The Prescription Charges Coalition

The Prescription Charges Coalition brings together more than 30 organisations concerned with the detrimental impact that prescription charges are having on people in England with long-term conditions who are of working age.  

www.prescriptionchargescoalition.org.uk

Introduction and Context

Prescriptions now only carry charges in England, where the system of exemptions, established in 1968 and largely unchanged today, is outdated, arbitrary and inequitable. Certain medical conditions entitle people to exemption from charges, but the majority do not. For those who are diagnosed with a long-term condition at a young age, this can mean paying for prescriptions on an ongoing basis throughout their working lives.

The Prescription Charges Coalition’s latest survey explores the impact of prescription charges on the working lives of people with long-term conditions. More than 5,000 people of working age, with a range of long-term conditions, completed the survey. The results are detailed more fully within this short report.

Key Findings

• Over one third of the total sample reported that the cost of their medication had prevented them from taking it as prescribed, reconfirming the significant impact that prescription charges have on medicine adherence and effective self-management

• Three quarters of those who said that they were not taking their medication as prescribed because of the cost reported that this had affected their ability to work; for 70% of these, this had included time taken off work

• Prescription charges have a detrimental impact on the working lives of people with long-term conditions at all income levels and of all ages, although this is greatest for those on the lowest incomes and for those who are younger.
The Impact of Prescription Charges

This survey builds on previous research undertaken by the Prescription Charges Coalition\(^2\), published in March 2013. This found that prescription charges had a significant, negative effect on medicine adherence, self-management, quality of life and health outcomes.

It also indicated a significant knock-on societal impact in terms of employment and productivity and additional costs to the NHS, for example, through emergency hospital admissions.

Employment for People with Long-Term Conditions

While many people with long-term conditions can and do work\(^3\), it is well-documented that long-term conditions can have a negative effect on educational attainment and working life, including career opportunities and choices, aspirations and premature retirement.\(^4\)

In addition to improving productivity, enabling people with long-term conditions to enjoy “good work” can improve quality of life and well-being, reduce poverty and lead to better health outcomes.\(^5\) This is particularly important given the increase in co-morbidities and the high proportion of those with associated mental and physical health conditions.

Consequently, Government initiatives, such as the Health, Work and Wellbeing Initiative\(^6\), Health at work – an independent review of sickness absence\(^7\) and the Work Programme, aim to support more people with health conditions to stay in work or enter employment.

Against this context, and that of the current economic circumstances, we sought to explore the extent to which prescription charges impact on the working lives of those with long-term conditions.

Survey Findings

Methodology

The survey ran for five weeks between 6th January, and 10th February 2014. Prescription Charges Coalition members advertised the survey on their websites, Facebook and Twitter accounts. In total, 5,159 respondents participated in the survey. Of these, 777 were excluded because they responded that they did not pay for prescription charges and 179 because they did not have a long-term condition.

Overall Impact of Prescription Charges

Overall, 37% (1,519) of respondents reported that the cost of medication is prohibiting them from taking their medication as prescribed.

This reconfirms the results of earlier research by the Prescription Charges Coalition that the cost of prescription medication is a key barrier to adherence. Furthermore, this suggests that cost is a significant component of the national figure for medicine adherence, which is stated as being between 30-50\(^{\%}\).

<table>
<thead>
<tr>
<th>Has the cost of your medication prevented you from taking it as prescribed (e.g. not collecting items or taking smaller doses)?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Yes</td>
</tr>
<tr>
<td>No</td>
</tr>
</tbody>
</table>
Comments from respondents support previous findings that people with long-term conditions cut their pills in half to make them last over a longer period, reduce doses or only collect a proportion of the items prescribed by their doctor because of the cost:

“In the past, I have tried to make it last longer but then ended up in hospital with a flare up of Crohn’s as a result.”

“I have spread out painkillers that are used when needed - a bit more pain is more manageable than collecting more pills sometimes.”

“I have chopped a dose up to make it last longer.”

The survey also found that the impact of prescription charges as a barrier to collecting medicines was greatest for younger respondents, but affected those of all ages.

Impact of Prescription Charges on Employment

Our survey found that 77% (2,952) of respondents reported being in full or part time employment. Additionally, 74% (2,829) of all respondents did not receive any benefits. 74% (1,107) of those respondents that explained that the cost of prescription charges prevented them from taking it as prescribed reported that this has impacted on their ability to work in some way.

