

ROLE PROFILE

Member of the National MND Lived Experience Network

The purpose of this 'Role Profile'

This document gives important information for members of the 'National MND Lived Experience Network' (ie. LEN). It will be provided to all new members following registration.

What does 'lived experience' mean?

Lived experience refers to the first-hand knowledge and understanding a person gains by living with a specific health condition, or being involved in a person's healthcare journey as a carer. It focuses on experiences, thoughts, emotions, challenges, coping strategies and overall journey as people connect with the health system.

What is the 'National MND Lived Experience Network (LEN)'?

MND Australia (ie. MNDA) operate the LEN, with additional funding support provided by FightMND. The LEN Program Manager connects LEN members with professionals who would like to work together with people with lived experience of MND, on specific activities that relate to care, advocacy, information development, or research. Members are also kept up to date on relevant national initiatives.

People living in Australia over 18 years of age can join, if they meet one of the following criteria:

- have been diagnosed with MND
- are an asymptomatic carrier of an MND-related gene
- currently care for a family member living with MND, or
- previously cared for a family member living with MND, *within the past 2 years*

The sorts of professionals or organisations that members might connect with include:

- Researchers
- Not-for-profit organisations (eg. MND Australia, FightMND)
- Health professionals
- Pharmaceutical industry
- Others (such as equipment developers, education facilities, or government agencies)

Members might be invited to participate in a variety of ways, for example:

- Join a working group, focus group, or committee (usually online)
- Give feedback on information resources that educate people about MND
- Help to design a new project or program
- Participate in a research study (if eligible)
- Complete a survey

Please note: Requests for LEN members to participate in direct fundraising activities will be declined, as this is not the primary focus of the LEN.

What does the LEN hope to achieve?

We hope that the LEN contributes to:

- More lived experience voices being included in MND-related activities and decisions
- Members feeling empowered to get involved in activities that help the MND community.
- Stronger relationships between people with lived experience and professionals working in the MND community, so we can work together to inform and create positive change.
- Ensuring projects, programs and research better meets the needs and priorities of people impacted by MND.
- Better care and support services for people impacted by MND.
- Information material that is relevant, readable and understandable for people impacted by MND.

How long does a membership last?

There is no minimum or maximum term for membership.

Can I cancel my membership?

Members may choose to cancel their membership at any time. MNDA understands that a sudden change in a member's health or circumstances may mean they are unable to

continue with an activity. Where reasonable, we ask that the member, or a nominated carer, provide written notice to MNDA about the request to cancel. MNDA will then help the requesting organisation or group involved to explore other options.

How will MNDA communicate with members?

MNDA will share regular emails regarding general communications for LEN members, as well as any new requests from professionals, including a brief overview and any requirements. Emails may go to all members or specific groups, depending on the request. Interested members should notify the LEN Program Manager. If there are more expressions of interest than needed, participants will be selected fairly. MNDA will then contact selected members to confirm interest and ask permission to share their contact details and support needs with the professional, who will follow up directly.

Payment and Reimbursement

LEN members should be reimbursed for any out-of-pocket expenses incurred, as well as their accompanying carer, to participate in an activity. Some activities may also be able to offer payment for your time and expertise. Others may not have the funds available to provide payment. This will be made clear to members before accepting a request. Members are free to accept or decline any offers of payment or reimbursement using their own judgement; and are encouraged to seek independent financial advice on whether this may impact their Centrelink payments or tax return.

Member Roles and Responsibilities

To ensure a respectful, inclusive, and meaningful experience for everyone, members are expected to:

Required:

- Attend a brief online 'introduction session' with the LEN Program Manager after registering. Support to participate can be arranged if needed.
- Treat everyone with courtesy, respect, and kindness.
- Share personal experiences and insights related to MND, if comfortable.
- Decline to speak on topics outside their experience or knowledge.
- Consider the broader MND community, while not feeling responsible to represent all people impacted by MND.
- Read LEN emails and consider any opportunities to get involved.
- Prior to submitting expression of interest in an activity, consider the level of input, knowledge and experience required.
- Understand that expressing interest in an activity does not guarantee selection. If

oversubscribed, MNDA will select participants fairly.

- Refrain from promoting products, therapies, or services.
- Avoid offering medical, professional, or spiritual advice.
- Respect confidentiality of all shared information.
- Keep MNDA informed of any changes to contact details.

Encouraged:

- Join online forums related to the LEN.
- Be open to meeting others impacted by MND, including those with different experiences or disabilities.
- Reach out to the LEN Program Manager with any with any feedback, questions or concerns.

If expectations are not met, MNDA staff will contact the member to discuss concerns, offer support, and determine next steps.