

Preliminary findings: research areas and symptom-based experiences shared by people affected by MND

Between September and December 2022, we asked people affected by MND in Scotland about what mattered to them via our 'MND: What Matters' survey. This included questions about what areas or questions they'd like research to look at, and what symptoms were most challenging for them. Throughout the survey, 378 people affected by MND shared their thoughts. Respondents to the full survey included those diagnosed, family members/carers, and bereaved family members. The preliminary findings to some of these questions are below, for interest, and to assist with your application if relevant. *Please note, these are preliminary results only. There will be further aggregation and analysis of this data.*

Research questions and selected areas

We also invited respondents to share the questions or areas that they would like future research to look at. We outlined that cure and treatments that slow progression would remain our priority, but we were keen to know whether there were other aspects they would also like research to look at.

Across the three survey audiences (those diagnosed, current family members/carers, and bereaved family members), the responses can be roughly grouped into the four areas below.

1. Diagnosis and cause (the questions here are primarily orientated around improved and faster diagnosis, and research which explores the cause of the disease)
2. Progression and triggers (this included questions around whether aspects like injury, environmental factors, illness, anything else affects the progression of the condition)
3. Symptomatic management (research that deals with particularly challenging symptoms, such as those listed in the first half of this document)
4. Possibility of passing on the disease, and research into the genetic components of the condition.

Founders: John and Peigi Macleod Royal Patron: HRH The Princess Royal

Troublesome symptoms

People diagnosed with MND were invited to select and share which symptoms related to their MND caused the most significant problems for them. They could select as many as were relevant from a list of symptoms compiled by a group of health and social care professionals. Respondents were also invited to add in symptoms missed from this list via a free text function.

- 77% of people diagnosed with MND selected fatigue as causing significant problems. Out of all the symptoms listed, this was the most selected
- Almost as common, 76% of people diagnosed selected weakness in their legs, and matching this, 76% selected weakness in their hands
- 62% of those diagnosed reported that cramps and pain were causing significant issues, and specifics around cramps and pain were most listed in the free text option responses too.
- 51% reported speech loss or changes caused significant issues,
- 49% reported issues with saliva. Using prompting options, 58% of these respondents shared that this issue was around having excess saliva (sialorrhea), with the remainder indicating that having saliva that felt too thick was the problem.
- For those identifying as current carers and/or family members, the biggest issues facing them as result of caring for someone with MND orientated around fatigue as a result of the emotional and physical elements of care work (68% selecting this). This was followed by anxiety (59%) and issues with sleep caused by night-time caring responsibilities (56%).
- When current carers and/or family members were asked about whether there were any symptoms experienced by loved ones/the person they care for which they found particularly challenging, the most mentioned were loss of communication, frustration on the part of the person with MND, concerns about the person with MND choking, and the loss of movement which increased the physicality of care required.

The findings from this research will be shared in full later this year.

January 2023

Founders: John and Peigi Macleod Royal Patron: HRH The Princess Royal