Some 54% (815) of these reported that their inability to take their medication had affected their performance at work. Another 32% (474) said they had found it difficult to get up, or motivate themselves to work. A further 21% (311) explained it had impacted their ability to travel to work, and 16% (236) said they had found it difficult to seek work, as a result of not taking their medication.

In free text responses, survey participants explained:

“I have had chest infections because I didn’t take all my inhalers. And the pain has been unbearable because of the arthritis. Sometimes I went to work but sat in a car park or motorway service station waiting for the flare up to hopefully calm down.”

“I have been skipping some of my medication so that it lasts longer. MS hurts me whatever I do, my medication stops the pain completely overwhelming me, I only work part time as it is, so force myself to do the few hours a week I do, although performance is hugely affected.”

72% (797) of those who reported that the cost of prescriptions prevented them from taking their medicine as prescribed said they had to take time off work as a result.

Around 41% (315) of these reported taking over 10 days off, and a further 18% (139) explained they had taken between six and ten days off because of not taking their medication as prescribed due to the cost.

Respondents provided further detail in their comments:

“I work for myself and am 50p over the free prescription threshold ...this means I am massively out of pocket and might as well be on the dole.”

“My depression meds help me to sleep which means I am able to stay awake during the day. Without them I sleep only a few hours a night and this can lead to me becoming overtired and, in turn, can cause migraines which then mean I can’t work.”

“I could not afford my prescription for an inhaler, therefore I had an asthma attack and ended up in hospital, so had to miss a few days work.”

“Making a conscious choice to stop taking medication because of the cost contributed to prolonged relapse of illness, resulting in four months off work.”
**Income/Cost Findings**

Survey findings revealed that there is a clear relationship between an individual's annual pre-tax income, and their ability to afford prescription medication. Accordingly, those on lower incomes are more likely not to take their medication as prescribed due to the cost. However, a proportion of respondents earning above average salaries, or with higher household incomes, also reported difficulties affording their prescription charges as those on the lowest incomes.

The Office for National Statistics states that the median gross income for the year ending April 2013 stood at £27,000. The responses to our survey indicate that the median gross income of participants is in the region of £20,000 per year, somewhat lower than the UK average. It should be noted that this question was optional, and 1,489 respondents chose not to answer.

44% (1,645) of all respondents did not have a Prescription Prepayment Certificate (PPC) of any length. However, 41% (678) of these collected between 14 and 17 items or more in the previous year, indicating that they could make a saving by purchasing a PPC.

34% (1,284) of all respondents told us that they were also paying prescription charges for other members of their family, including spouses and children.

**Lower incomes and prescription charges**

73% (2,688) of survey respondents reported individual, pre-tax incomes of under £25,000 per annum. Of the respondents in the lowest income band of £0-£4,999, 47% (305) reported cost as a barrier to collecting their medicines. For respondents that identified their earnings as falling between £5,000 and £15,000 a year; 45% (452) felt that cost had prevented them from collecting medicine. Finally, among participants who reported their salary as between £15,000-£24,999, 40% (416) said that cost was a barrier to collecting their medicine.

**Higher incomes and prescription charges**

Of the respondents who reported earning £25,000-£34,999 before tax annually, 30% (164) said the cost of medication had prevented them from taking it as prescribed. Among those respondents earning over £35,000 a year; 20% (88) reported that cost was an issue.

This trend is also seen in those reporting household incomes of £50,000-£70,000 and over. Of the total survey respondents that had a shared income of £50,000-£69,000 a year; 25% (117) reported cost as a barrier.

---

**How many days to date would you estimate you have taken off work as a result of not taking your medication as prescribed because of the cost of the prescription?**

<table>
<thead>
<tr>
<th>Days</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>More than 10 days</td>
<td>40%</td>
</tr>
<tr>
<td>6-10 days</td>
<td>18%</td>
</tr>
<tr>
<td>5 days</td>
<td>11%</td>
</tr>
<tr>
<td>4 days</td>
<td>8%</td>
</tr>
<tr>
<td>3 days</td>
<td>11%</td>
</tr>
<tr>
<td>2 days</td>
<td>9%</td>
</tr>
<tr>
<td>1 day</td>
<td>3%</td>
</tr>
</tbody>
</table>

[Graph showing distribution of days missed due to cost of prescription]
These findings suggest that a significant proportion of survey respondents are facing difficulties affording their prescriptions and managing the consequences of this on their health and working lives, despite not receiving any financial support from the Government.

