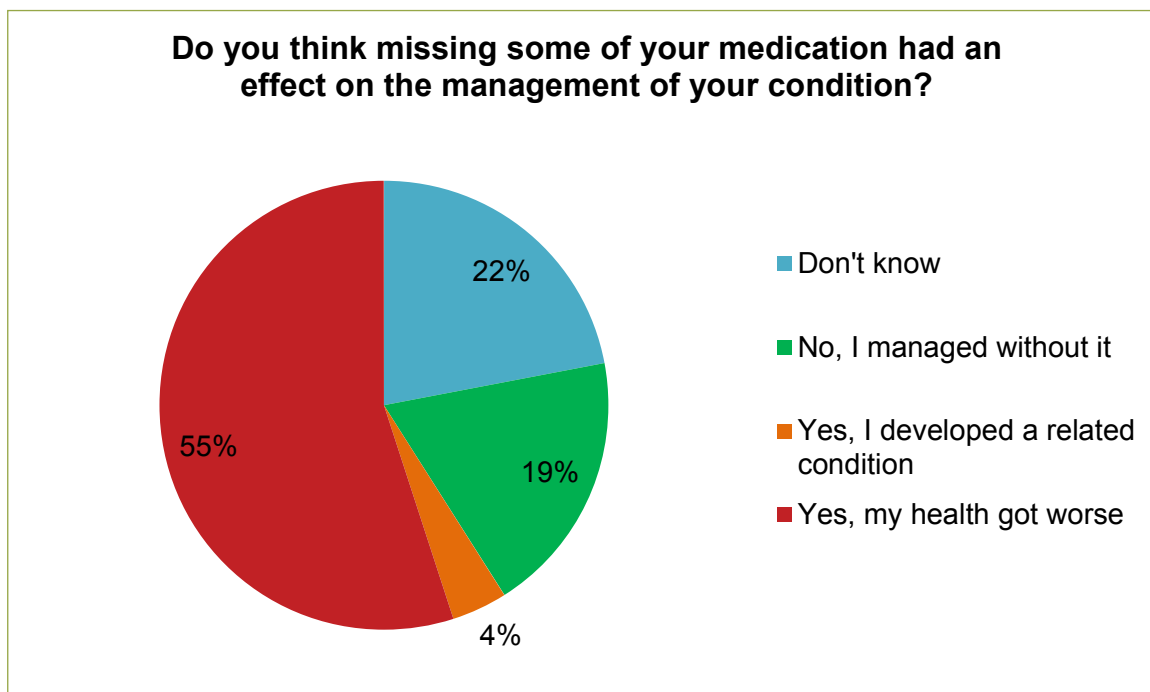
Among those whose condition limits their ability to work, more sacrifices may be required in order to afford medication.

“I moved back to my parents’ to be able to afford living costs, including keeping up with prescription costs, since my condition affects my ability to work – I have only ever been able to work part-time since having my condition.”

## B. THE EFFECTS OF NON-ADHERENCE

59% (759) of those who reported reducing or skipping doses of their medication stated that either their health had deteriorated or they had developed a related condition as a result.

“I have had to go without antidepressants, which had an awful effect on my mental health, which in turn had an effect on my physical health.”



Among those who experienced negative health outcomes as a result of reducing or skipping doses of their medication, 50% (375) had taken time off work as a result.

“I have a mortgage and kids to feed so I just go without pain relief. It makes me tired and less able to do things. My pain affects my work and I’ve had warnings for sick leave.”

26% (329) of those who report reducing or skipping their doses had required a doctor’s appointment, with a further 9% (114) requiring hospital treatment. Overall, 34% (443) of those not adhering to their medication regime had required additional medical treatment as a result.

“I was 19 at the time and couldn’t afford my medication for asthma. [I] ended up collapsing at work and [an] ambulance was called and I was in hospital for a week. I stopped breathing and my heart stopped all because I had to pay for my asthmatic medication.”

