

## **Parkinson's UK policy statement**

### **Prescription charges**

*"My drugs are my lifeline. Without them I would have no movement at all – I would be sitting in my house, looking out the window - unable to dress, wash, cook. So I ask myself: 'Why should I have to pay?' "*

Evidence of person with Parkinson's

## **What we believe**

**Parkinson's UK believes that all people with Parkinson's and other long-term conditions should be exempt from prescription charges wherever they live in the UK.**

## **Why we believe this**

Parkinson's is a progressive condition, for which no cure currently exists. Medication is extremely important in helping people with Parkinson's manage their symptoms and continue to lead independent lives. Parkinson's UK is concerned that prescription charges act as a barrier to some individuals obtaining the medication they require. For people with Parkinson's this can lead to poor management of the condition and complications that may result in greater cost to health and social services.

### **The current situation**

Prescription charges were abolished in Wales in 2007, in Northern Ireland in 2010 and in Scotland in April 2011.

In England, a report written by Professor Ian Gilmore into prescription charges for people with long-term conditions was published in May 2010.<sup>1</sup> The new coalition government welcomed the report, but in the Autumn 2010 spending review the government said that free prescriptions for people with long-term conditions was not being considered. Thousands of younger people with Parkinson's in England could still face paying prescription charges for many years.

A list of conditions that qualify for exemption from prescription charges does exist in England but has barely changed since its creation in 1968, despite significant medical and technological changes.<sup>2</sup>

### **Younger people with Parkinson's**

Parkinson's UK is particularly concerned about the additional financial hardship prescription charges present for younger people with Parkinson's. The progressive nature of Parkinson's means that many people who develop the condition in their 30s, 40s or 50s need to leave paid employment before normal retirement age. As a person's condition progresses, their partner or other family members may also have to stop work to help care for them.

---

<sup>1</sup> Department of Health. *Prescription charges review: the Gilmore report* (2010)

[www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_116366](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_116366)

<sup>2</sup> See Appendix 1

When the income provided by the partner of a person with Parkinson's is combined with the individual's own benefits this can disqualify them from the NHS Low Income Scheme<sup>3</sup>, which entitles individuals to free prescriptions. Yet when financial commitments are fully accounted for, the resulting available family income is well below the threshold by which 'low income' is defined. Awareness of the scheme is also very low. The Prescription Charges Coalition's report 'Paying the Price' - which surveyed over 3,700 people with long-term conditions – found that 76% of respondents had not heard of the NHS Low Income Scheme.<sup>4</sup>

### The cost of Parkinson's

Additional costs associated with Parkinson's include increased travel costs, such as taxi fares and parking charges for hospital appointments, higher than average fuel bills due to additional heating and washing needs, and paying for respite care. Prescription charges are yet a further financial burden for those who do not fall within one of the exemption categories. With these costs in mind, even for those individuals who fall just outside of the low income threshold, prescription charges can present a significant financial challenge.

People with Parkinson's are often required to pay multiple prescription charges, due to the number of medications prescribed for the management of a wide range of motor and non-motor symptoms. This number inevitably increases as the condition progresses. Although pre-payment certificates (PPCs)<sup>5</sup> exist to reduce the costs of prescription charges for people who require multiple medications, many people with Parkinson's remain unaware of this scheme. In addition, Parkinson's UK has heard from many individuals, through our helpline and local support services, who are not able to afford the up-front costs of PPCs.

Although people in England are now able to pay for a twelve month PPC in ten monthly instalments by direct debit, this option is only available to people who have a bank account, which as a consequence will tend to exclude the most socially disadvantaged and potentially vulnerable individuals.

## What's the evidence?

Prescription charges have consistently been flagged up by our members as a key campaigning priority for Parkinson's UK.

### Numbers affected by prescription charges

Although many people with Parkinson's qualify for exemption<sup>6</sup> from these charges, there are still a very significant number who are having to pay for their prescriptions.

Using prevalence figures for people with Parkinson's<sup>7</sup>, we can estimate that there are approximately 7,124<sup>8</sup> people under the age of 60 in England with the condition who are

---

<sup>3</sup> See Appendix 1 for details of the exemption criteria for prescription charges across the UK, including the NHS Low Income Scheme.

<sup>4</sup> Prescription Charges Coalition *Paying the Price: Prescription Charges and people with Long-term Conditions* (2013)

<sup>5</sup> See Appendix 1

<sup>6</sup> See Appendix 1 for details of the exemption criteria for prescription charges across the UK.

<sup>7</sup> Parkinson's UK *Parkinson's prevalence in the United Kingdom 2009* (2012)

<sup>8</sup> The figure was reached as we know that 85% of people who have Parkinson's within the UK, live in England (see the above reference). The prevalence data from 2009 shows there are 8,381 people living with Parkinson's in the UK who are under the age of 60. Therefore, to estimate the number of people in England who are under the age of 60 with Parkinson's we calculated 85% of this figure, which comes to 7,124.

subject to paying prescription charges. A survey from 2008 revealed that 24% of people with Parkinson's under the age of 60 don't use, or are unaware of, pre-payment certificates.<sup>9</sup> This means that there could be as many as 1,710 people in England with Parkinson's paying substantially more for their prescriptions than necessary due to low awareness of this scheme.

