



Friend, here is an update from the support and research teams at MND Scotland.



A warm welcome to our latest support and research newsletter.

Firstly, a thank you to everyone that took the time to sign our open letter ahead of the Scottish Parliament elections earlier this month. There is more information below on our Manifesto campaign, but we really appreciate your support for the work we do to influence meaningful change at Government level.

At the end of last month, we shared a survey with people living with MND and their carers to share views on a European care pathway for MND.

[**There is still time to take part in the survey by clicking this link.**](#)

A reminder that anyone who requires support with technology, we have partnered with AbilityNet, a UK-wide network of Tech Volunteers who are

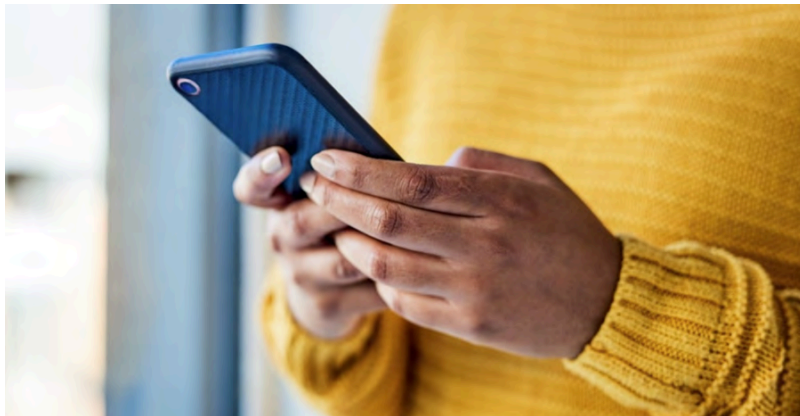
available to offer free technology support. [Read more about how AbilityNet can help you.](#)

Remember, if you need any support, please don't hesitate to contact

support@mndscotland.org.uk.

Nicola Povey, Head of Support Development, and Jane Haley, Interim CEO and Director of Research

Coffee afternoons in Dundee and Glasgow - June 2026



MND Scotland is hosting two pilot coffee afternoon events next month, one in Glasgow and one in Dundee, for people currently living with MND, or those who have a loved one currently living with MND.

Our coffee afternoons provide an opportunity to meet others affected by or living with MND, share experiences, and connect with one another. At the events the MND Scotland support team will give a presentation on our services. We will also be joined by our legal partners Caesar and Howie, who will talk about free wills and power of attorney for those affected by MND and answer any questions you may have. MND Specialist Nurses will also attend to have a chat and answer your

questions, and both events will have a complementary therapist present.

Dundee: 16 June 2026, 1-4pm, Hegarty Suite, Tannadice Park

Glasgow: 18 June 2026, 1-4pm, Thornton Suite, Ibrox Stadium

If you would like to attend, please register your interest here so we can organise the tea, coffee and biscuits - [**MND Scotland Coffee Afternoons – Registration – Fill out form**](#)

For full details about the event, including travel and parking advice, please visit the event pages on our website:

Dundee: <https://mndscotland.org.uk/events/mnd-scotland-coffee-afternoons-dundee/>

Glasgow: <https://mndscotland.org.uk/events/mnd-scotland-coffee-afternoons-glasgow/>

Register for our pilot coffee afternoons

Manifesto - thank you for your support



Ahead of the recent Scottish Parliament Election, we appealed to the next Scottish Government to legislate and recognise the urgent statutory rights

and needs of those with terminal illnesses like MND.

Our **Manifesto** highlighted the devastating impact of statutory services and research not keeping pace with the rapidly progressing nature of MND.

[Learn more about our 2026 Manifesto](#)

We also welcomed the SNP's explicit mention of MND in their Manifesto commitment to fast-track social care for people with MND, and invest in MND research. The language used directly reflected our Manifesto, which was shared with all parties in January, and through our work last year.