## 5. THE PRESCRIPTION PREPAYMENT CERTIFICATE

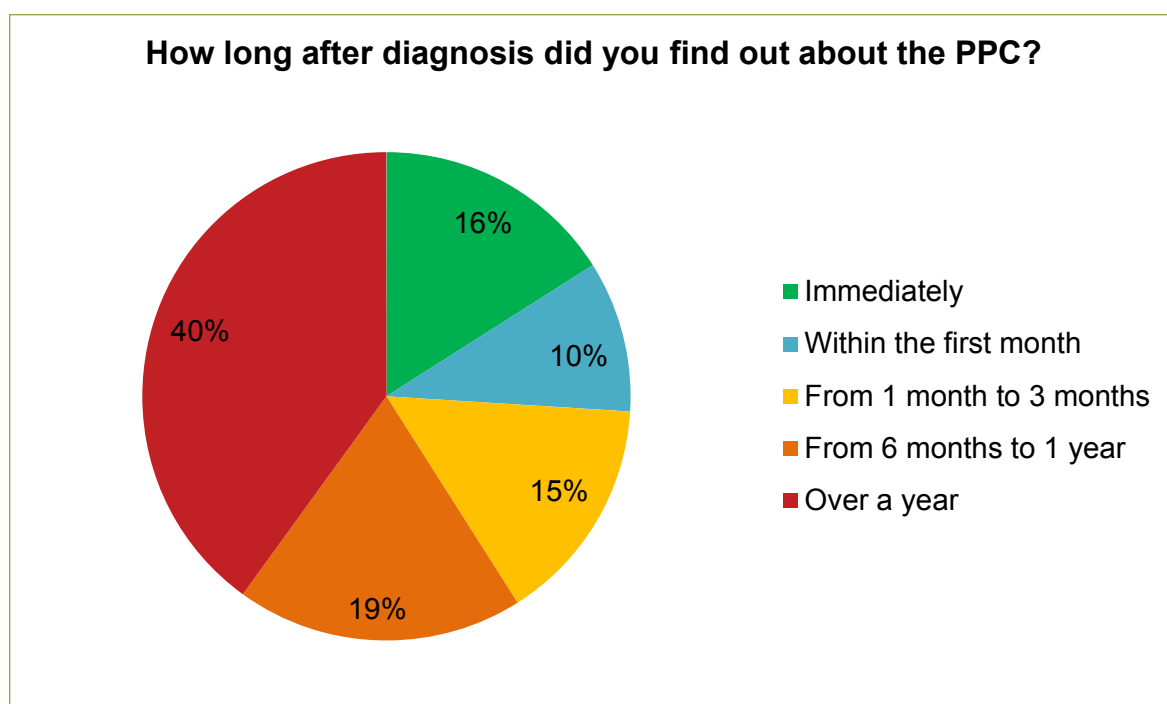
### A. AWARENESS

The Prescription Prepayment Certificate (PPC), which covers all prescriptions for the period the certificate is valid, costs £29.10 for three months or £104 for 12 months. People using the scheme can save money if they need more than three prescriptions in three months or more than 12 in 12 months.

88% (3,746) of those paying for their prescriptions reported having, on average, two or more items on their prescription each month (meaning they could potentially benefit from a PPC). However, only 65% (2,565) of those paying for prescriptions currently have a PPC.