Prioritisation

In free text responses, a strong theme of ‘prioritisation’ emerged, where people differentiated between paying for ‘essentials’ required for survival – such as heating, food, rent and essential medication, versus ‘coping’ medication, such as painkillers and preventative medicine.

“Money is very tight. I have to make sure my family have a roof over their head and food to eat. If it is close to pay day, I normally have to delay getting my prescription as I need to prioritise family, food and bills.”

“I had to go without my naproxen over Christmas as my GP only supplied one month’s worth in early November. I don’t earn a lot and overtime is hard to do so I couldn’t afford to pay for another prescription.”

“As a single parent, I have to struggle to pay for the medication that I need. I do not get any help or financial support and without my meds I will become ill and have to return to hospital. I feel that it’s a never ending struggle to stay well, and to look after a family.”

Conclusions and Recommendations

The findings of this survey support earlier research which demonstrates that the cost of prescriptions is leading to self-rationing of medication for people with long-term conditions of working age.

This is compounding the difficulties that people with long-term conditions face in securing and retaining suitable employment. Consequently, there is a significant impact on the individual’s quality of life and ability to manage their condition, which in turn affects health outcomes, societal costs and productivity. For those with multiple long-term conditions, the situation is more complicated still.

The cost of prescriptions is felt most by those with the lowest incomes, but those on higher incomes are also affected. This is in the context of incomes that are lower overall than in the general population due to the impact that long-term conditions can have on educational attainment and working life, including career opportunities and choices, aspirations and premature retirement, as described earlier. Additionally, there may be other health-related costs to find, such as travel and car parking for medical appointments and the need to pay for prescriptions for other members of the family.
Younger people are more likely to ration their medication. Rationing decisions were made on the basis of a number of factors, including putting other members of the family, such as children, first. Some respondents classified costs, including medication and household bills in terms either of “survival” or “coping” costs. They indicated that pain and preventative medication could fall into the latter category, even if this affected their ability to function and could lead to flare ups and potential hospital admission.

The impact of prescription charges has intensified where people have been moved from a prescription which would last them for several months to one which is only valid for 28 days. 28 day prescribing policies aim to reduce medicine waste, although this has been disputed by recently published research. For the individual requiring regular prescription medication, it has led to their costs being doubled, trebled, or more, literally overnight. The Prescription Prepayment Certificate continues to help for a proportion of those with long-term conditions, who are aware of this. However, the Prescription Prepayment Certificate remains a significant cost for individuals and is not always worthwhile for those with fluctuating or unpredictable conditions.

It is held that prescription charges raise valuable revenue for the NHS. However, the evidence from our surveys and previous research indicates that this may be outweighed by the costs to the NHS and society as a whole of continuing to charge people with long-term conditions in England for their prescriptions. The evidence suggests that removing this barrier to effective self-management of long-term conditions should lead to improved use of medicines and reduced costs to the NHS, to employers and to society. By enabling people with long-term conditions to manage their condition/s more effectively, prescription charge exemptions would enable them to be more productive and to participate more fully in all aspects of society.

**Recommendations**

**Key Recommendation:** Extend prescription charge exemption to all those with long-term conditions

This could be managed in a measured and cost-effective way through a staged reduction in the cost of the Prescription Prepayment Certificate until charges are phased out altogether, as recommended in the Prescription Charges Review, undertaken by Professor Sir Ian Gilmore.

**Recommendation:** The frequency and duration of prescriptions for people with stable, long-term conditions on long-term maintenance medication should be agreed between the prescriber and patient and allow for greater flexibility to prescribe for more than 28 days.

Reducing medicine waste could be best achieved by ensuring the most effective treatment is in place and medicines are optimised for the individual patient.

Our previous research found that 36% of respondents were unhappy with their schedule for repeat prescriptions, citing cost and inconvenience as the main reasons for this. Repeat dispensing schemes enabling a prescriber to issue a batch of up to six, monthly prescriptions, which can be held by a pharmacy of the patient’s choice, are already in place. However, they could be more effectively utilised, where identified to be appropriate for the patient, by linking the prescription charge to the prescriber’s repeat authorisation, so the patient pays one prescription charge for a batch of prescription items rather than for each prescription item.

This would mean that a patient with a stable, long-term condition collecting regular prescriptions from their pharmacist would only need to pay a single charge for up to six months of treatment. This is likely to increase medicine adherence by lowering the cost to the individual. It would also avoid unnecessary visits to GPs for a repeat prescription, while ensuring medicine use was under close review by a pharmacist.

