

Key messages

Despite the severe challenges brought on by motor neurone disease (MND), many people living with the condition in England are still made to pay prescription charges. These costs place a significant financial burden on individuals already dealing with the devastating physical, psychological, and financial toll of the disease. The current exemption criteria for free prescriptions have remained virtually unchanged in over 50 years, with little rationale for excluding conditions like MND that require multiple, continuous, and often life-extending medications.

This outdated system often delays access to a medical exemption certificate until the disease's later stages. Evidence shows that prescription charges make people less likely to adhere to their medications, leading to avoidable complications, hospitalisations, and worsening health outcomes. Removing these charges for people with MND would not only alleviate financial stress for the individual but may also reduce costs for the NHS in the long term.

The government's decision to freeze the prescription charge for 2025 is a welcome step forward, but much more must be done to ease the financial burden on people with MND. We believe that no one living with MND should be made to pay for their medications and urge government to cease the current inequity by scrapping prescription charges for people living with MND in England, to align with the rest of the UK. At a minimum, we call on decision-makers to commit to freezing the prescription charge for 2026, stop reducing prescription durations, provide entitlement information to those with MND at the point of diagnosis, and review the prescription charge exemptions list, to ensure it meets the needs of patients and the NHS.

Background

There are around 5,000 people in the UK living with MND at any one time. However, despite the severe challenges posed by the condition, an MND diagnosis does not automatically exempt one from paying prescription charges. England remains the only country in the UK to still charge for prescriptions, with Scotland, Wales, and Northern Ireland scrapping them in 2011, 2007, and 2010, respectively.

Prescription prices in England continue to rise every year at a rate that outpaces wage inflation. As of May 2024, the prescription charge is £9.90 for each medicine or appliance dispensed in England. The three-month Prescription Payment Certificate (PPC) costs £32.05 and the 12-month PPC costs £114.50, equating to a 2.59% increase from 2023.¹ For those living with MND, this means having to pay a higher price for their life-extending medications. This is an additional burden on top of the already high psychological and financial costs associated with managing the condition².

The recent freeze on prescription charges for 2025 is a positive step, but it is not enough to address the broader and ongoing financial challenges faced by people with MND. While the UK Government state that 89% of prescriptions in the UK are currently dispensed free of charge, only a small number of conditions and criteria qualify for a medical exemption certificate. In fact, except for the addition of cancer in 2009, the prescription charges exemptions list has remained unchanged for over 50 years. Other exemption requirements depend on the person's age, whether they are in qualifying full-time education, whether they

are pregnant or have recently given birth, or whether they are in receipt of certain benefits or a war pension.³

There remains little to no rationale on why certain conditions are exempt and not others, and there are currently no plans to review the exemptions list or the list of conditions that entitle someone to apply for a medical exemption certificate⁴. For instance, while those with continuous physical disabilities that require assistance to leave the house can qualify for prescription charge exemption, those living with MND would not be able to access this benefit until the later, more severe stages of the disease. This delay can mean that many people living with MND face significant financial barriers for longer than necessary, at a time where their needs are at their most critical.⁵

The challenge:

Accumulating costs

The prescription charge in England, currently £9.90 per item, has steadily risen at rates exceeding wage inflation. We know that those with MND are disproportionately impacted by the cost-of-living crisis due to many having to give up their primary sources of income, and dealing with the additional costs associated with managing the condition. Households impacted by MND typically spend an average of £14,500 on the costs of their disease annually, on top of regular living expenses, with many incurring much higher costs⁶. Rising prescription charges mean more and more people with MND are being forced to choose between everyday essentials and their lifesaving and life-extending medications. While the 2025 freeze offers temporary relief, it does not go far enough and long-term reform is still needed to ease the medication costs faced by people with MND.

Survey data by the Prescription Charges Coalition paints a grim picture of the consequences of these costs. One in ten people with a long-term condition report skipping their medication in the past year due to cost. Of this group, a third have additional health problems as a result, almost four in ten have new or additional mental health problems and over half have had worsening health to the point of having to take time off work. However, it doesn't have to be this way. Two thirds of respondents claimed that they would be more likely to adhere to their medications if they were provided free of charge.⁷

The unique way MND affects each individual means that other medications requiring a prescription may be needed to manage various potential symptoms. Riluzole is the only licenced medication for the treatment of MND in the UK. It has been shown to have a life-extending effect and is prescribed to most people recently diagnosed with MND. However, riluzole alone costs approximately £130 annually for a single person living with MND who does not meet the exception criteria.⁸ In addition to riluzole, people with MND may need to be prescribed up to seven other medications to help alleviate their symptoms, and as the £9.90 charge is per item, not per prescription, an individual just over the income threshold can face a £80 charge for eight items⁹. Additional over-the-counter medications that may be needed to manage symptoms inflate this expense further.¹⁰ In 2018, NHS England introduced new guidance that meant that some medications previously available through prescription would now be available over the counter. For some people with MND who may be managing symptoms such as pain, muscle stiffness, coughing, and constipation with over-the-counter medications, this has meant their individual medication-related costs have increased on top of the rising prescription charges.¹¹

At a minimum, we are calling on government to freeze the prescription charge for 2026 and stops reducing prescription durations to help stop the costs for MND from climbing further. The trend of reducing the duration of prescriptions – meaning people need to refill medications more frequently – is compounding hardship for those with complex conditions like MND where multiple medications – and thus multiple payments – are needed to manage symptoms.

