Cyflwynwyd yr ymateb i ymgynghoriad y Pwyllgor Cydraddoldeb a Chyfiawnder Cymdeithasol ar Tlodi Tanwydd yng Nghymru

This response was submitted to the Equality and Social Justice Committee consultation on Fuel Poverty in Wales

FP05
Ymateb gan: Cymdeithas Clefyd Niwronau Motor | Response from: Motor Neurone Disease (MND) Association

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Fuel Poverty in Wales

MND Association Response

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These are the views of:	The MND Association – the leading charity in England, Wales and Northern Ireland focused on funding research, improving access to care and campaigning for people living with or affected by MND.

What is Motor Neurone Disease?

Motor neurone disease (MND) is a fatal, rapidly progressing disease that affects the brain and spinal cord. It attacks the nerves that control movement so muscles no longer work. It leaves people locked in a failing body, unable to walk, talk and eventually, breathe.

Six people are diagnosed with MND every day in the UK, and six people die. The lifetime risk of developing the disease is 1 in 300. MND affects around 5,000 adults in the UK at any one time, around 200 of whom are living in Wales.

MND kills a third of people within a year of diagnosis and more than half within two years. There is no cure.

Why are warm homes essential for people living with MND?

The right to adequate housing is enshrined in international law[1]. This involves more than just four walls and a roof, Governments must make sure this includes safe, warm, dry and healthy housing.

This is even harder to achieve during the winter months, where excess deaths are exacerbated by colder conditions. Indeed, the NICE guidelines for excess winter deaths and

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[1] Universal Declaration of Human Rights | United Nations

the risks associated with cold homes recommends we ‘be aware that living in a cold home may have a greater effect on people who spend longer than an average amount of time at home. This could include those with chronic health conditions (including terminal illnesses) or disabilities’[2].

Motor neurone disease is one of these chronic health conditions. MND causes significant muscle wastage, which reduces the body's natural ability to insulate and retain heat. This can lead to several symptoms such as muscle stiffness, severe pain, and cramps.

To manage these symptoms and maintain their comfort, it is essential for people with MND to keep their homes consistently warm. In many cases, people living with MND need to keep their home at an even higher temperature than prior to diagnosis to remain comfortable. Many people living with MND also report increased usage of items like electric blankets and heated seat pads.

Due to the progressive nature of the disease, people living with MND also spend more time, on average, in the home. Combined, these lead to consistently increasing energy consumption and significantly higher utility bills when managing the symptoms of the disease.

Broader energy costs

Outside of their increased heating costs, people living with MND incur extremely high energy costs whilst managing their condition. To live safely and independently, people with MND require essential powered equipment including communication devices, medical devices like artificial ventilators, cough assist machines, and saliva suction devices, and mobility aids such as powered wheelchairs, adjustable furniture, and hoists.

Combined, these are extremely costly to both acquire and maintain.

Our Through the Roof (2023) report[3] found that:

- 74% of people with MND have cut back on heating due to increased energy costs, and 67% plan to continue reducing heating usage over the next year.
- Some individuals experience electricity bills as high as £10,000 per year due to their reliance on essential powered equipment.

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[2] Recommendations | Excess winter deaths and illness and the health risks associated with cold homes | Guidance | NICE

[3] Through the roof report_0.pdf

- 28% of people reported reducing their use of assistive equipment to cope with rising costs, putting their health and wellbeing at risk.

These results show that while the cost of living remains stubbornly high, the social security system is not providing adequate support to protect people with complex health conditions like MND from the effects. People living with MND are still facing extremely difficult choices between maintaining their quality of life or prioritise their health and wellbeing.

Winter Fuel Payment

Changes to the eligibility criteria for the Winter Fuel Payment are leaving people living with MND in Wales without vital support.

Our research shows that people living with MND spend an additional £14,500 per year to manage the condition, with much of this comprising energy costs. The Winter Fuel Payment helps alleviate some of this financial burden, and we are concerned that without it, even more people living with MND will be forced to cut back on their use of heating and assistive equipment.

Many people living with MND either cannot or do not claim means-tested benefits due to their age at diagnosis or the existence of savings. However, with such rapid disease progression and high costs, these resources can become depleted very quickly, leaving people living with MND and their families in financial precarity. The means-testing process overlooks these situational factors and the unavoidable expenses incurred after being diagnosed with MND. This will leave many vulnerable individuals without the support they need.

