

## **Consultation Response:**

### **Standing charges: domestic retail options**

**September 2024**

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#### **About MND and the MND Association**

Few conditions are as devastating as motor neurone disease (MND). It is a fatal, rapidly progressing disease of the brain and central nervous system, which attacks the nerves that control movement so that muscles no longer work.

There is no cure for MND. While symptoms vary, over the course of their illness most people with MND will be trapped in a failing body, unable to move, swallow, and ultimately breathe. Speech is usually affected, and many people will lose the ability to speak entirely. Up to half of people with MND will also experience changes in cognition, some of whom will develop frontotemporal dementia.

There are up to 5,000 people living with MND in the UK at any one time. It can affect adults of any age. MND kills a third of people within a year of diagnosis and more than half within two years, typically as a result of respiratory failure. A small proportion of people experience slower progression and live with MND for longer, but survival for more than ten years is highly unusual.

The MND Association is the only national organisation supporting people affected by MND in England, Wales and Northern Ireland, with 90 volunteer-led branches and groups, and 13,000 volunteers. The MND Association's vision is of a world free from MND. Until that time, we will do everything we can to enable everyone with MND to receive the best care, achieve the highest quality of life possible and die with dignity.

#### **Impact of energy prices on people living with MND**

The nature of MND means that many households affected by MND spend more to manage the symptoms and its impact on daily living. For example, they may spend more on electricity due to their reliance on personal powered equipment. Assistive equipment for MND enables people to remain safe, independent, and well, in and outside their homes. We know that almost three-quarters (72%) of people with MND use personal powered equipment to manage the condition.<sup>i</sup>

The 2023 MND Association report "Through the Roof"<sup>ii</sup> details the experiences of people with MND who reported significant anxiety around the impact of the cost of living crisis on maintaining these pieces of equipment. It showed that over one-quarter (28%) of people reduced their use of personal powered equipment in the last 12 months in response to rising energy costs, placing their health and wellbeing at risk.<sup>iii</sup>

Some families managing advanced stages of the condition have told the MND Association that they currently spend between £800 and £900 a month on their household electricity bill,

which equates to an astronomical £10,000 a year. It is so expensive because these people require a wide range of assistive equipment to keep them alive and independent. These can include: 24/7 ventilation, cough assist and saliva suction, powered wheelchairs, communications equipment, powered adjustable beds and hoists among many more. They may also include adaptations in the home such as through-floor lifts, stairlifts and bath lifts.

People with less advanced MND may use a smaller range of equipment but are still likely to rely on powered home equipment to enable them to live safely at home. We estimate that people with MND spend, on average, an additional £600 a year on electricity costs – based on the October 2022 Energy Price Guarantee unit rate – for charging and using assistive equipment, on top of other household costs and other additional costs of MND.<sup>iv</sup>

**What are your views on the range (£20-£100) of operating costs we are considering shifting from standing charges to unit rates? Should it be higher? Within this range, is there a value you would favour and why?**

Overall, we welcome the decision by Ofgem to acknowledge that “Abolishing standing charges in the absence of more fundamental market reform risks increasing costs for a significant proportion of consumers, in particular low income, high demand households.

Standing charges present significant challenges for many individuals. This issue disproportionately affects individuals with lower incomes who utilize minimal energy. Even after discontinuing electricity and gas usage, these charges continue to accumulate, resulting in mounting debts for individuals who aren't actively heating or powering their residences. There exists many examples of people struggling to top up their meters, only to find that their payments are instantly allocated to standing charge debts instead of fulfilling their immediate need for warmth and electricity.

However, individuals with MND often have heightened energy needs, especially those reliant on at-home medical equipment. Their increased energy usage could mean that transitioning from standing charges to a unit-based method of covering fixed costs might impose an additional burden on them. Recognizing the distributional impacts, Ofgem acknowledged the potential consequences and outlined the differential effects of redistributing standing charges into volumetric costs, separately assessing electricity and gas.

Given this we would support any move which minimises the move away from standing charges, which would mean closer to a £20 shift than £100 shift. The consultation outlines an exemplar family which most aligns with MND families. This was a two/three bedroom house with gas heating occupied by a family, including one who has a disability requiring medical equipment and constant heating. The impact of a £20 shift was only £15 compared to a £78 increase on a £100 shift.

**In enabling greater diversity in standing charges on default tariffs, what, if any, safeguards would be needed to protect vulnerable consumers?**

Safeguards are essential to protect vulnerable consumers from negative consequences of diverse standing charges on default tariffs. Vulnerable groups like people with MND, who rely

heavily on energy for life-sustaining equipment, are particularly at risk if standing charges were to increase or shift unpredictably. Key safeguards could include:

1. **Energy Social Tariff:** An Energy Social Tariff would provide a much-needed safety net for those affected by MND. Given that people living with MND often face significantly higher energy costs due to their use of medical equipment, the introduction of a social tariff that provides discounts on unit rates for low-income and medically vulnerable households would help alleviate financial strain. Such tariffs should be applied directly to the unit cost of energy rather than through later reimbursement, providing immediate financial relief.
2. **Improvements to the Priority Services Register (PSR):** Improving the PSR would enable energy providers to better identify and support vulnerable customers. In addition to collecting data on medical conditions, the PSR should ensure energy providers understand the specific energy needs of these customers, offering tailored support such as standing charge exemptions or energy-saving advice.
3. **Data Matching and Smart Technology:** Using smart meter data and enhanced customer billing information can help energy suppliers identify sudden increases in usage, which might indicate the need for additional support, such as standing charge exemptions or tailored tariffs. By working with other departments, such as the Department for Work and Pensions (DWP), Ofgem could more accurately target support for vulnerable consumers, particularly those managing conditions like MND that require constant use of powered medical equipment.

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<sup>i</sup> MND Association. (2023). Through the roof: The experience of households affected by MND during the cost-of-living crisis. Available: [https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report\\_0.pdf](https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report_0.pdf)

<sup>ii</sup> MND Association. (2023). Through the roof: The experience of households affected by MND during the cost-of-living crisis. Available: [https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report\\_0.pdf](https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report_0.pdf)

<sup>iii</sup> MND Association. (2023). Through the roof: The experience of households affected by MND during the cost-of-living crisis. Available: [https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report\\_0.pdf](https://www.mndassociation.org/sites/default/files/2023-08/Through%20the%20roof%20report_0.pdf)

<sup>iv</sup> MND Association. (2023). 2023 Spring Budget Statement. Available: <https://www.mndassociation.org/2023-spring-budget-statement/>