

## CYSTIC FIBROSIS AND PRESCRIPTION CHARGES

### The problem

In England, people with certain medical conditions are exempt from paying prescription charges.\* However the list of exempt conditions does not include Cystic Fibrosis. The reason for this is that the exemption list was drawn up in 1968, when most of those with Cystic Fibrosis died as children. Children, plus those over 60 years of age, as well as those on means tested benefits were and still are also exempt from paying prescription charges. So in 1968 this was not an issue of particular importance to those affected by Cystic Fibrosis.

Fortunately, the outlook for those with Cystic Fibrosis has improved markedly over the past 30 years and most now live until adulthood, although still with a considerably reduced life expectancy compared with the population as a whole. Unfortunately, the exempt list has not been properly revised since 1968, and despite many people with Cystic Fibrosis now reaching adulthood, many still have to pay for their prescriptions.

Most of them are 30 years of age or under and are often not earning high salaries, as health considerations have affected their education and their employment prospects. They and their families bitterly resent having to pay for drugs for this life-threatening disease, which has an extremely high burden of treatment and without which they would deteriorate rapidly. This is made worse when they learn of others who get free prescriptions for conditions which do not seem as serious as Cystic Fibrosis.

*\*Prescription charges have been abolished for everyone in Wales since April 2007. Northern Ireland plans to abolish prescription charges for everyone by April 2010 and Scotland by April 2011.*

## How does the system work?

Once a person is on the exempt list, they get their prescriptions for everything, including all other routine complaints such as coughs and colds, free of charge. Many Cystic Fibrosis patients have to pay for all of their prescriptions, unless they develop diabetes, a complication of Cystic Fibrosis which affects about 15% of Cystic Fibrosis patients and which is included on the exempt list.

Some adults with Cystic Fibrosis are exempt from prescription charges for other reasons, such as those still in higher education and on income support, or those too ill to work and those on very low income. Some who are in receipt of state benefits such as Disability Living Allowance still have to pay prescription charges.

For those who do have to pay, there are two methods of payment: single items can be purchased as and when required, or a pre-payment certificate (PPC) can be purchased which will cover costs for three, four or 12 months and works out cheaper if a lot of prescriptions are required.

## What are the current prescription charges?

The current prescription charges (as of 1 April 2009) are as follows:

### **England**

Single prescription: £7.20

Three-month PPC: £28.25

12-months PPC: £104.00

### **Northern Ireland**

Single prescription: £3.00

Four-month PPC: £9.00

12-month PPC: £25.00

## **Scotland**

Single prescription: £4.00

Four-month PPC: £13.00

12-month PPC: £38.00

## **Wales**

In April 2007, prescription charges were abolished completely in Wales.

## **The Government's position**

When in opposition, the Labour Party indicated its intention of reviewing prescription charges, and in its consultative paper of 1994 entitled "Labour 2000", it used Cystic Fibrosis as an example of current injustices it intended to put right. "We will seek to provide free medication as part of ongoing treatment for long term requirements. For example, those suffering from Cystic Fibrosis who reach adulthood should not have to rely on some other category, such as diabetes, in order to obtain free prescriptions."

However, the Labour Government, now in its third term, has not yet honoured this commitment. Prescription charges were considered in the Government's initial Comprehensive Spending Review, but in November 1998 the then Minister of State, Alan Milburn, wrote to the Cystic Fibrosis Trust saying: "The list of medical conditions conferring prescription charge exemption was introduced in 1968 after being agreed in discussion with the medical profession and no clear consensus for extending it has since emerged."

In September 2008, Prime Minister Gordon Brown announced that prescription charges for all those with long-term conditions would be abolished 'over the next few years', however no clear timelines have been given. As at April 2009, a Prescription Charges Review organised by the Royal College of Physicians was underway, and expected to report to the Minister for Public Health and the Secretary of State for Health in summer 2009.

## The CF Trust's position

The Cystic Fibrosis Trust believes that all adults with Cystic Fibrosis should be exempt from prescription charges, wherever they live in the UK, for the following reasons:

- 1 Cystic Fibrosis is a life-threatening medical condition for which daily medication is essential. Adults with Cystic Fibrosis are often considerably disadvantaged in economic terms by their condition. Further financial hardship is caused by having to pay prescription charges.
- 2 For those adults with Cystic Fibrosis who are in financial difficulty, there is a danger that having to pay for prescriptions may act as a disincentive to take essential treatment.
- 3 It is illogical and unjust that others with similar or less serious conditions are exempt from prescription charges whilst those with Cystic Fibrosis are not.
- 4 Cystic Fibrosis meets the requirements laid down by the British Medical Association in 1968 and accepted by the Government as criteria for exemption, specifically that conditions to be included on the exempt list should be “readily identifiable conditions, which in virtually all cases call automatically for prolonged continuous medication.”

Cystic Fibrosis fills all of these conditions exactly. The only reason we were not on the list in 1968 is that all children were exempt from prescription charges, thereby including all those with Cystic Fibrosis at the time. Thus as children with the condition rarely lived beyond childhood, there were no adults with Cystic Fibrosis to exempt in 1968 and therefore their case would not be considered at that time.

The Cystic Fibrosis Trust has consulted extensively with Consultants caring for Cystic Fibrosis patients, adults with CF, families of people with CF and professional bodies involved in healthcare. All consulted agree that Cystic Fibrosis meets the criteria for inclusion in the exempt list. We assume, therefore, that the Government has received no advice from any professional body that it would be inappropriate to include Cystic Fibrosis on the exempt list. It would seem then, that the lack of a clear consensus refers to other medical conditions.

The Cystic Fibrosis Trust does not accept that an adjustment to the exempt list could not or should not be made for Cystic Fibrosis because of a lack of consensus on other conditions. *The case for including Cystic Fibrosis on the exempt list is made and is accepted.* It is wrong to continue to discriminate against these young adults who clearly meet the criteria of the exempt list, and who may not be covered by any other category of exemption.

We expect the Government to act because our case is clear cut and just.

## Conclusion

The time for excuses is over. The Cystic Fibrosis Trust is hard pressed to meet its commitments for research, both to improve symptom control and to progress the gene therapy work which we hope will lead to the cure for Cystic Fibrosis, at the same time as propping up an ailing NHS. Our research commitments account for several million pounds each. In addition we have contributed over £1 million a year to the NHS to pay for doctors, nurses and other clinical staff. The Cystic Fibrosis Trust is also addressing the problem of unacceptable wards for in-patient provision for many young adults with Cystic Fibrosis and is working to bring care for Cystic Fibrosis in the UK up to acceptable standards.

We want to help and we are prepared to co-operate with the Government in a positive and constructive way. However, a charity cannot and should not be expected to do the job of the NHS or the Government. The current arrangements for prescription charges for adults with Cystic Fibrosis are demonstrably unjustifiable. Prescription charges for those with Cystic Fibrosis should be abolished without further delay. We expect the Government to remedy this situation, both because our case is just and to honour their promise of 1994.

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