

**APPG ON MOTOR NEURONE DISEASE**

**15:00-16:00 on Wednesday 15 November 2023**

**Meeting minutes**

**MPs Present:**

1. Andrew Lewer MBE MP
2. Peter Dowd MP
3. Nick Thomas-Symonds MP
4. Peter Aldous MP (staff member representing)
5. Phillip Hollobone MP
6. Mary Robinson MP
7. Nigel Evans MP
8. Louie French MP
9. Justin Madders MP
10. Heather Wheeler MP
11. Richard Fuller MP
12. Jim Shannon MP
13. Jason McCartney MP

**Others:**

1. Mark Jackson – Senior Policy and Research Manager, Marie Curie
2. Kielan Arblaster – Policy Manager, MND Association
3. Nicky – Wife and carer
4. Secretariat - MND Association

**Apologies:**

Marion Fellows MP  
Lord Mackenzie of Culkein   
Baroness Finlay of Llandaff  
Lord Alf Dubs

1. **Welcome and introductions**

Alex Massey, Head of Policy, Public Affairs and Campaigning at the MND Association stepped in for Chair, Andrew Lewer MBE MP and welcomed everyone to the meeting. He informed the group we would be discussing the impact rising cost of daily essentials is having on those with MND and more broadly those living with terminal illnesses.

1. **‘The cost of dying’ - Mark Jackson – Senior Policy and Research Manager, Marie Curie**

Mark Jackson spoke about speak about Marie Curie’s work on [‘The cost of dying’](https://www.mariecurie.org.uk/globalassets/media/documents/policy/dying-in-poverty/k406-povertyenergyreport-finalversion.pdf), and recommendations on the extension of the NHS rebate scheme.

Mark stated that energy bills can rise around 75% after someone has received a terminal diagnosis, on top of the already rising cost of living costs. Due to a terminal diagnosis, the individual will usually need to reduce hours at work and so do their loved ones who care for them, resulting in a double financial squeeze. Marie Curie’s research found that in the last year in England and Wales alone, 150,000 people have died from conditions which are commonly treated by common medical devices. Higher costs and lower income result in more people being below the poverty line, with around 90,000 people dying and spending the last years of their lives below the poverty line.

Mark highlighted some of the recommendations in the report. He spoke about improving support with the cost of running medical devices by extending the eligibility criteria of the NHS rebate scheme, targeted support for wider energy costs for those with a terminal illness, energy bill support scheme, extension of the warm homes discount to all of those families who has someone who is terminally ill, and an energy social tariff on energy prices.

1. **‘Through The Roof’, The impact of the cost-of-living crisis on people with MND - Kielan Arblaster – Policy Manager, MND Association**

Kielan Arblaster spoke about the MND Association’s new report ‘Through the Roof’, which looks at the impact the cost-of-living crisis is having on people with MND. The report shows that people living with MND have been disproportionately affected by rising costs, particularly energy prices. This has forced them to make some difficult, and sometimes impossible, choices between essential items and their own health and wellbeing.

Kielan went on to explain in detail three of the themes from the report which found that people living with and affected by MND were making difficult choices on things such as:

* Affording basic living essentials - The research found that half reported their households experienced difficulties paying for essentials such as food, home heating and energy in the previous 12 months and 87% were worried about being able to pay for living essentials over the next 12 months.
* Managing a reduced income – The research found that on average people with MND spend more than £14,500 a year on living with MND, although, many spend significantly more**.** MND is a very costly condition to deal with and it is also rapidly progressing, which can result in the loss of one or more incomes and reliance on the social security system. However, eligibility criteria barriers and inadequacy of benefits were mentioned.
* Prioritising health and wellbeing – Research found that 72% of MND households rely on assistive equipment but 28% have reduced their use in the last 12 months due to rising energy cost.

Kielan then outlined some of the report's recommendations for change such as asking Government to review the adequacy to the eligibility criteria and the level of Personal Independence Payments, Attendance Allowance and Carers Allowance, ensure Universal Credit is set at a rate capable of covering life essentials, extend the disability cost of living payment into 2024 and implement an energy social tariff for households effected by MND.

1. **Nicky – Wife and carer affected by MND**

Nicky, who cared for her husband with MND, gave a very powerful presentation about the impact the cost of living crisis has had on herself and her family. Nicky’s husband was diagnosed in 2019 after he had been experiencing symptoms for around 6-9 months prior, he was only 48.

Nicky stated that in 2021, her husband went in for a second attempt at fitting a feeding tube however, the operation did not go very well and he ended up in intensive care. He then had to have a tracheostomy fitted. After 4 months in hospital, he finally went home where Nicky cared for him. Nicky did 160 hours of nursing training to allow her to care for her husband at home, whilst working full time. Financially their lives were drastically impacted, incomes went down whilst his needs increased resulting in costs going up, in addition to the general increase in the cost of living.

Nicky listed all the pieces of medical equipment that needed to be charged every day to ensure her husband was kept safe and secure, she listed 15 separate machines. On top of that, the cost of water, electricity and heating was rising and the need for them for keeping him safe and secure was also rising. Not only did Nicky need to keep him safe and warm, but she also needed to keep the 13 shift workers safe and warm too. Nicky highlighted an additional list of products which were not provided by the NHS such as creams, tissues, mouth swabs and pads that Nicky had to purchase herself, costing around £400 a month.

