Latest support and research news from MND Scotland

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MND Scotland
Making time count

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

Welcome to the latest edition of the support and research newsletter.

Some of you may remember that in 2022, we invited people affected by MND to share their views in our **What Matters Survey**. Early next year we will invite you to share your opinions again as we revisit the research, and refine it to help us understand how our focus as an organisation can best meet your needs. We will share the survey once it's available in the New Year, so please watch this space. We encourage as many people as possible to take the opportunity to share your views.

As part of ongoing work to offer more helpful information about MND, we are planning a series of virtual information webinars. People affected by MND are at the heart of everything we do, so to help inform the subjects, structure and timing for these sessions, we are looking for volunteers to join a webinar focus group. If you would be interested in sharing your thoughts to help us shape this new activity, please email **involvement@mndscotland.org.uk** and a member of the team will be in touch.

Thank you for your continued support this year. As always, we are keen to hear your feedback. Please continue to share your thoughts by emailing **communications@mndscotland.org.uk**.

Angela Harris, Director of Support Development, and Jane Haley, Director of Research

Ways we can support you this winter

Financial support

If you have been affected by the changes to winter fuel payments, MND Scotland may be able to help with a one-off payment for families affected by MND to help ease your financial burden. Please reach out to us today to find out how we can help.

Emotional support

The nights are getting darker and it can often help to talk to someone outside of your own family and friends if you're feeling isolated. Our Counselling Service gives people living with MND and their families the opportunity to access up to 12 free one-to-one counselling sessions. These sessions are led by a qualified therapist and could help you understand and manage difficult feelings you may be experiencing.

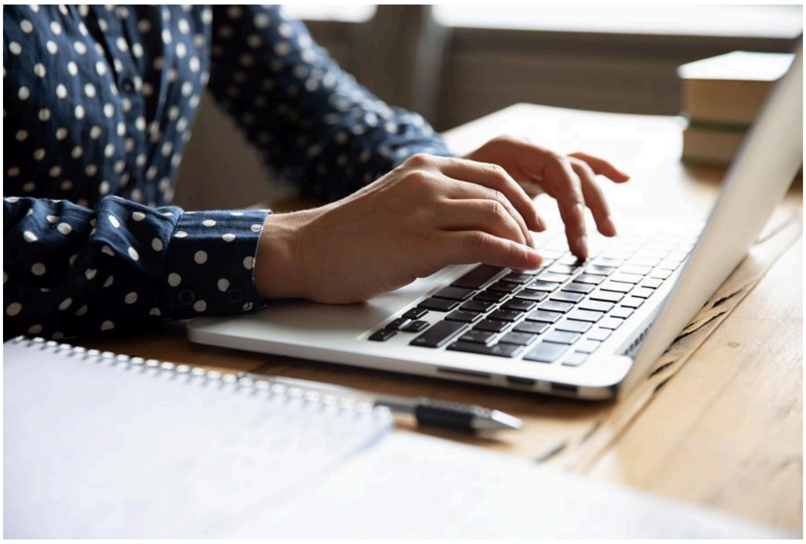
Feedback from people who have received counselling:

"I would recommend counselling to anyone going on this horrendous journey as an MND carer, especially at the beginning."

"I always stubbornly refused counselling but I have to say I am so glad I went ahead as the therapist encouraged me to always look at the wider picture and encouraged me to set my boundaries. She was a fabulous help, so thank you so much."

For more information, **please visit our website** or call **0141 332 3903** to speak with a member of our team.

Opportunities to get involved in research



We have been asked to invite people affected by MND in Scotland to get involved in several different research opportunities. These projects are not funded by MND Scotland, however, they offer a chance for you to help impact and shape MND research.

A summary of each opportunity can be found below. For more information on the involvement opportunities **click here**, or email **involvement@mndscotland.org.uk** and indicate which opportunity you are interested in.

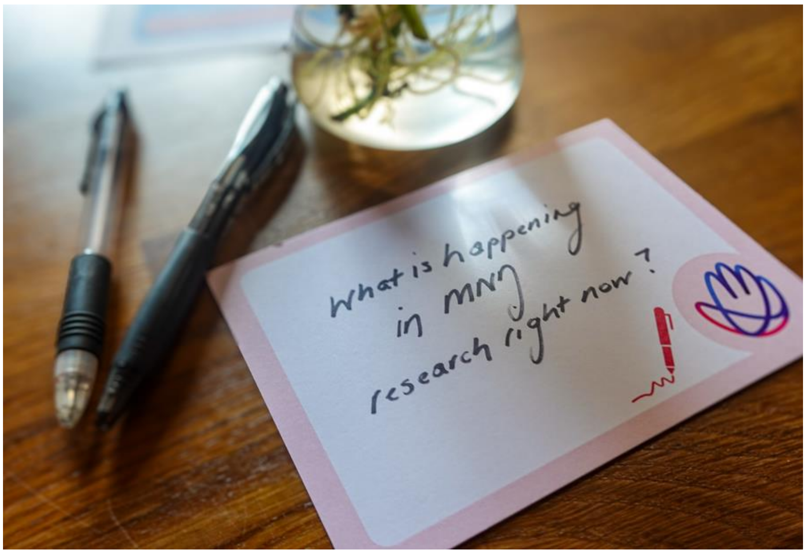
- Researchers at the University of Sheffield are seeking people with MND to be interviewed to help develop a new quality of life questionnaire.
- Researchers at the Sheffield Institute of Translational Neuroscience (SITraN) would like to interview people with C9orf72 or SOD1 gene changes to help further understand MND risk factors.
- Researchers from the University of East Anglia would like people with MND, especially if they have experienced behavioural changes, to review and give their opinions on research study materials such as information sheets and consent forms.
- The medical research charity LifeArc would like people affected by MND to fill out a short survey to help identify how new technologies could improve the lives of those with MND and help guide research into the development of these technologies.

