



**For better
mental health**

Written evidence to Professor Ian Gilmore's Prescription Charges Review

Response from Mind

About Mind

Mind is the leading mental health charity in England and Wales, working to create a better life for everyone with experience of mental distress by:

- advancing the views, needs and ambitions of people with mental health problems
- challenging discrimination and promoting inclusion
- influencing policy through campaigning and education
- inspiring the development of quality services which reflect expressed need and diversity
- achieving equal rights through campaigning and education.

Summary of evidence

- Mind welcomes the opportunity to contribute to Professor Gilmore's Prescription Charges Review.
- We call on the Government to exempt all patients with long term mental health conditions from all prescription charges.
- People with long term mental health conditions should be exempt from prescription charges even if the condition itself does not require medication. This is due to the correlation between poor mental health and poorer physical health outcomes.
- We believe that a long term mental health condition can only be defined by the principle of duration.
- We define a long term mental health condition as one where the patient will experience symptoms over a six month period or more, even if these symptoms are experienced on a fluctuating basis. This definition is based on our belief that to experience symptoms for that amount of time will have a significant impact of a person's life. Six months is also the amount of time that people must experience symptoms in order to claim Incapacity Benefit/Employment Support Allowance.

- We understand that for mental health conditions the discretion of a clinician will be necessary in determining whether a person's mental health condition will be long term.
- We understand that whilst patients currently need to reapply for exemption every five years, a different system may need to be put in place for those with long term mental health conditions due to the unpredictable nature of such conditions.

Introduction

Although exemptions from prescription charges cover about 85 per cent of all prescriptions, 80 per cent of people aged between 18 and 60 have to pay for their medication.¹ MORI estimates that around 800,000 people a year go without the prescriptions they need because they simply can not afford the cost. This undermines the Government's assertion that the present system of exemptions ensures that people in need do not go without treatment on the grounds of cost²

Mind believes that the current system of prescription charging is out of date and does not address the health needs of today's population. It is inequitable and inappropriate, discriminating against people who experience mental distress, as well as other people with long term health conditions that require medication. Those on low incomes, in particular those on incapacity benefit, are also left disadvantaged. Shaun Johnson, a service user who gave oral evidence to the Prescription Charges Review with Mind, described the problems he has experienced as a result of prescription charges:

"If people are in a situation, and I've been there many times, when you're having to make a choice between essentials like food and heating and utility bills and medication, often it's the medication that doesn't get taken... frankly, both your physical and mental health suffer if you're denied any of these. And this is particularly bad at the moment. I know in my case, my food bill has doubled, my utility bills have gone up by a third, and my income has gone up by something like £1.50 a week."

We welcome the Prime Minister's announcement in September 2008 to abolish prescription charges for all people with long term conditions and call on the Government to implement this promise urgently, and certainly before the next election. Without these exemptions, the Government undermines its self-stated principle that the NHS provide a universal service based on clinical need, not ability to pay³.

Response to Prescription Charges Review questions

¹ MORI in Citizens Advice (2001) Unhealthy Charges

² Department of Health (2006) Government Response to the Health Committee's Report on NHS charges

³ Department of Health (2000) NHS Plan

When answering the below questions we focus specifically on the needs of those with mental health problems and defer to the expertise of other organisations regarding the needs of other conditions.

Question 1

What are the guiding principles to bear in mind when seeking to extend prescription charge exemption to people with long term conditions? For example what consideration needs to be given to issues such as:

- severity
- level of impairment
- duration
- time between having and not having symptoms
- amount of treatment required
- the potential to improve health outcomes

Whilst Mind recognises that duration would be a very useful principle with which to define long term mental health conditions, we are concerned that the other principles proposed are unmanageable and rely too heavily on subjective judgment. We are therefore unconvinced that they could be implemented consistently and transparently.

Severity

Defining long term conditions on the principle of severity is unfeasible and potentially harmful. It would be extremely difficult to measure given that for many people with mental health problems their condition is fluctuating and treatment is designed to minimise the severity.