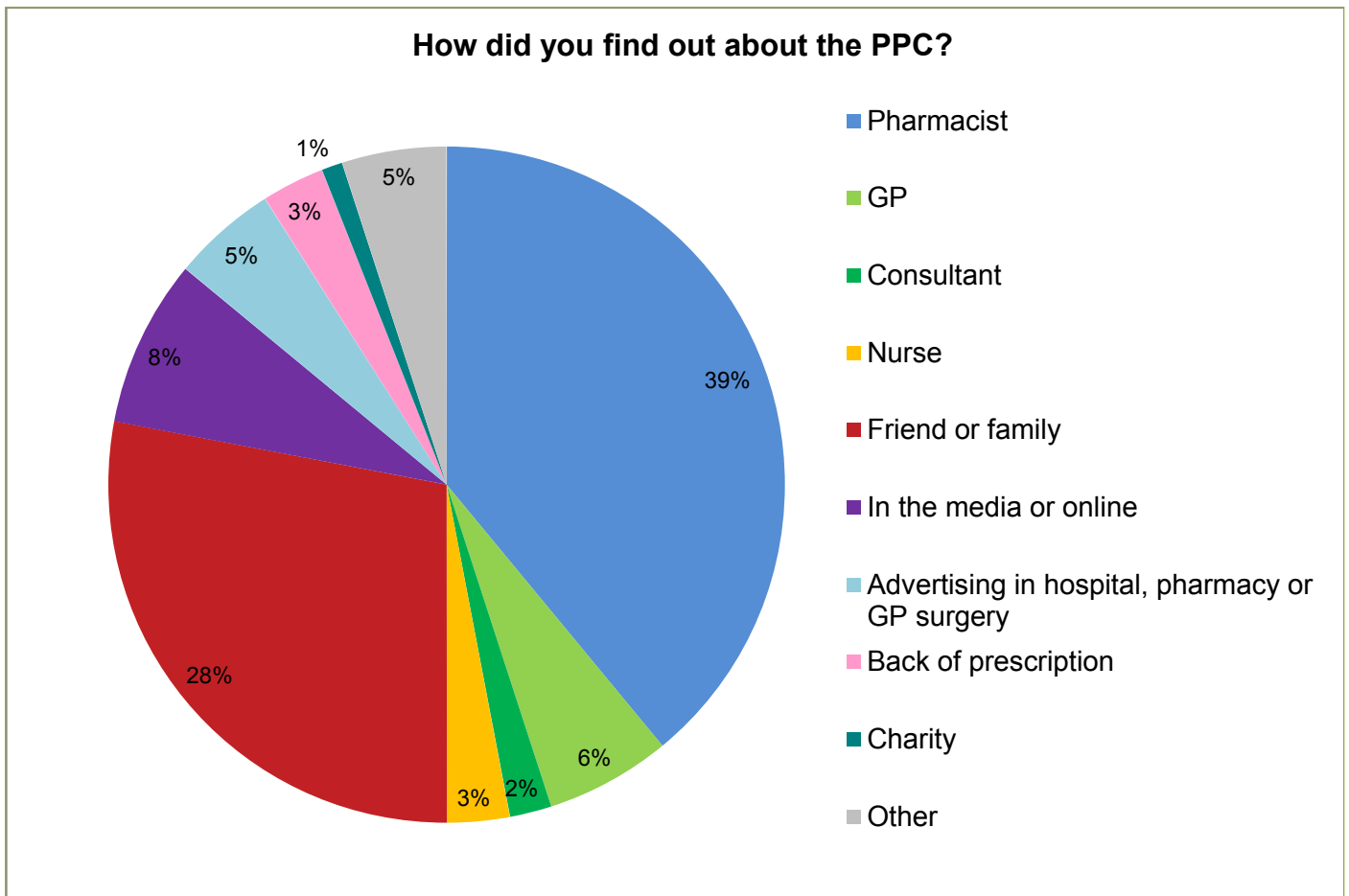
Among respondents who reported paying for prescriptions on a per-item basis, 20% (320) were not aware of the PPC.

Among respondents who pay for prescriptions and have, or are aware of, the PPC, only 16% (615) found out about it immediately upon diagnosis. 40% (1,578) waited more than a year before learning of the scheme.



“I have had my condition for 20 years and only found out about the pre-pay certificate around 3 years ago. Having to pay for individual prescriptions meant I wouldn’t use my medication every time I became ill with a migraine as I knew each tablet was costing me money, and I couldn’t afford to take as many as I needed.”

Only 6% (253) of those who had, or were aware of, the PPC found out about it from their GP, with a further 2% (83) finding out from their consultant. This is far fewer combined than the 28% (1,108) who found out from friends or family.



## B. UNDERSTANDING

Among respondents who pay for prescriptions and are aware of the PPC but do not currently have one, 25% (343) said they were not sure if having a PPC was worth it.

However, of those who said they were not sure if a PPC was worth the money, 82% (279) reported requiring two or more prescription items per month – enough to potentially benefit from a PPC. This indicates that understanding of the benefits of the PPC remains low. Free text responses also indicate that many people remain unaware of the direct debit payment option for the annual PPC.