Opportunities to have your say

Below is a list of surveys relevant to the MND community, including the 2024 Euan's Guide Access Survey, the UK's largest access survey on disabled access. Please follow the links if you would like to share your views:

- **The 2024 Euan's Guide Access Survey**
- **Neurological Alliance - My Neuro Survey**

LEARN feedback and UNITE



During September and October, we held four local LEARN events in Aberdeen, Edinburgh, Glasgow and Dundee. We'd like to say a huge 'thank you' to the 98 people who joined us, and hope you got something out of the events. We were pleased that so many people were able to come along and engage with the presentations and discussion and were truly touched by your stories and kind comments. If you were at any of our four events, please take 5 minutes to fill out our **feedback survey**, if you haven't already done so.

If you were unable to attend, or are interested in the talks from the other events, these will be available on YouTube shortly. We will share links via our website and social media, or you can ask to be sent a direct link by emailing **involvement@mndscotland.org.uk**.

Building on the success of the LEARN events, MND Scotland is teaming up with My Name'5 Doddie Foundation to deliver a full day UNITE event for MND researchers and people affected by MND in Scotland. The event will take place on **Monday 03 March 2025**, at **Dynamic Earth** in **Edinburgh**.

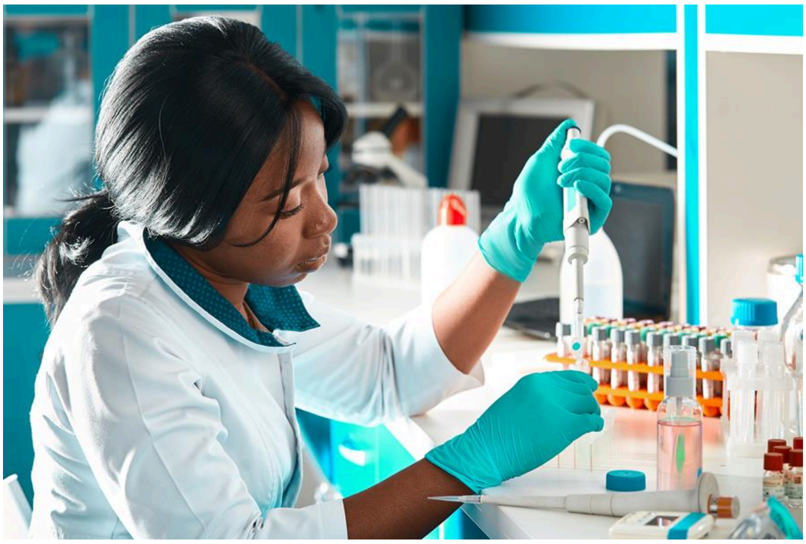
UNITE will bring together people who are united in their hope of finding an effective treatment for MND, improving diagnosis and care.

The day will be split into two parts. In the morning, we will have sessions for researchers, including talks and tutorials to help early career researchers develop skills for their future in research. We will invite people affected by MND to join the researchers for lunch and take part in the afternoon sessions. These sessions will provide the chance to learn about MND research and share thoughts and experiences with researchers from across the UK.

Registration will open later in November and we will be inviting anyone who would like to attend to fill out a registration form. We will send out the link to this mailing list, or you can keep an eye on both MND Scotland and My Name'5 Doddie Foundation's social media pages and websites for more information.

Share your feedback on our LEARN events

MND-SMART results published in The Lancet Neurology



In September, we welcomed the timely publication of the MND-SMART trial results on memantine and trazodone in **The Lancet Neurology**.

It was confirmed in September 2023, that there was no benefit from the first two drugs in the trial and that enough evidence was gathered to stop testing them. While it is disappointing that the data shows memantine and trazodone have no benefit for people with motor neuron disease (MND), it is a positive outcome that the trial has provided a definitive outcome and that the results have been published quickly.

Read more about the MND-SMART results

Rachel Maitland, MND Scotland's chief executive, is keen to meet people with MND face to face and listen to your experiences and thoughts about our services and activities. If you would be happy for Rachel to visit for a cup of tea and a chat, please email **communications@mndscotland.org.uk** and we will be in touch.

We welcome feedback on our quarterly newsletter. If you have any comments or suggestions, please get in touch **communications@mndscotland.org.uk**.

MND Scotland

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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.