Level of impairment

As with the principle of severity, the level of impairment would be difficult to measure due to the fluctuating nature of many mental health problems.

Duration

This is a very useful principle with which long term conditions may be identified. We support the Prescription Charges Coalition's view that a lifelong condition or any condition that lasts for longer than six months should qualify a patient for free prescriptions.

For many people with mental health problems they will experience fluctuating symptoms and the need for medication will vary over time. This should not suggest that the severity of the condition nor the need for prescription charge exemption is any less significant. For example, a patient with fluctuating bouts of depression can experience great disruption to their lives and the obligation to pay for prescriptions could unfairly exacerbate such problems. With this in mind, we call for the definition of a long term condition to take into account that patients eligible may experience symptoms on a fluctuating basis.

It should also be noted that many people will have experienced months of symptoms before they consult a clinician. This should be taken into account when eligibility for prescription charge exemption is decided.

Time between having and not having symptoms

Due to the individual complexity of mental health problems, the time between having and not having symptoms will vary markedly between person and diagnosis. As such, it would be an unmanageable task to predict the recurrence of mental health problems from the point of diagnosis.

In addition, to exempt those whose symptoms recur on a more regular basis undermines the severity and need of a patient who has a long term condition that recurs at longer intervals. It also discriminates against those whose medication is working. The intervals themselves should not play a part in the definition process . it is the fact that the symptoms recur over any stretch of time that should qualify an individual for exemption.

The amount of treatment required

The fluctuating nature of many mental health problems and the ways in which people may respond (or not) to medication for mental health problems, means that the type and amount of medication is not always easy to predict.

Furthermore, that one condition may require more medication than another should not mean that the treatment is any more critical to his or her recovery. That a patient has a long term condition at all should be the guiding principle, and not the quantity of medication prescribed.

The potential to improve outcomes

A patient should not have the burden of prescription charges simply because the prognosis of their treatment is less positive than another.

It may be that this principle has been proposed to ensure that unnecessary prescriptions are not exempt from charges. However, this is irrelevant as the responsibility for the suitability of a prescription should be held by the clinician, in consultation with the patient.

Question 2

How can these principles be applied to define the basis for exempting people with long term conditions from prescription charges? For example, should there be a revised list of medical exemptions? Or should the approach be based on a broader definition of long term conditions that takes account of the above principles? How do we ensure that the approach is fair, transparent and, as far as possible, based on objectivity?

A revised list of medical exemptions

Whilst Mind is supportive of the Prescription Charges Coalition and its recommendation for a revised list of medical exemptions, we acknowledge that for many mental health conditions a list of exemptions will not work. In such

situations, we believe a clinician would be required to make a subjective decision in order to ascertain how long a condition is likely to last.

An approach based on a broader definition of long term conditions that takes account of the above principles

If this approach was taken, it would be critical to ensure that the thresholds for qualification were not set at a level that inappropriately excluded people. In particular, the variance in severity and impairment due to fluctuating mental health problems would need to be taken into account. With this in mind, we recommend that the guiding principles work as ~~an~~/or criteria.

However, we believe that the only proposed principle that can be used to fairly and accurately define a long term condition is duration. A person should be defined as having a long term mental health condition if it is predicted that they will experience or will require medication to prevent experiencing symptoms of the condition over a period of six months or more. This definition should include patients who will experience symptoms on a fluctuating basis.

Our definition is based upon the belief that experiencing symptoms over a period of six months or more will impact heavily upon a person's life. In addition, those claiming Incapacity Benefit/Employment Support Allowance are currently required to demonstrate that they have experienced symptoms for at least six months. Our definition would make the process simpler from the service user's perspective as it would ensure a level of consistency between the benefit system and prescription exemption.

Mental health diagnoses are often contested by service users and between different clinicians and are therefore subject to change. This should not put a patient's eligibility for prescription charge exemption at risk. Exemption should include those with a working diagnosis. In addition, a fair, accessible and transparent appeals system should be put in place should a patient wish to contest their eligibility for prescription exemption.

