



MEETING OF THE APPG ON MOTOR NEURONE DISEASE

14:00-16.00 on Tuesday 29th November 2022

Present

Andrew Lewer MBE MP (Chair)
Barbara Keeley MP
Mary Robinson MP
Stephen Timms MP
Sir Mike Penning MP
Jerome Mayhew MP
Lloyd Russell Moyle MP
Ben Lake MP
Duncan Baker MP

Peers

Baroness Finlay of Llandaff

In attendance

Jane-Howard Smith – Office of Sally Hart MP
Graeme Dolphin – Office of Margaret Attwood MP
MND Association – Secretariat
Zoe Nixon
Katy Styles
Julie Davies
Jessica

Apologies

Baroness Hollins
Lady Masham
Craig Whittaker MP

1. Welcome by the Chair, Andrew Lewer MBE MP

Andrew Lewer MBE MP welcomed colleagues to the meeting for the launch of the Motor Neurone Disease Association's 'Support MND Carers' campaign.

Paid tribute to Doddie Weir and the huge role he played in raising awareness about MND. Also highlighted the role he and his foundation played in the United2EndMND coalition in helping to secure the £50million ring-fenced funding from Government for targeted MND research. Passed on sympathies on behalf of all APPG members to Doddie's family circle and friends.

Introduced Alex Massey, Niall Murphy, Jessica and Julie as the four key speakers for the meeting.

2. Support MND Carers Campaign

- **Summary of the report's findings – Alex Massey, Head of Campaigning, Policy and Public Affairs at the MND Association**

Highlighted the presentation would be a snapshot of the report's findings and recommendations.

To conduct the research 250 unpaid carers for people with MND were surveyed, through focus groups and interviews. MND Association volunteers were also spoken to about some of the issues.

Many people caring people with MND are suffering from physical and mental exhaustion which has an impact on their own physical and mental health. Feelings of being exhausted, worrying about the future was common amongst the carers spoken to. Caring for someone with MND takes a lot of time. Over half the carers spoken to reported they spent over 75 hours a week caring for someone with MND which is significantly more than most full-time jobs. Over a third said their health was impacted. Tiredness, exhaustion were some of the most common effects listed.

Despite the legal right to have a carers assessment under 2014 Care Act, and needs assessed through Care Act 2014 and other legislation in devolved nations. That right is not being fulfilled and not being delivered. Fewer than a quarter of carers spoken to had never received a carers assessment.

The research showed assessors often didn't understand the extent of responsibilities of caring for someone with MND. Inappropriate support options were therefore offered, which often didn't meet needs for those being cared for, or for the carer.

Carers frequently highlighted significant financial impact of caring responsibilities. When it came to accessing financial support, the research found that over a quarter of carers don't know what benefits they were entitled to or outlined it wasn't easy for them to access. The research highlighted that 15% of people caring for someone with MND also cared for children which often gets lost: that people have other family responsibilities. Feelings of guilt were also expressed by many carers.

COVID-19 had a significant impact by social distancing measures, lots of support services were paused. When services were introduced, people with MND had to take significant precautions so people still felt reluctance with reengaging with support. Carers became cut off from that and couldn't rely on the sources of support that they normally had. Many people with MND still have to take significant precautions about COVID.

The 'SupportMNDCarers' campaign is therefore calling for:

1. National and devolved Government to undertake reviews of carers assessments to understand why carers assessments are not delivered and when they are, why they aren't leading to access to meaningful forms of support.
2. Local authorities to work closely with local NHS bodies to improve identification of carers, ensure that communication of information is out there so carers understand their right to a carers assessment.
3. Improved statutory social care services. Many carers of people with MND don't feel like they can rely on support from statutory social care services. People with MND need high skill care, for example, carers who know how to use complex equipment.
4. New targeted investment to fund regular respite for carers to support and improve physical and mental health of carers.
5. Increased financial support for carers with a full review of financial support currently provided. Carers are often left out of the conversation around cost of living and financial pressure. Therefore, the rate of carers allowance should be uplifted by £20 a week and rise in line with inflation.
6. The MND Association are working with partners in carers coalition and the care and support sector to call on the UK and devolved governments to devise respite and recovery plan for carers. The covid-19 enquiry must consider the impact on carers and have recommendations to fully support them.

[With a division bell called, Baroness Finlay took over chairing whilst MPs went to vote]

Baroness Finlay asked the guest speakers with lived experience of caring Jess and Julie to summarise the key points of what they had come to share, explaining her background in palliative medicine and concern at decreased beds in hospice care:

- **Jessica – social care sector in desperate need of reform to ensure enough skilled care workers to allow MND carers to access respite.**

Highlighted the inadequacies in care system and skill level of care staff meant she couldn't safely leave her husband. With that basic need not even able to be met, accessing respite care was a far reality for her. Told story of how she left her husband for 10 minutes with a carer in order to put her six-year-old son to bed and he almost died due to carer being unable to get saliva secretions under control resulting in him choking. She subsequently had to perform CPR in front of her six-year-old son and call emergency services. Highlighted that because MND is such a complex condition, care workers need special training to be able to cope with things.

