



MEETING OF THE APPG ON MOTOR NEURONE DISEASE

Wednesday 18 November 2020

Attendees

Andrew Lewer MBE MP (Chairman)
Peter Aldous MP
Caroline Ansell MP (researcher)
Duncan Baker MP
Steve Baker MP
Simon Baynes MP (researcher)
Ben Bradley MP
Sir Graham Brady MP
Ian Byrne MP
Jack Dromey MP
Nigel Evans MP (researcher)
Tim Farron MP
James Gray MP (researcher)
Nia Griffith MP
Drew Hendry MP

Wera Hobhouse MP
Sir George Howarth MP
Christine Jardine MP (researcher)
Gillian Keegan MP (constituency capacity, researcher)
Barbara Keeley MP
Tony Lloyd MP
Jerome Mayhew MP
Jason McCartney MP
Jessica Morden MP
Mary Robinson MP
Mark Tami MP
Matt Western MP (researcher)
James Wild MP
Dame Rosie Winterton DBE MP

Peers

Baroness Finlay
Lord Hector MacKenzie

1. Welcome and introductions

Mary Robinson MP took the chair and welcomed everyone to the meeting.

2. Updates:

2.1 The DWP's review of the Special Rules for Terminal Illness

Alex Massey (Policy Manager, MND Association) updated the Group on the Department for Work and Pensions' (DWP) review of the benefits system for people who are terminally ill. The review, launched in July 2019, has been concluded by the DWP and sent to the Treasury for approval. The review is expected to recommend removing the requirement for people to prove they have six months or less to live in order to qualify for the fast-track route for claiming benefits. The review is also expected to recommend the removal of reassessments for terminally ill claimants after 3 years. Alex thanked the Group for their support for the Association's *Scrap 6 Months* campaign. These changes will make a significant difference to people with motor neurone disease (MND) and other terminal conditions. Alex asked members to treat this information as confidential until the DWP announces the changes. Those present agreed to write to the Chancellor recommending the swift approval of this policy change. [Letter sent 23 November 2020].

2.2 The impact of Covid 19

Sally Light (Chief Executive, MND Association) updated the Group on the impact of Covid-19 on people with MND and the MND Association. The MND Association has become increasingly concerned about delays in referrals to neurology. Twelve of the MND care centres they fund reported a drop in referrals of nearly 20% compared to 2019, with a mean increase in waiting times of nearly 2 months. This is resulting in delays to diagnosis and subsequently access to health and social care services, including time-sensitive respiratory support. The APPGs on MND, MS, Parkinson's, Epilepsy and Acquired Brain Injury are holding a joint meeting to discuss the impact of the pandemic on neurological services and members were encouraged to attend [Monday 7 December 2020, 4.30-6pm].

Sally discussed the interim prioritisation list for access to a Covid-19 vaccine. She explained that people with MND under 65 were due to receive the vaccine in the 6th wave. Sally recounted the case of a young family in London where the husband has MND and their six-year old son has had to be removed from school as infection rates have risen. They have been told the father wouldn't survive Covid and until he can access a vaccine, the child could be missing out on months more of vital education. [The interim plan has subsequently changed so that people with MND under 65 classed as clinically extremely vulnerable will receive the vaccine in the fourth wave, and the remainder in the sixth wave].

Lastly, Sally updated the Group on the impact of the pandemic on the charity's finances. The MND Association anticipate a deficit of around £400,000 in 2020. They haven't been able to access the £750 million package of support allocated to charities by the Government, although have benefitted from the furlough scheme. Sally said 2021 is expected to be very challenging for charity fundraising, and they are forecasting a 20% drop in income next year. The charity is particularly concerned about its ability to continue to contribute significant funds to MND research, in the hunt for effective treatments and ultimately a cure.

2.3 Government funding for MND research

Jill Douglas (Chief Executive, My Name's Doddie Foundation) introduced the Foundation, which was established exactly three years ago by the former Scottish and Lions rugby international Doddie Weir. Jill stated that the Government currently only spends around £3m a year specifically on MND research, with charities contributing more. The UK is currently amongst the best in the world for MND research but could be world-leading with the right support. Jill stated that the Foundation is currently working jointly with the MND Association, MND Scotland, scientists and people with MND on a proposal to establish a virtual MND Research Institute. Jill introduced representatives from the coalition who were present. The coalition is seeking £10m a year over 5 years from the Government to establish the new Institute. The Institute would bring together the finest brains in MND research and invest in ground-breaking research.

Many building blocks are already in place - an MND Register, the beginnings of much more efficient and flexible trial techniques, stem cell models and world leading biomarker research. The Institute would bring all these initiatives together, consolidating the UK's leadership in research and attract greater investment from global pharmaceutical companies.