Although we support the Prescription Charges Coalition's call for exemptions to last for five years where a condition is not lifelong, we believe that a different approach may be needed for those with mental health problems. People with a long term mental health problem can and do recover, often within a five year period. As such, we would support a system in which a person could come off prescription exemption within five years of diagnosis if it was decided that they no longer had a long term mental health condition. We would be very happy to discuss this in further detail with the Review team in future. Any such system should:

- be transparent and fair

- have a standardised review process to ensure that all patients are assessed with the same frequency (for example, patients could have their exemptions reviewed annually)
- have an accessible and simple appeals system in place for people to contest a decision made to end their exemption
- take into account that if someone experiences symptoms after having their prescription exemption withdrawn it should be made extremely simple and quick for that person to re-qualify for prescription exemption.

Question 3

Taking account of your views on questions 1 and 2, which conditions do you think should definitely qualify for exemption, and which conditions do you consider should not qualify? Please give your reasons.

Mind believes that all mental health conditions that are thought to last over a period of six months or more, even if on a fluctuating basis, should qualify for exemption from all prescription charges.

Question 4

What could be the anticipated health benefits of extending exemption to patients with long term conditions? What other potential benefits could be achieved by extending prescription charge exemption?

Improved compliance

It is estimated that, every year, 800,000 people go without the prescriptions they need because they simply can not afford the cost. The failure to complete or even begin treatment is potentially detrimental to a person's health. For many mental health service users, medication will be the only available treatment option. Clearly, exempting those with long term conditions from prescription charges will ensure that a patient's compliance with treatment will not be affected by cost. In addition, patients would no longer be put off taking their medication because of being unable to afford prescription charges for medication to combat any side effects of their original treatment. It can be assumed that improved compliance would normally improve health outcomes.

However, medication is not always the most suitable type of treatment for someone with a mental health problem and people can often be reluctant to take medication because of the much reported negative side effects of some psychiatric medication⁴. Therefore any decision to prescribe medication for a person with a mental health diagnosis needs to be made in consultation with them. Many other evidence based alternatives exist for mental health problems on the NHS. Such alternatives include cognitive behavioural therapy, counselling and exercise on prescription.

⁴ Reed, J (2005) Coping with Coming Off

Addressing physical health inequalities for people with mental health problems

The Disability Rights Commission (DRC) inquiry into the physical health of people with mental health problems and/or learning disabilities found that people with mental health problems are more likely than the general population to have physical health conditions such as heart disease, high blood pressure, respiratory disease, diabetes and stroke.⁵ The DRC also found that people with a diagnosis of schizophrenia are ninety percent more likely to get bowel cancer and women with this diagnosis are forty-two percent more likely to get breast cancer. This means that those who experience mental distress may require a relatively high number of prescriptions that are not directly related to their mental health diagnosis but are necessary to maintain their physical health. Furthermore, for many service users the presence of a physical illness will exacerbate mental distress and vice versa. As a result, service users can find themselves needing a high number of prescriptions in a very short space of time and many of these prescriptions will not be directly related to their mental health condition.

“Like many people with mental distress, I’m very prone to physical health problems when I’m mentally not well, due to not looking after myself, or through just not having the money to eat properly. So I regularly get migraines, joint problems, back problems, eye problems, abscesses, gum infections, tooth problems and pretty much any infection or virus that’s going around.”

(mental health service user)

Enabling people who experience mental health problems to receive medication free of charge would help address the physical health inequalities experienced by people with long term mental health problems. It is for this reason that we believe all those with long term mental health conditions should qualify for prescription exemption, even if their mental health condition does not necessarily require medication.

Improved lifestyles

Being exempt from prescription charges would mean people have more money to pay for healthier food and to keep warm and safe. Such lifestyle changes have been known to aid the process of recovery.

