



ONLINE AGM OF THE APPG ON MOTOR NEURONE DISEASE

Wednesday 23rd FEBRUARY 2022

Present

Andrew Lewer MBE MP (Chairman)
Alberto Costa MP
Amanda Solloway MP
Barbara Keeley MP (researcher)
Brendan Clarke-Smith MP (researcher)
Chris Clarkson MP (researcher)
Chris Grayling MP (researcher)
Chris Evans MP
Christina Rees MP
Christine Jardine MP
Sir Graham Brady MP (researcher)
Henry Smith MP
Ian Byrne MP (researcher)

Jason McCartney MP
Dr Luke Evans MP (researcher)
Mark Tami MP
Nia Griffiths MP (researcher)
Karin Smyth MP (researcher)
Kerry McCarthy MP (researcher)
Richard Fuller MP
Dame Rosie Winterton MP
Sarah Olney MP (researcher)
Simon Fell MP (researcher)
Stephen Hammond MP (researcher)
Steve Baker MP

In attendance

Alex Massey – MND Association
Jonathan Collier – MND Association
Christine Panayi – Person affected by MND

Jacqui Ford – Person affected by MND
Sian Guest – APPG Secretariat
Lana Ghafoor – APPG Secretariat

1. Welcome and introductions

Andrew Lewer MBE MP welcomed everyone to the AGM and meeting to discuss improved access to housing adaptations for people living with MND. Andrew informed attendees that the meeting would be recorded, and the video placed on the APPG's webpage after the meeting. In addition, photos would be taken throughout the meeting.

2. Election of Officers and appointment of Secretariat

The following Officers were elected to the APPG:

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| Chair | - | Andrew Lewer MBE MP |
| Vice-Chairs | - | Barbara Keeley MP |
| | - | Brendan Clarke-Smith MP |
| | - | Chris Evans MP |
| | - | Christina Rees MP |
| | - | Christine Jardine MP |

- Jessica Morden MP
 - Sir John Hayes MP
 - Mark Tami
 - Steve Baker MP
- Treasurer - Rosie Duffield MP

The MND Association was re-appointed as the Secretariat to the Group. It was confirmed that the financial contribution to the APPG does not exceed the sum of £12,500.

3. United to End MND and Scrap 6 Months campaign updates

Andrew Lewer MBE MP gave an update on the United to End MND campaign and the announcement by the Government of £50 million investment into targeted MND research. He encouraged colleagues to contact DHSC and BEIS to push for clarity with regards to how and when the £50 million will be allocated.

Andrew went on to give an update on the Scrap 6 Months campaign which was successful in gaining agreement from the DWP to move from a six-month definition of terminal illness to a 12-month definition for the purpose of gaining fast-track access to benefits. Legislative changes to Universal Credit and Employment and Support Allowance will be made this Spring, however changes to Personal Independence Payments, Disability Living Allowance and Attendance Allowance have yet to be announced and will be made when 'Parliamentary time allows'.

Andrew stressed the fast-progressing nature of MND and urged colleagues to contact Ministers to make sure the legislative changes progress quickly so that people living with MND can benefit from the impact of these changes.

4. Housing adaptations

Alex Massey, Policy Manager, MND Association

Alex provided an update on national policy developments regarding housing adaptations and the Act to Adapt campaign. He highlighted that Act to Adapt focuses on the provision of safe and accessible homes for people living with MND, on the understanding that everyone deserves to live in a safe and suitable home. For people living with MND, this means an accessible home that enables them to maintain independence, dignity and quality of life as the disease progresses.

Alex shared the MND Association's survey which highlighted a number of issues including the high cost of adaptations, lack of financial help, length of time taken to deliver adaptations, availability of accessible homes, lack of support locally and consistency of information.

The survey also showed issues relating to the Disabled Facilities Grant (DFG) processes including:

- Means testing system perceived as widely unfair as it excludes the outgoings required to live with and manage MND. A savings threshold of £60,000 was seen as too low.
- Maximum mandatory grant sometimes inadequate for major adaptations (£30,000 in England, £36,000 in Wales and £25,000 in Northern Ireland).
- People living with and affected by MND not knowing where to go for support and information.

- Lengthy waiting times – speed of MND progression not reflected in urgency of delivery.
- 26% of local authorities in England do not process all DFG applications within nationally specified timeframes.

Alex spoke about the work of the Association engaging with local councils to ask them to enact their discretionary powers to apply a fast-track process and to apply non means testing for adaptations below £5,000.

The Act to Adapt campaign has also made recommendations to national government:

- National governments must maintain a clear commitment to ongoing central funding for DFGs when current allocations end. This must continue to rise to reflect demand and demographic change.
- National governments should review the mandatory means test to address key identified problems including
 - The low savings threshold
 - Account not taken of real outgoings, including housing costs and the extra costs of disability

It is disappointing that the DFG budget will not be increased. The DFG budget will be £570m in 2022-23, 2023-24, 2024-25, compared to £573m in 2021.

More positively on the Social Care White Paper (December 2021), there are a number of commitments on DFGs including:

- Reviewing the means test
- Increasing the DFG upper limit
- Expanding DFG scope to include more assistive technology
- Altering the system for allocations to local authorities
- Forthcoming new guidance about delivery

Alex highlighted work on currently driving the implementation of the Equality and Human Rights Commission's recommendation to require all new housing to be built to accessible and adaptable standard by default, and a minimum of 10% to wheelchair accessible standard.