“The prepayment certificate is not advertised/clear enough, especially the direct debit, and the possibility of a short term. It should be mentioned to everyone for 3 meds or more, even if only once.”

## C. AFFORDABILITY

Of those respondents who pay for prescriptions and are aware of the PPC but do not currently have one, 27% (363) said they could not afford one.

39% (157) of those who could not afford a PPC were working full-time and 63% (252) were not in receipt of any state benefits, indicating that cost may be an issue across the board, irrespective of employment or benefits status. As discussed above, this may be partly due to the additional costs associated with having a long-term condition. Respondents also discussed their fears of being unable to afford the PPC while on statutory sick pay or if emergency expenses arose.

“Even paying the PPC charge leaves me short each month. I’ve had to walk places instead of drive and I’ve had to miss out on socialising with friends as I have to prioritise with my medication. This is the only way I can attempt to stay in work. If I didn’t have my medication I would not be able to work, costing a lot to the state to take care of me financially.”

“I can’t afford the up front cost of a prepay certificate so have to scrimp together the pennies for prescriptions as and when I can.”

Many respondents noted that the PPC may not be an economical option for them due to the difficulty of forecasting medication needs for conditions that fluctuate and may go into remission or flare unpredictably. Someone who requires only one item per month during a period of remission but multiple items during a flare up may find themselves overspending on a PPC during periods when their condition is under control. If they decide not to purchase a PPC on this basis, they may face the sudden cost of multiple prescriptions if an unexpected flare-up occurs. This makes the prepayment scheme inappropriate for a significant proportion of those with long-term conditions.

“I do not use prepaid prescription certificates because I never know how much money I will need to spend on my medicine – my condition fluctuates so much that I could end up losing or saving money, and there is no way to predict this.”

## 6. THE NHS LOW INCOME SCHEME

The NHS Low Income Scheme provides help with a range of health costs on a means-tested basis, including free prescriptions for those found eligible. Individuals need to apply to the NHS Business Services Authority, giving details of their circumstances on Form HC1.

Our survey found low awareness of the NHS Low Income Scheme, with 79% (3,368) of those who pay for their prescriptions saying they were not aware of it.

Among those who pay for prescriptions and were aware of the scheme, 84% (751) had not applied. 21% (161) of that group said they had not applied because they did not know whether or not they would be eligible.

“I don’t think that the prepayment card is advertised enough and up until completing this survey had not heard of [the] NHS low income scheme.”



## 7. LOW-COST MEDICATIONS

One argument that is sometimes made against extending prescription charge exemptions is that it will lead to a rise in people obtaining low-cost over-the-counter medications for free on prescription, creating additional costs for the NHS. We asked respondents about their behaviours and intentions with respect to obtaining low-cost medicines like paracetamol, ibuprofen and aspirin.

Among respondents who currently pay for their prescriptions, 78% (3,335) said they would continue to buy these low-cost medicines over-the-counter if exempt from prescription charges, with a further 9% (383) stating that they do not require such medications.

Among those currently exempt from prescription charges, 69% (807) said they still pay for these low-cost medicines over-the-counter, with a further 9% (104) stating that they do not use such medications. This indicates that the risk of prescription charge exemptions being used to obtain low-cost medicines for free is significantly lower than has been suggested. This is also evidenced by research conducted after prescription charges were abolished in Wales, which found that there was no notable effect on the amount of over-the-counter medication prescribed or sold in Wales.<sup>5</sup>

## 8. INEQUALITY

Throughout the survey, unfairness and inequality were key themes emerging from respondents' free text responses. There were three aspects of the system that respondents highlighted in particular.

### A. PAYING FOR HEALTH

Respondents viewed it as unfair that being diagnosed with a long-term condition meant a lifetime of medication costs just to stay alive and well.

“I have had to pay for prescriptions for over 30 years which I find both unfair and a financial drain. It is a tax on illness.”

“I think the system is very unfair and penalises people who through no fault of their own have to live with chronic conditions and have to pay for treatment.”