Mary Robinson asked about the role of the new institute. Professor Al-Chalabi (Kings College London) replied that it would bring together world-leading expertise based in the UK, provide a platform for co-ordinating research and accelerating the drug discovery process. Mary went on to ask if there were lessons to be learnt from the response to developing a vaccine for Covid-19. Professor Al-Chalabi replied that it demonstrated how clinical trials could be successfully carried out remotely.

Barbara Keeley MP asked about the impact of Covid on MND research. Professor Al-Chalabi replied that there were positives and negatives. Increased digitalisation had facilitated some aspects of research but that the pandemic had led to delays in diagnosis and difficulty monitoring the progression of the disease, for example monitoring breathing problems in patients.

Tony Lloyd MP asked how far MND research overlapped with other neurological conditions. Professor Al-Chalabi replied that he is conducting research funded by the Medical Research Council to look at the overlaps. He went on to say that MND can teach us about other conditions, as abnormal proteins accumulate in all the conditions.

Andrew Lewer MBE MP takes over the Chairmanship

3. Access to home adaptations and accessible housing for people with MND:

Alex Massey (Policy Manager, MND Association) presented some research the MND Association has carried out into access to home adaptations and accessible housing for people with MND. A copy of his slides is attached to the Minutes. A summary of the research findings is below:

The MND Association surveyed 387 people with MND and asked them about their experiences of adapting their homes. The top three challenges identified were:

- Cost of adaptations (96%)
- Lack of financial help (39%)
- Length of time taken for the adaptations (25%)

Alex continued to explain that lengthy waiting times mean that the speed of MND progression is not reflected in the urgency of delivery; the means testing for Disabled Facilities Grants (DFGs) is seen as unfair as it excludes outgoings, which increase significantly as the disease progresses; and the savings threshold of £6000 is too low. The maximum DFG grant (£30,000) is seen as inadequate for major adaptations; there is a shortage of existing accessible homes and lack of accessible/adaptable home registers.

The delivery of DFGs is slow - 26% of local authorities in England do not process all DFG applications within nationally specified timeframes; 42% of authorities did not pay all approved DFGs within one year; and seven authorities in England reported they funded projects within one year in 50% or less of all cases.

The MND Association's report includes the following recommendations for local authorities with responsibility for DFGs:

- Put in place a transparent, fast-track, non-means tested process for adaptations under £5,000.
- Introduce a fast-track process for people diagnosed with a terminal illness
- Review compliance with target timescales to ensure these are met in 100% of cases.
- Develop a policy using powers under the Regulatory Reform (Housing Assistance) Order to introduce discretionary support, which could include:
 - 'Lean' or no means tests for low-cost high impact adaptations
 - Increasing the cap on the maximum grant
 - Removing the means test for common low-cost adaptations such as stairlifts

The MND Association's report includes the following recommendations for 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 cost and the extra costs of disability
 - Implement 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.

The Chairman thanked Alex for his presentation and opened the meeting to questions. Barbara Keeley and Mark Tami MP asked if the MND Association could share local authorities' performance data on DFGs, including waiting times. Barbara asked what actions MPs could take to support this work, for example tabling questions. Alex Massey replied that MPs could ask their local authority if there is a fast-track in place for DFGs, if the local authority has used its DFG allocation and if the local authority uses its discretionary powers when awarding DFGs.

A personal perspective - Len and Nadine Johnrose

Len is a former professional footballer and teacher. He was diagnosed with MND in 2017 and has needed to adapt his home as the disease progresses. Len now uses a wheelchair, has little use of his hands and his speech is affected.

When Len needed ramps to be able to leave his house, the Professional Football Association (PFA) stepped in and funded the ramps to the tune of £65,000. The work was carried out quickly and efficiently. However, in March this year Len was assessed as requiring ceiling hoists to enable him to transfer between his wheelchair and bed/chair and applied to Ribble Valley Borough Council. Unfortunately, he has faced significant delays in the hoists being fitted and does not anticipate them being installed until 2021, over 9 months after they were requested.

The lack of a hoist meant that Len suffered a fall in October and his wife Nadine was unable to assist him. They had no choice but to call an ambulance and the paramedics helped Len back up onto the bed. Len and Nadine don't expect the hoists to be fitted before January/February next year and as Len candidly says, "I might not be here".

Len and Nadine commented that they are younger than many couples facing MND and have a good support network. They expressed their concern about how people with MND without a support network would cope.

The Chairman thanked Len and Nadine for sharing their experiences which illustrated the problems people with MND and their families face when they adapt their homes. Andrew Lewer MBE MP reiterated that MPs can support the MND Association's campaign by writing to their local authorities to find out if they have a fast-track system in place for DFGs. The MND Association has provided a template letter for this and a copy is attached to the Minutes with a copy of Alex Massey's slides.

Andrew Lewer MBE MP thanked all the speakers, especially Len and Nadine, and colleagues for attending the meeting.

November 2020