One person living with MND in Wales told us he was worried about losing his winter fuel payment this year. He lives alone and is 74 years old. He does not qualify for pension credit due to a small private pension, limited by the shortening of his working life after his diagnosis, which does not cover his expenses but leaves him ineligible for Government support.

While lack of data and cross-Government competencies makes it hard to assess exactly how many people this decision will impact, we are concerned that there are many people in similar circumstances living with MND in Wales, who have extremely high day-to-day living costs, less ability to generate income and often low savings which are rapidly depleted, but are just above the threshold for Government support.

To highlight our concerns, on 12th September, we delivered a letter to the Treasury co-signed by healthcare professionals and politicians from around the UK. In this, we highlighted the story of another person living with MND who is unable to claim pension credit due to savings after cashing in a private pension to buy a wheelchair accessible vehicle, a ground floor extension, and a wet room along with a riser recliner and a mobility scooter[4].

Adequacy of Welsh Government Support

Warm Homes Programme

As one of Welsh Government's primary approaches to reducing fuel poverty, we believe the Warm Homes Scheme does little to address the needs of high-energy users such as people with complex health conditions like MND.

The scheme focuses heavily on improving carbon efficiency which, while extremely important, does little to address the immediate need for support for people living with MND or the underlying inequity that is both a cause and consequence of fuel poverty.

Indeed, it is disappointing to see that eligibility criteria for the scheme includes very limited chronic health conditions which does not include people with terminal illnesses such as MND[5]. Further, we are concerned to see that despite Welsh Government identifying that people living with long-term illnesses are particularly vulnerable to fuel poverty[6] and the well-established links between fuel poverty and disability[7], the equality impact assessment for the Programme has not been published and no reference was made to disability in the integrated impact assessment.[8].

Warm Hubs

We also note the Welsh Government's recent announcement that £1.5 million will be distributed to local authorities to fund warm hubs across the winter[9].

While we appreciate this vital funding, we are concerned that such spaces are often not accessible to people living with MND who are struggling to pay their bills. Particularly in the latter stages of disease progression, people with MND may have extremely limited mobility and many are unable to leave the home so will be unable to benefit from warm hubs if they are unable to afford to heat their own homes.

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[4] Over 40 MPs from eight parties sign MND Association letter questioning government over Winter Fuel Payment | MND Association

[5] Get free home energy efficiency improvements from Nest: Eligibility | GOV.WALES

[6] Tackling fuel poverty 2021 to 2035 [HTML] | GOV.WALES

[7] Fuel poverty set to double | Disability charity Scope UK

[8] New Warm Homes Programme: integrated impact assessment [HTML] | GOV.WALES

[9] £1.5m for safe and warm hubs across Wales | GOV.WALES

Discretionary Assistance Fund

We welcome the Welsh Government's establishment of the discretionary assistance fund (DAF). The fund provides emergency financial support for people in immediate need but is not intended to be a long-term solution for support.

Indeed, it provides little relief for people living with MND as their increasing energy usage is not transitory. As the disease progresses, the need for both heating and assistive technology and, therefore, the cost of energy, will become both greater and more constant. As such, people living with MND need a targeted, long-term solution for support with their energy bills.

Beyond this, we are concerned that monitoring of the impact of the DAF remains difficult. Despite quarterly published statistics, it is unclear how many disabled people in Wales benefit from the fund.

Further, uptake of the fund remains low among certain groups. Despite Wales having a larger proportion of older people than anywhere else across the UK, the most recent data release shows people aged 60 and above received the smallest value through both arms of the DAF[10]. It is important to note that this may not be down to lack of need but more lack of awareness and accessibility.

Conclusions and Recommendations

We believe that the loss of winter fuel payments disproportionately impacts people with complex health conditions like MND due to their high energy need and lack of access to suitable benefits.

We welcome the steps Welsh Government have made to mitigate the impacts of the loss of the winter fuel payment alongside the broader increases in cost-of-living. However, we believe these are insufficient to properly support vulnerable people with particularly high fuel and energy costs like people living with MND.

We recommend the following:

1. Welsh Government to call on UK Government to restore the universal winter fuel payment.
2. Targeted, long-term financial support for high-energy users such as people living with and affected by MND.

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[10] Discretionary assistance fund: April to June 2024 [HTML] | GOV.WALES

3. Better communications around the current support available.
4. The consideration of the needs of people with complex health conditions like MND within all impact assessments for schemes designed to tackle fuel poverty.
5. Work with the Equality, Race and Disability Evidence Units to better evidence the energy requirements of disabled people, particularly those who are high-energy users such as people living with and affected by MND.