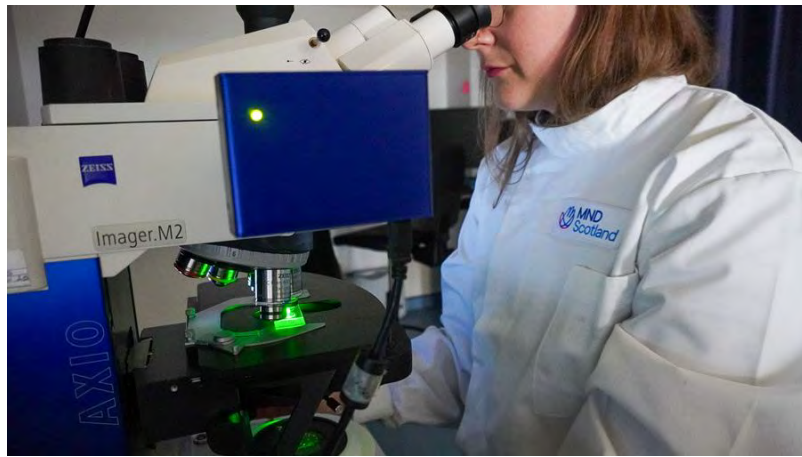
We further shared our Open Letter to the First Minister, which received over 600 signatures from the MND community. Thank you to everyone that signed the letter to support our work. Our Policy team is now working with members of the newly elected parliament to make sure the voices of people with MND are heard.

We are already starting to see changes in some local areas, and will share more about our work with the next government in future newsletters. If you would like to be involved in any policy work, such as sharing your experiences or meeting with MSPs, please do get in touch at policy@mndscotland.org.uk.

Throughout the campaign, we were grateful to four families who allowed us to share their stories of challenging experiences accessing home adaptations. Thank you to [Lisa](#), [Lynda & Bill](#), [Katie](#) and [Nicola](#).

Read the MND Scotland Manifesto 2026

**Update on amantadine
from MND-SMART trial**



In March, **MND-SMART** announced the latest results of the third drug to be tested by the innovative clinical trial.

An independent trial committee reviewed the data for amantadine and decided that the trial should stop testing the drug. The interim analysis results show that amantadine has not demonstrated a benefit in slowing MND progression.

Dr Jane Haley, Interim CEO at MND Scotland, said: “We are incredibly proud to have worked with the MND-SMART team and wider MND community to create lasting MND clinical trial infrastructure for the UK’s biggest ever MND clinical drug trial. While these results about amantadine are disappointing, we would like to thank everyone who has participated in the trial to date. People with the disease taking part in clinical trials is vital to help us find effective treatments and a cure.”

[Read more about the MND-SMART update](#)

Guidance published for OTs



Having a safe and accessible home is critical to enabling someone to live with the dignity and care that everyone deserves. Occupational therapists are key to supporting people with MND to continue living in their own homes.

A practice note, developed by MND Scotland, the Royal College of Occupational Therapists, consultants and neurology occupational therapists, the Association of Local Authority Chief Housing Officers (ALACHO), and Marie Curie, has been developed to offer guidance for occupational therapists on supporting people living with terminal illnesses when they require housing adaptations.

[Read more about this story on our website.](#)

[Read the practice note here](#)

New PhD Studentship



MND Scotland has partnered with **LifeArc** to co-fund a new PhD Studentship.

Dr Marta Vallejo at Heriot-Watt University will receive almost £100,000 to explore whether changes in gut tissue can provide early warning signs of MND.

Currently, diagnosis usually happens once symptoms are well established, leaving limited options for intervention. By looking for signs of disease before symptoms begin, researchers hope to develop tools that support early intervention and more personalised care for people living with MND.

[Read more about Marta's research here](#)

And finally ...



As shared in the Winter newsletter, our survey indicated you are keen to see more regular staff updates and photos. Over the next few newsletters, we are going to share a bit more about the team.

Meet Tali Noble

I am one of the National Support Advisors at MND Scotland, and I strive to help clients as much as I can. I provide support with a range of queries including, but not limited to, financial reviews, benefit applications, wills and power of attorney applications, and counselling referrals. I also help with housing and social care issues and work closely with our policy team to advocate for positive changes within these areas.

Something I love about working at MND Scotland is that there are always opportunities to help out and get involved in different events and activities. I was involved in a bucket collection at Ibrox Football Stadium last year, and I am hoping to take part in one of the firewalks next! Working with other organisations and meeting people in the community is a particularly empowering

component of working at MND Scotland.

In my free time, I love to try different arts and crafts. So far, I have tried clay making, gem painting, crocheting, colouring in books and paint by numbers. Next on my list is candle making! I also love spending time with my two black cats, Jack and Victor (yes, they are named after 'Still Game').

We welcome feedback on our quarterly newsletter. If you have any comments or suggestions, please get in touch by emailing

communications@mndscotland.org.uk.



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MND Scotland is the only motor neuron disease (MND) charity providing direct support to people living with MND in Scotland. We campaign to create lasting change and invest in pioneering MND research to find a cure.

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