Mental health and debt

Paying for prescriptions may also contribute to further monetary hardship which can exacerbate existing mental health problems. Mind published new research in 2008 that indicates a circular relationship can exist between debt and experience of mental distress . that being in debt may negatively affect a person's mental health, while living with a mental health problem can increase the likelihood of

⁵ DRC (2006) Equal Treatment: Closing the Gap: A formal investigation into physical health inequalities experienced by people with learning disabilities and mental health problems

falling into debt.⁶ People with mental distress are three times more likely to be in debt and those with a diagnosis of bipolar disorder or schizophrenia are four times more likely.⁷ This is often as people are living on a low income or can't work due to difficulties getting a job because of stigma, or due to ill health.

Cost effective

Improved health outcomes should lower the overall cost to the NHS of caring for people with long term conditions by reducing in-patient and emergency care needs. If someone is better able to manage their condition, they will be more able to stay in work or education, maintain friendships and relationships and live a full life.

Addressing fairness

At the moment some long term conditions are exempt from charges whereas others are not. This is deeply unfair. In a survey conducted by Mind, seventy-two per cent of people ~~strongly agreed~~or ~~agreed~~that it was unfair for people with long term mental health problems to pay for prescriptions.

Question 5

What impact could the widening of prescription charge exemption for people with long term conditions have on (a) prescribing practice (b) medicines usage/wastage? (c) wider initiatives for people with long term conditions . such as care planning? How can potentially positive aspects be maximised and adverse impacts be mitigated?

Prescribing practice

A study based on a focus group with 51 GPs found some doctors feel obliged to change their prescribing practice to minimise the impact of prescription charges on their patients.⁸ Strategies included recommending cheaper over the counter drugs, increasing the quantity prescribed, prescribing more expensive medicines rather than trying a cheaper option first and supplying medicines returned by other patients. At present, guidelines state that ~~costs~~ and value of prescriptions should be considered not just at the point of prescribing but at all stages of the process.⁹ Exempting those with long term conditions from prescription charges would give GPs the freedom to prescribe treatment purely on the basis of medical need and not cost. For example, a GP may feel more comfortable prescribing medication for shorter periods in order to monitor the progress of a patient at risk of self-harm.

“I’ve often had occasions where I’ve been at risk of suicide or severe self-harm and should have been on weekly prescriptions to stop me overdosing but have not been able to afford the four prescriptions a month

⁶ Mind (2008) In the Red: debt and mental health. London: Mind

⁷ Office for National Statistics (2002a), The Social and Economic Circumstances of Adults with Mental Disorders, Stationary Office, London

⁸ Weiss M, Hassell K, Schafheutle El, Noyce PR, (2001) Strategies used by general practitioners to minimise the impact of the prescription charge, European Journal of General Practice, Vol 7, pages 23-26

⁹ The National Collaborating Centre for Primary Care (2009) Royal College of General Practitioners

that this would involve. This puts me at severe risk of damaging myself, or worse”.

(mental health service user)

Usage/wastage

The financial burden of prescription charges can lead some people to develop coping strategies that are detrimental to their health. For example, people may choose to self-medicate by deciding what treatment they can do without or risk side effects from coming off a drug too quickly.

“I’ve often had to stretch out medications or self-medicate because I can’t afford another prescription. Or I don’t take medications designed to off-set the adverse effect of other medications because I can only afford one prescription.”

(mental health service user)

The clinician is responsible for prescribing the correct type and amount of treatment, in consultation with the patient. If a treatment has been prescribed, we can assume that this medication is needed. As a result, we do not anticipate that the widening of prescription charge exemptions for people with long term conditions would increase drug wastage as patients should not be able to receive prescriptions without real need. If people fail to take the drugs prescribed, this should be seen as a non-compliance (not wastage) issue that is unrelated to cost and therefore out of the scope of this Review.

Wider initiatives

The absence of prescription charges for those with long term conditions would allow clinicians and patients to develop appropriate care plans and prescribing practices that need not consider someone’s financial situation. Prescribing medication should only be an aspect of a patient’s care plan and other methods of treatment and support (for example, psychological therapies and exercise) should also form part of the care plan.