In 2020, before Nicky’s husband’s condition declined their gas and electricity bills were £150 a month, by 2022 they were over £800 a month. Nicky’s elderly parents had to help look after her husband whilst Nicky was working to keep a roof over their head and pay for all of these additional costs, in addition to the usual cost of living. Nicky highlighted the ripple effect around financial worries was felt by not just them but other around them such as their children, their families and their friends.

Nicky stated that families impacted by MND are grateful for everything they are given, but it needs to be proportionate to the costs that they incur. She stated that when you are faced with something as devastating as MND all you want to do is help and care for the person you love the most. She asked those in the room and Government to think about the costs and stresses involved for the families who are impacted by MND.

1. **Discussion**

Mary Robinson MP raised the point of what more can energy companies do. Mark commented the sector could be doing more but the challenge is how they are able to identify who needs support. At the moment, those vulnerable people are reaching out to the energy companies, however, the energy companies could start reaching out to those who need it by looking at e.g smart meter data and those who are struggling to pay their bills. The use and ease of accessing data however is a persistent issue.

Mary Robinson MP also raised concern for carers with Nicky responding saying that respite care would’ve been something that she would’ve really appreciated that.

Heather Wheeler MP spoke about experience she had had with a constituent who received significant financial remuneration for the care they required at home due to their condition. Heather highlighted that this may be due to the difference in welfare payments that were being received.

Andrew Lewer MBE MP asked the MND Association if they had explored within their research the difference and benefits between providing extra support from DWP and the benefits system in comparison to industry bodies and energy companies doing things. Kielan stated that the report did not investigate this but from the Association’s perspective energy costs for assistive equipment fall between a number of departments and there seems to be a hesitancy to lead on tackling the issue. Alex Massey stated that it is difficult to see how the benefits system would be able to necessarily deal with the level of need that has been mentioned today. It is tough for the benefit system to respond to this very specific and level of need which impacts a small number of people. There is an inequity in terms of the NHS’ support for energy costs as currently dialysis and oxygen concentrators are the only two pieces of assistive equipment which are eligible for the NHS rebate scheme.

Mary Robinson MP asked how many people are living with MND at any one time and what is the average cost per patient. Alex Massey said that more work needs to be done on this issue. He stated that there are 5000 people living with MND at any one time who will use a range of equipment. There is a spectrum of need and ultimately cost which is due to the progressive nature of the disease. The needs and symptoms of those living with MND get worse however each case is different. In terms of working out the overall costs, there is more work that needs to be done.

Andrew Lewer MBE MP referenced the ‘Act to Adapt’ campaign and highlighted concern at too many layers of solution to a problem. He outlined with consensus on the issue – addressing the cost of living and impacts it is having on people with MND – a solution needed to be found that didn’t involve delay, and heavy amounts of process, otherwise it would become an impractical solution. He highlighted two options: firstly, the NHS rebate scheme to cover all of the pieces of apparatus that is necessary and secondly smart meters to record the cost of the different pieces of equipment that are used and take that money off the bill. He was keen to find solutions which would limit the impact on people before it could be implemented.

Mark Jackson stated that dialysis and oxygen concentration are the two applicable to the rebate scheme as energy companies are able to take a meter reading from the machine, however you cannot do that for the other machines. This would require design improvements or the Government to agree on estimated amount of usage which they could generalise and rebate.

Nicky highlighted that the two solutions Andrew put forward were both short and long term. Adjusting the rebate scheme would be a quick, short-term action which would benefit people who are impacted by MND right now.

Andrew Lewer MBE MP stated the APPG had a good record in identifying specific issues with narrow policy solutions. E.g. 50 Million MND research funding and Act to Adapt. If the group decided to be specific about the pieces of medical equipment that needs to go on the rebate scheme, that may encourage success of campaigning.

Kuai Peng, who also cares for her husband living with MND, stated that the population of people on ventilation on MND is very small, but their need is significant. In 2019, 1% of people living with MND were on tracheostomy in comparison to 30% in Israel and America.

Nicky suggested that anyone living with MND who has a ventilator, cough assist and suction machine – three very vital pieces of equipment – should be covered. She felt this would be a good place to start.

1. **AOB**

Andrew Lewer MBE MP provided an update on UK MND Research Institute which was officially launched on 3 November. Andrew represented the APPG and was joined by leading researchers, charities and other relevant stakeholders. He stated that the launch was very well attended.

He also highlighted the issue around Riluzole shortages which is the main treatment available for people living with MND, at pharmacies in central, west and southeast of England over the lats month. He stated that the MND Association have been working with medicine supply agencies, MND Care Centres and NHS England to address this. He told colleagues to be aware should any constituents contact them, and any further action need to be taken.

Finally, he also highlighted the challenges of re-forming the group in March given APPG rule changes, but desire to do so. He asked colleagues to help out if he is in need of any help

1. **Thank-you and close**

Andrew Lewer MBE MP thanked colleagues for attending and for Mark, Kielan and Nicky for their presentations. He outlined the secretariat would collate the minutes, share these on the website and circulate to all officers.