“It's very expensive to pay for something to help me breathe when others can take this for granted. I prioritise this cost in budgeting of course because I literally can't live without it.”

### B. DISCRIMINATION BETWEEN CONDITIONS

Respondents viewed it as discriminatory that certain conditions were exempt while others weren't, and expressed frustration at the lack of any underlying rationale for these distinctions. In this respect respondents echoed the thoughts of the House of Commons Health Select Committee, which in 2006 stated that “there are no comprehensible underlying principles” to the system of prescription charge exemptions.<sup>6</sup>

“When you need medication for the rest of your life because you have a condition they can't cure, it seems really unfair when other conditions are given free prescriptions.”

“I believe that the current rules are ridiculous. For example, I am not entitled to free prescriptions even though I am on multiple medications for the rest of my

life and have severe respiratory and mobility issues and suppressed immunity and simply cannot work. An acquaintance is able to hold down two jobs and receives free prescriptions because they are eligible due to having a thyroid problem. I don't begrudge that thyroid problems are included, I appreciate that their medication is required for life. I am on corticosteroids every day for the rest of my life. Why is there discrimination? Steroids mean I have to have all sorts of other meds to counteract their side effects and prevents me from ever having a normal life ever again!!! Yet I must pay. The system is unfair and unjust!"

"I feel that it is unfair that my condition is not considered equally to other conditions that are exempt. Lupus can be fatal and my medications are a necessity not a desired item. This needs to change. I didn't ask to be put on this medication. My life depends on it."

"I do find it unfair that if you have a lifelong condition such as hypothyroidism, you automatically get exemption, regardless of income. My condition is genetic and my symptoms are now lifelong. There should be no discrimination."

### **C. NATIONAL DIFFERENCES**

As noted above, prescription charges have been abolished in every other part of the UK. As a result, respondents felt they were being treated unequally compared to their fellow citizens in Wales, Scotland and Northern Ireland.

"Moving from Scotland to England was a big shock. My budget was already very carefully managed in Scotland to make it stretch but adding in the price of paying for medication too has meant having to give up private physio which makes my condition worse which means I need more meds which exacerbates my GI symptoms which means I need more meds..."

"I have had to give up a lot in my life since I became too ill to work, and it seems very unfair to me that I have to pay financially too, especially since people in Scotland currently do not have to pay for any of their prescriptions."

"It really infuriates me that people with chronic, long-term health conditions like myself have to pay for our prescriptions yet those in Scotland and Wales get theirs for free. I class this as extremely cruel and discriminatory."

## **9. CONCLUSION AND RECOMMENDATIONS**

The findings of this survey support earlier research<sup>7</sup> in demonstrating that charging working-age people with long-term conditions for prescriptions is leading to self-rationing of medications. This in turn leads to poor health outcomes and problems maintaining employment, which are likely to create losses to the economy through unemployment and increased pressure on the health and benefits systems.

## THE COST OF PRESCRIPTIONS

Prescription charges are a significant expense for working-age people with long-term conditions, having risen almost every year since 1979 (in most years well above inflation<sup>8</sup>). While the cost is likely to be felt most by those on the lowest incomes, even those working full-time report struggling with the cost. Many note the compounding issues of lower than average incomes and significant additional costs associated with managing a long-term condition. Where prescriptions are rationed as a result, some find themselves in spiralling situations where rationing medication leads to worsening health, time off work and even higher medication costs for recovery. This is in addition to the costs to society of emergency treatment, lost productivity, sick pay and medicines waste (due to ineffective use of dispensed medications that are being rationed).

Many also report experiencing significant stress and anxiety due to the fear of not being able to afford their medication, exacerbated by social isolation due to prioritising medication over the costs of going out. Where people with long-term conditions are managing to afford their medication and avoid rationing, this is often at the cost of other essentials that are important to the management of their condition – such as an adequate diet or heating their home.

## AN UNEQUAL AND OUTDATED SYSTEM

It is clear that the medical exemption criteria are arbitrary, out-of-date and inequitable. Life-threatening conditions requiring extensive medication regimes are omitted, with no rationale other than historical fact. People who have paid into the system through tax and national insurance find themselves spending thousands of pounds over a lifetime just to stay well, while those with other long-term conditions, or in other nations of the UK, benefit from complete exemption from prescription charges.