The NHS electronic record programme could be used to automatically flag patients who become eligible for prescription charge exemption.

Maximise positive aspects

All health workers, including pharmacists, must be trained to comprehensively inform people of the exemptions that they are entitled to. The Government should use any changes to the prescription charge system as an opportunity to raise awareness amongst the public of all health benefits and exemptions available.

Question 6

Taking into account your responses to the previous question, what will be the key practical considerations that determine how policy changes can be phased in?

Changes to prescription practice must be made as simple as possible for the clinician and for the patient. It is imperative that there is no phasing in of free prescriptions for some conditions before others as this would unfairly suggest that some conditions are seen to be more important than others.

Question 7

What other issues would you wish to raise about exempting people from long term conditions from prescription charges?

Right to free treatment under Section 117 of the Mental Health Act and under Community Treatment Orders (CTOs)

Currently, people subject to section 117 (aftercare) of the Mental Health Act are entitled to free aftercare, including prescriptions, if that prescription is part of the agreed aftercare package. However, in practice, many people are not aware of this, and some pay for their prescriptions whilst others do not.

“...I have on a number of occasions and under several different CMHT's been subject to a section 117 but have never been told that this entitles me to free prescriptions... in my experience awareness of this is not out there or being shared. I say this with experience of multi-disciplinary CMHT's, social services, psych nursing staff, welfare advisors and a broad involvement with other service users and organisations”.
(mental health service user)

Those on CTOs are entitled to the same exemption. Although CTOs are relatively new, we make the reasonable assumption that there may be similar problems regarding the awareness of prescription charge exemption with CTOs just as there has been with the section 117 aftercare package. It is contrary to justice to allow someone to pay for prescriptions upon which their liberty is dependent. We urge the Government to ensure that information on prescription charge exemption in these cases is better disseminated and to learn from this example to ensure that similar information problems are not replicated when any new prescription charge exemptions are put in place.

Incapacity benefit (IB)

At present, some people on IB do not qualify for free prescriptions because their benefit is paid at a rate that is just above the current threshold for exemption. A survey by the Citizens Advice Bureaux showed that of the respondents who failed to get all or part of their prescriptions due to cost, 16 per cent were on IB.¹⁰ For example, a Citizens Advice Bureau in Northumberland reported a client with severe mental health problems who required three prescription items per month to manage his condition. However, his income from Incapacity Benefit left him only five pence above the level at which he would have been entitled to free prescriptions. As a result, he could not afford his medication.¹¹

¹⁰ Citizens Advice Bureaux (2001) Unhealthy Charges

¹¹ Citizens Advice Bureaux (2001) Unhealthy Charges

The introduction of Employment Support Allowance (ESA) further complicates this as people on contributory ESA would be exempt from prescription charges on low income grounds but people would need to apply for it. This would mean further strain on benefit administration. In addition to this, people who are currently claiming IB will eventually be migrated over to ESA.

We believe that this complicated and unfair system can prevent people from getting the medication they need when at their sickest and poorest. We call for all those on IB and ESA to be exempt from prescription charges.

Pre-payment certificates

For those that would still not qualify for exemption, Mind believes that the pre-payment certificate (PPC) system has the potential to reduce the burden of cost but is not currently being used effectively. Research by the Citizens Advice Bureaux showed that twenty seven per cent of those surveyed did not know about PPCs.¹² The Government should work to ensure that pre-payment certificates are better publicised to all that might benefit. For example, pharmacists should be required to discuss pre-payment certificates to anyone that presents with a repeat prescription.

Mind also supports the introduction of a yearly cap on payment for medicines. Although the Government has responded to this recommendation by stating that PPCs already place an annual limit¹³ on the amount that patients are required to pay in prescription charges¹³ this does not take into account that for many it may not be possible to predict how much medication will be required in a given period.

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¹² Citizens Advice Bureaux (2001) Unhealthy Charges

¹³ Department of Health (2006) Government Response to the Health Committee's Report on NHS charges