### **A barrier to taking prescribed medication**

A poll conducted by Citizens Advice revealed that 800,000 people did not get a prescription dispensed in England in 2008 due to its cost.<sup>10</sup> Furthermore, the Prescription Charges Coalition's 'Paying the Price' report revealed that 35% of respondents who paid for each prescription have not collected at least one item due to the cost.<sup>11</sup> Three quarters of this group reported that their health got worse as a result and 10% said they ended up in hospital as a direct consequence of not taking their medication.

### **The financial burden of prescription charges**

Prescription charges present an additional burden to people with Parkinson's who are already struggling with the cost of living. A Parkinson's UK 2013 survey of 4,777 people showed that two in five (40%) respondents have seen their day-to-day bills increase due to their Parkinson's and a further one in five (20%) have to pay more insurance.<sup>12</sup> Charges are also likely to impact on the wider family, who may already be incurring financial loss as a result of giving up work early to care for the person with Parkinson's, as was revealed in the survey. Overall, almost as many of three-fifths (58%) were not working at all and nearly a quarter (23%) of those in paid employment have had to reduce their working hours in order to look after someone with Parkinson's. Furthermore, a similar proportion who were not in full or part-time employment at the time of the survey had to give up working due to caring responsibilities (23%).

## **What Parkinson's UK is doing**

In England we are campaigning with the Prescription Charges Coalition to ensure people with all long-term conditions – including Parkinson's – are exempt from prescription charges, wherever they live in the UK. We are also working to raise awareness of the PPC, which reduce the costs of prescription charges for people who require multiple medications.

In the devolved nations that have abolished prescription charges, we will work to make sure that people with Parkinson's and other long term conditions continue to be exempt from prescription charges.

## **Acknowledgement**

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on prescription charges. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

---

<sup>9</sup> Parkinson's UK *Life with Parkinson's today – room for improvement* (2008)

<sup>10</sup> IPSOS Mori Poll commissioned by Citizens Advice conducted in January 2008.

<sup>11</sup> Prescription Charges Coalition *Paying the Price: Prescription Charges and people with Long-term Conditions* (2013)

<sup>12</sup> Parkinson's UK *Survey of people with Parkinson's and their friends, family and carers* (2013)

## **Further information**

Please contact the Policy and Service Improvement team. Tel: 020 7932 1325 or email: [campaigns@parkinsons.org.uk](mailto:campaigns@parkinsons.org.uk)

**Parkinson's UK April 2014**  
Review date: February 2017

## Appendix 1 – Prescription charges exemption criteria

Individuals qualify for exemption from prescription charges in England if they meet one or more of the following criteria. They:

- are 60 or over
- are under 16
- are 16-18 and in full-time education
- are pregnant or have had a baby in the previous 12 months and have a valid maternity exemption certificate
- have a specified medical condition and have a valid medical exemption certificate
- have a continuing physical disability that prevents you from going out without help from another person and have a valid medical exemption certificate
- hold a valid war pension exemption certificate and the prescription is for your accepted disability
- are an NHS inpatient<sup>13</sup>

You are also entitled to free prescriptions if you or your partner (including civil partners) are named on, or are entitled to, an NHS tax credit exemption certificate or a valid HC2 certificate (full help with health costs), or you receive either:

- Income Support
- Income-based Jobseeker's Allowance
- Income-related Employment and Support Allowance, or
- Pension Credit Guarantee Credit
- Universal Credit

### A) Medical exemptions

If you have one of the following medical conditions, you can apply for an NHS Medical Exemption Certificate that will allow you to receive NHS prescriptions free of charge.

The medical exemptions are:

- A permanent fistula (for example caecostomy, colostomy, laryngostomy or ileostomy) requiring continuous surgical dressing or requiring an appliance
- A form of hypoadrenalism (for example Addison's disease) for which specific substitution therapy is essential
- Diabetes insipidus or other forms of hypopituitarism
- Diabetes mellitus, except where treatment is by diet alone
- Hypoparathyroidism
- Myasthenia gravis
- Myxoedema (that is, hypothyroidism requiring thyroid hormone replacement)
- Epilepsy requiring continuous anticonvulsive therapy
- A continuing physical disability which means the person cannot go out without the help of another person. Temporary disabilities do not count even if they last for several months

Or are undergoing treatment for cancer:

- including the effects of cancer, or
- the effects of current or previous cancer treatment

---

<sup>13</sup> NHS Choices: <http://www.nhs.uk/nhsengland/Healthcosts/pages/Prescriptioncosts.aspx>

People can obtain a medical exemption certificate from their doctor. Ask for a FP92A Form.

### **B) Pre-payment certificates**

Prescription prepayment certificates (PPC) are available in England and they can save you money on the cost of your prescriptions. The figures shown for England apply from 1 April 2013.

#### **England**

Each prescribed item costs £8.05. A three-month PPC costs £29.10, so anyone with four or more prescriptions in that period saves money. A 12-month PPC costs £104, so anyone with 14 or more prescriptions in that period saves money. The 12-month PPC can be paid by ten monthly direct debit instalments.