- **Julie – lack of communication about supports available.**

Julie's husband Ian was only diagnosed in 2019 after having been ill for several years, doctors did not know what was wrong. Outlined that she was glad they didn't know it was MND for so long because "once you know your husband has MND, that is the end of your hope."

Highlighted the eight hours of support she received a week from the point Ian was diagnosed were a lifeline as they gave her time to care for herself, go for a walk and get through the days. Julie spoke about how despite pleading for continuity with carers that was rare, and it was only by chance she found out about night sitters, as towards the end Ian was struggling with his breathing and couldn't be left on his own throughout the night. There was other help she was not aware of, simply because no one told her about it.

[With MPs returning from the division, the Chair resumed the proposed agenda of speakers]

- **Highlighting how MPs can help support the campaigns through actions they can take Niall Murphy – Senior Campaigns Adviser at the MND Association**

Outlined the ask of the first phase of the campaign was for the Government to conduct an urgent review of carers assessments, with a particular focus on improving awareness, availability and access.

Asked:

- *English MPs* - Write to the Secretary of State for Health and Social Care highlighting these findings and urging them to consider launching a review into carers assessments
- *Wales MPs* - Keep pressure on the Welsh Government to publish the findings and recommendations from planned 18-month review.
- *Northern Ireland MPs* – Write to the Department of Health asking them to launch a review into carer’s assessments.
- *Scotland MPs* - MND Scotland are focused on improving social care for people with living with MND who can end up waiting weeks, or months, for essential care to be fully put in place.

- **Personal experience of caring - Julie Davies**

Despite suffering symptoms as early as 2004, Julie outlined her husband Ian was not diagnosed with MND until September 2019. From 2017 Julie had started to reduce her working hours to care for Ian. She outlined she “felt she had no choice,” even though she sometimes felt like running away as things were so hard. Julie shared there was nowhere for them to go for a break, and leaving the house was difficult.

In August 2019 a social worker came to speak with Julie and Ian, and after this she was initially given eight hours of help a week which allowed her to recharge her batteries, go for a long walk and take care of herself. She outlined this was a lifeline for her own mental and physical health.

In November 2019 she was given the formal carers assessment and started receiving a small allowance for caring, but this left like too little too late.

In August 2020, Ian’s MND had significantly progressed. He was now having trouble sleeping with the necessary breathing equipment, and it was only by chance that Julie found out about night sitters. When she enquired she was offered four nights of night sitting a week, a help Julie outlined she wished she had known about sooner as it was so valuable.

Ian passed away 28th February 2021. Whilst Julie recognized that there were man services and individuals who worked during Covid to supply them with the equipment and strategies needed there were serious shortcomings at a number of points. The first with delays, a bed was ordered for Ian in April 2020, but did not arrive to December 2020, a wet-room was installed in

November 2019, but it wasn't usable until February 2020. She had to chase for a social worker, she had to chase for help with using equipment, and they were denied continuing health care.

- **Personal experience of caring - Jessica**

Jessica outlined that many people think of unpaid carers as older people, choosing to care for their spouse out of love after many years of marriage. Jessica's husband however was diagnosed with MND when he was only 32. Over the last six and a half years, her husband has needed her every step of the way.

Initially, she tried juggling to keep her job, care for her husband and be a young mum to their son, but with the onset of the pandemic she became a full-time carer overnight. Despite her husband having carers, his needs are so complex Jessica cannot leave him.

She outlined she has struggled to get skilled, experienced carers, as a result she has gone through years of lifting her husband from the toilet, in and out of bed, sitting him up in his wheelchair, feeding him and repositioning his hourly, every night. She told the room this has pushed her body far beyond its natural limits.

She highlighted that she feels what she does as an unpaid carer is seen as so little value by the state, and if she has had a carers assessment she hasn't benefited from it.

Jessica commented "It is a myth this kind of thinking that all unpaid carers make a free choice out of love and should therefore forfeit any right to proper benefits and support. For many, being an unpaid carer is an exhausting necessity done with love because of the failures of the care system to provide any kind of adequate support structure."

3. Questions and discussion

Barbara Keeley outlined the issues discussed by Jessica and Julie closely mirrored those raised in reports she had written whilst working as an advisor to a national charity for carers. Raised commitment to seeing these changes.

Katy Styles, from the We Care Campaign spoke about how on Carers Rights Day (24th November) she was hearing from MND carers who had no understanding of what the Care Act 2014 meant for them. Outlined the report had not picked up on the wider piece about funding, where local authorities put out to tender every three years, so carer's support organisations don't know whether they're going to get the bid.

4. AOB

Andrew Lewer raised progress of the National MND Institute, and the meeting taking place in London 29th November launching the Institute. Re-affirmed commitment of APPG members to continue pressing Government on issues around applications for funding in Phase 2.