## PROBLEMS WITH THE PRESCRIPTION PREPAYMENT CERTIFICATE (PPC)

While the PPC affords some relief to many who are prescribed multiple medications and cannot afford to pay per item, it does not solve all of these problems. Respondents reported being unable to afford the initial outlay for either the three or 12 month certificate, with others stating that their financial situation was not stable enough to commit to a 10 month direct debit. Respondents whose conditions fluctuate can end up losing money by purchasing a PPC if they go into remission, with the result that many decide not to take the risk. Even among those who would definitely benefit, take up of the prescription prepayment certificate is lower than it should be due to lack of awareness of the scheme. Rather than being told about it by their doctors upon diagnosis, some patients are waiting years just to learn about the certificate from family and friends.

## RECOMMENDATION: PRESCRIPTION CHARGE EXEMPTION SHOULD BE EXTENDED TO ALL THOSE WITH A LONG-TERM CONDITION.

Professor Sir Ian Gilmore's Prescription Charges Review<sup>9</sup> proposed a broad-based definition of long-term condition, against which a person's doctor would assess their eligibility for a prescription charge exemption lasting three years (with an opportunity for renewal). We would support this approach, together with Professor Gilmore's suggestion to introduce the exemption in a managed fashion by gradually reducing the cost of the PPC.

## RECOMMENDATION: INFORMATION ABOUT PRESCRIPTION CHARGE ENTITLEMENTS SHOULD BE PROVIDED TO ALL THOSE WITH A LONG-TERM CONDITION AT DIAGNOSIS.

People with long-term conditions should be routinely informed upon diagnosis of any applicable prescription charge exemption, the PPC (including the option to pay for annual certificates by direct debit instalments) and the NHS Low Income Scheme. Such information should also be given when medicines are dispensed and reviewed. Leaflets and posters covering these topics should also be displayed at all GP surgeries and pharmacies.

Many thanks to all those who participated in the survey and contributed to the report coordinated by Parkinson's UK.



## References

<sup>1</sup>See <http://www.prescriptionchargescoalition.org.uk/coalition-members> for a full list of members.

<sup>2</sup>Paying the Price: Prescription Charges and People with Long-Term Conditions. Prescription Charges Coalition, 2013, [http://www.prescriptionchargescoalition.org.uk/uploads/1/2/7/5/12754304/paying\\_the\\_price\\_report.pdf](http://www.prescriptionchargescoalition.org.uk/uploads/1/2/7/5/12754304/paying_the_price_report.pdf)

<sup>3</sup>Paying the Price: Prescription Charges and Employment. Prescription Charges Coalition, 2014, [http://www.prescriptionchargescoalition.org.uk/uploads/1/2/7/5/12754304/prescription\\_charges\\_and\\_employment\\_report\\_feb\\_2014.pdf](http://www.prescriptionchargescoalition.org.uk/uploads/1/2/7/5/12754304/prescription_charges_and_employment_report_feb_2014.pdf)

<sup>4</sup>The full list of exemptions, including the medical exemption criteria, is set out on <http://www.prescriptionchargescoalition.org.uk/about-the-campaign>

<sup>5</sup>Helping to improve Wales' Health: Free Prescriptions Three Years On, Welsh Assembly Government, March 2010 <http://www.wales.nhs.uk/documents/prescriptions-report-three-years.pdf>

<sup>6</sup>House of Commons Health Select Committee: NHS Charges. July 2006, <http://www.publications.parliament.uk/pa/cm200506/cmselect/cmhealth/815/815-i.pdf>

<sup>7</sup>See Paying the Price (Note 2 above), in particular 'Evidence of the Impact of Prescription Charges'.

<sup>8</sup>See Paying the Price (Note 2 above), in particular 'The History of Prescription Charges'.

<sup>9</sup>Prescription Charges Review: Implementing Exemption from Prescription Charges for People with Long Term Conditions, Professor Sir Ian Gilmore, November 2009, [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213884/dh\\_116367.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213884/dh_116367.pdf)