Jonathan Collier, National Campaigns Manager, MND Association

Jonathan highlighted the Act to Adapt campaigning and the MND Association's work liaising with local authorities to improve conditions for people living with MND. The Association sent Freedom of Information requests sent to councils in England in May 2021 about the support they provide. Data showed that many councils are failing to provide the support that people living with and affected by MND need.

The Association will continue to work with local campaigns groups, volunteers and local authorities in order to improve housing adaptation processes for people living with and affected by MND by asking local councils to introduce formal fast-track process for people living with MND and remove financial assessments for DFGs for adaptations up to £5,000.

Jonathan shared examples of good practice from the Wirral and some recent successes in achieving policy change with Sefton Council and Dartford Council following collaboration with the Association, local volunteers and campaign groups. This has been supported by tools which including the MND Association's housing adaptations map, developed using FOI

data providing an overview of council policy in each area, enabling supporters and campaigners to enter conversations with their local authorities.

Jonathan made a request on behalf of the Association to MPs to write to local authorities and reiterate the two key campaign asks – the fast-tracking of people living with MND in DFG processes and scrapping of means testing for adaptations up to £5,000. He also asked that MPs put pressure on the Government to issue guidance to local authorities, asking them to use their discretionary powers to fast track people with MND and scrap means testing for adaptations up to £5,000.

Question: Steve Baker MP asked if a template could be prepared to support MPs in this engagement. Jonathan responded by saying that the Association would share a template letter via Andrew Lewer MP to enable them to write to their relevant local authorities.

Christina Rees MP, APPG Vice Chair

Christina Rees MP provided an update on the Welsh Homes for MND Campaign which was launched in 2021 to highlight problems faced by people living with MND in Wales so that, when needed, people can access housing adaptations. The campaign called on the Welsh Government to issue guidance to local authorities to instigate fast track, non-means tested process for adaptations and to report to the Welsh Government on timely adaptations.

In response to this campaign the Welsh Government Housing Minister announced the removal of means testing for small and medium adaptations, with an additional £1 million for local councils to support this change. To support and drive this change Peter Fox MS became the MND Champion in the Senedd holding meetings with people living with and affected by this process. He launched the Act Now report in the Senedd which highlighted the challenges people were facing and why a fast-track process for housing adaptations for people living with MND was vital due to the rapid progression of the disease.

Christina shared details of a debate that was held in December where 41 MSs voted in support of the campaign request, which was then noted. The Welsh Government Health Minister has confirmed that all local authorities should remove means testing for small and medium adaptations by 2022, this was followed by a statement from the First Minister stating that as the numbers of people living with MND in Wales were relatively low, then local councils should apply a personal approach to support the fast-track process.

Ongoing work with the WLGA will look to implement a unified fast track model later in 2022.

5. Personal experience – panel discussion

Sian Guest, Public Affairs Manager at the MND Association held a discussion with Christine Panayi and Jacqui Ford, both who shared their experiences of navigating the housing adaptation process.

Jacqui spoke about her experiences of losing her husband Chris to MND and the adaptations made to their home. They paid for the adaptations largely independently as the grant process was lengthy and would take too long, and they were fortunate to have been able to make that financial decision. She felt that the installation of a washer/dryer toilet for Chris was done in a speedy manner and took three months. Jacqui felt her experience of the housing adaptation process was largely positive, but it was acknowledged that the reason for this is because they were paying for the adaptations themselves and the local authority collaborated well with themselves and others.

Christine spoke about her experience of losing her partner Ray to MND in December 2021 and the frustrations encountered whilst navigating the DFG process with Enfield Council. Christine received misinformation and very little support from local occupational therapists and the local council.

Christine was told she would have to find £92,000 in order to fund necessary adaptations to the family home, despite the adaptations costing much less than this, with her outgoings not taken into account during the financial assessment. There was no appeals process and she was told by the council that she would be unable to make a complaint at that time, due to it being close to the financial year end.

As Christine's partner Ray's MND progressed, he was forced to live in their downstairs living room where Christine delivered his day-to-day care, his toileting and personal care. When a ramp was finally installed, the only time her husband was able to make use of it was when being taken to hospital, just weeks before he died. Christine spoke about juggling family and working alongside caring for Ray and her attempts to provide her partner with some quality of life. She described the experience as a living nightmare and felt that they were penalised as she was working.

Sian Guest shared the experiences of Nicola and Simon who have also had frustratingly slow and costly experiences of the housing adaptation process. Simon who is living with MND and his wife Nicola were told that they would have to fund an external extension to house a wet room themselves. The council finally agreed after 12 months of discussion that they would allow them a grant for the cost of a bathroom conversion however they would not release the funds until the work had been completed.

This has left Nicola and Simon without any savings and now deeming them eligible for funding from the council. They are now calling for local councils to have a clear processes, consistent messaging, support and guidance. Councils need to understand the needs of people living with MND and how important it is to act quickly to enable these people to live safely, independently and with dignity in their own homes.

Andrew Lewer MBE MP thanked Christine and Jacqui for sharing their personal experiences despite being difficult for them to share and reiterated how important it was to understand the challenges based on their personal experiences.

- 6. Questions:** MND Association Campaigns Volunteer, Siobhan asked for clarity on the sum allocated recently by the Government to MND research and also on the DFG budget.

7. Summing up

Andrew Lewer MBE MP thanked all for attending and said he would circulate the template letter for his colleagues to send to local councils requesting that they adopt fast-tracking of people living with MND in DFG processes and scrapping of means testing for adaptations up to £5,000. Andrew said he would raise the issues and press for guidance to be issued to local councils during a meeting with the Care Minister later that day.