While this would assist many patients with long-term conditions, it will not be appropriate for all. For example, many people with asthma, for whom a prescription may be significantly “stepped up” or “stepped down”, would not benefit from such a scheme. Additionally, prescription charges would continue to have an impact. Therefore, it does not remove the need for exemption, but could offer considerable benefits in the shorter term as a first step to achieving exemption from charges for all people with long-term conditions.
Recommendation: Information about prescription charge entitlements should be provided to people with long-term conditions at diagnosis

Information should be given routinely to people with long-term conditions about prescription charge exemptions, the Prescription Prepayment Certificate and NHS Low Income Scheme, at the point of diagnosis and when medicines are dispensed and reviewed. Information leaflets and posters should be displayed at all GP surgeries and pharmacies in addition to appropriate online platforms.

Employers and any agencies, including occupational health, assisting an employee’s return to work could also play a role in making this information available in workplaces and directly to employees or job-seekers with long-term conditions.

Recommendation: Any further changes to welfare benefits, for example, the introduction of Universal Credit, should take into account the ability of people with long-term conditions to afford their medication, as long as prescription charges remain in place for this section of the population.

Universal Credit will replace benefits which currently “passport” or automatically entitle people in receipt of those benefits to exemption from prescription charges. It is expected that an income or earnings threshold will operate to determine future entitlement. This will inevitably result in people suddenly having to start paying for medicine. This will be exacerbated when other health charges and support, such as free school meals, are also affected.

References

1 See www.prescriptionchargescoalition.org.uk/coalition-members.html for a list of members
2 Paying the Price: Prescription Charges and People with Long-Term Conditions, report accessible at www.prescriptionchargescoalition.org.uk/paying-the-price-report.html
4 For example, Life and Employment Opportunities of Young People with Chronic Conditions: Work Foundation, www.theworkfoundation.com
7 Health at Work – an independent review of sickness absence, Dame Carol Black and David Frost CBE, November 2011
8 Concordance, adherence and compliance in medicine taking Report for the National Co-ordinating Centre for NHS Service Delivery and Organisation R&D (NCCSDO), December 2005
Quotes From Survey Respondents

“Luckily, I have a supportive family and am able to continue working. However, having reduced my working hours due to ill health, I am then required to pay further towards maintaining my health in order to keep working. I am at a financial disadvantage compared with both my healthy co-workers and those on benefits and not working due to ill health.”

“I have to go without to get prescriptions but when my children need things then I have to go without my medication. I often cannot do both and so have to make a decision as to which should take priority. It does impact on my life because I then find it hard to deal with my pain and become more depressed which cannot be treated properly because it requires me to take medication on a regular basis in order to work.”

“I am only 20 years old and attended college for three years as I didn’t manage to complete my GCSE’s as I was seriously ill with Crohn’s Disease. When I reached 18, I was still a student and I had to struggle to pay for several different prescriptions. I found this difficult, having to borrow money from my family and was unable to do things with my peers because any money I had was to be spent differently than my friends and I became stressed. I am still on a very low wage as an apprentice. I am trying hard to work when I am ill and trying to get on with my life, but it is difficult when all my money goes on medication and sometimes I have to wait until I get paid.”

“I have £5.00 a month more than the Government says I need to live on so get no help with prescription charges. There is a choice between basic essentials or prescriptions. I have to forgo the prescription. There are the other costs to fund transport to appointments so there is no room for £10 a month direct debit for a pre-payment certificate and I certainly don’t have enough for the lump sum upfront for it.”

“I only work sixteen hours a week in a low paid job as a classroom assistant to be there for my son who has a chronic disease. We claim no benefits other than child allowance. My wages went down last year. My prescription charge doubled as I have to take more pills for high blood pressure.”

“I am unable to afford the cost of medication which has made me so ill I have had to take sick leave from work to recuperate - this is paid so I don’t lose financially although my employer loses manpower. I am not entitled to any benefits but the cost of living has meant I can either feed my child or pay for my prescription.”

“I only work part time on a self-employed basis due to my health. I receive no benefits but I do find it hard to find the current £104 per year to pay for my pre-payment certificate. I am wary of taking out a direct debit as I cannot guarantee that I will earn enough every month for this to be taken out of my account - some months I earn more than others.”

Many thanks to all those who participated in the survey and contributed to the report
Coordinated by Crohn’s and Colitis UK. Designed and printed by Cambridge Printers
February 2014