An outdated system

The exemption criteria for prescription charges remains rooted in outdated policies put in place over 50 years ago. Except for cancer in 2009, there has been no change to the exemptions list since 1968.¹² The NHSBSA states that those aged 60 or over are entitled to free prescriptions, those on income-based benefits, those with a valid HC2 certificate, those who receive War Pension Scheme or Armed Forces Compensation Scheme payments, and those with certain medical conditions including:

- a continuing physical disability which means you cannot go out without the help of another person
- conditions that require continuous treatments (diabetes, epilepsy)
- Myasthenia gravis - a rare long-term condition that causes muscle weakness. It most commonly affects the muscles that control the eyes and eyelids, facial expressions, chewing, swallowing and speaking. But it can affect most parts of the body.¹³

There is little to no rationale for why some conditions, particularly those that require long-term and continuous treatment like diabetes and epilepsy, are exempt over others. And while MND does cause progressive physical disability, many will not be eligible to apply for an exemption until the very late stages of the disease. We are calling for Government to urgently review the prescription charge exemptions list so that it reflects modern healthcare needs and recognises conditions like MND, which require ongoing, often life-extending treatment.

Recent YouGov polling shows that public opinion strongly favours abolishing prescription charges, with 90% of the British public supporting their removal.¹⁴ Healthcare professionals also agree that the charges are problematic, and the exemption criteria makes little to no sense. The Royal Pharmaceutical Society have called for England to follow the rest of the UK in providing free prescriptions to all patients.¹⁵ A survey found that one third of pharmacists reported an increase in prescribed medications not being dispensed or declined due to costs in the past year, and 84% of would support the widening of the exemption criteria. There were reports of patients rationing when to take their medications, and how often, bringing about concerns around the risk of worsening health outcomes as a result.

In England, 89% of medications are already dispensed free of charge. The remaining 11% provided about £670 million in revenue to England's NHS in 2022-23. However, an economic analysis by the York Health Economics Consortium in 2018 found that any loss in prescription revenue would be more than offset by the savings to the NHS that would be generated by scrapping prescription charges all together. The analysis found that by preventing avoidable complications and hospitalisations, £20.8 million could be saved per year from Parkinson's Disease and Inflammatory Bowel Disease alone.¹⁶

Expanding access to PPCs and the NHS Low Income Scheme

Although PPCs offer a way to mitigate costs, they remain financially and logistically inaccessible for many. Survey data found that over a third of people living with long-term health conditions are not made aware of the PPC option until over a year after their diagnosis. This is completely unacceptable for people with MND, where the first year after diagnosis is where

What we think about prescription charges

POSITION STATEMENT. LAST UPDATED: May 2025

riluzole is most effective. When they were aware, many cited that the upfront costs and direct debits to obtain the PPC were a barrier.

There has been some progress in expanding access to PPCs for specific groups. In April 2023, anyone in England will be able to apply for a new hormone replacement therapy (HRT) PPC which covers all HRT items licenced to treat symptoms of the menopause. The certificate costs £19.30 per year, saving individuals up to £90 per year. This is a welcome step forward, but those with MND still need to pay the full price of £114.50 for a 12-month PPC, which is a significant cost barrier for many.

The NHS Low Income Scheme provides support for prescription charges for those whose savings do not exceed a certain limit. However, 83% of respondents from the Prescription Charges Coalition survey were not aware of the scheme. There needs to be clearer signposting to the Low-Income Scheme and the PPC option at the point of diagnosis, as well as an expansion in the availability of low-cost PPCs for people living with MND to ease the financial burden and ensure they can access any medications they need.¹⁷

What changes do we want to see?

From Government:

We believe that no one living with MND should be made to pay for their medications and urge government to cease the current inequity by scrapping prescription charges for people living with MND in England, to align with the rest of the UK. We call on decision-makers to commit to reviewing the prescription charge exemptions list, to ensure it meets the needs of patients and the NHS. We call on the government to:

- Freeze the prescription charge for 2026.
- Stop reducing prescription durations.
- Review the prescription charge exemptions list urgently.
- Provide entitlement information to those with MND at the point of diagnosis.

What MND Association are doing:

- Influencing national policy through consultations, campaigns, and meetings, through the Prescription Charges Coalition, on the issues around prescription charges for people with MND.
- Lobbying MPs and other parliamentary stakeholders and groups through briefings and debates, ensuring that the experience of people with MND and their interactions with the current system around prescription charges remains high on government agendas.
- Engaging with local councillors and other local decision makers, in partnership with our Campaign Volunteers, to raise awareness of the impacts of prescription charges on people with MND, and signpost to available support services.

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What we think about prescription charges

POSITION STATEMENT. LAST UPDATED: May 2025

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