

ROLE PROFILE

Member of the National MND Lived Experience Network

About this role profile

This profile explains membership of the National MND Lived Experience Network (LEN). New members receive it after registering.

What does lived experience mean?

Lived experience is the first-hand knowledge gained from living with a health condition or caring for someone who does. It focuses on experiences, thoughts, emotions, challenges, coping strategies and overall journey as people connect with the health, disability and aged care sectors.

What is the National MND Lived Experience Network?

MND Australia (MNDA) operates the LEN, with additional funding from FightMND. The LEN Manager connects members with professionals seeking lived experience input into care, advocacy, information resources and research. Participation in engagement activities is optional. Members also receive relevant national updates.

People living in Australia who are over 18 can join if they:

- have been diagnosed with MND
- are an at-risk 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*

Members may connect with:

- Researchers
- Not-for-profit organisations (e.g. MND Australia, FightMND)

- Health professionals
- Pharmaceutical industry
- Other organisations (e.g. equipment developers and government agencies)

Members may be invited to:

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

Requests for members to participate in direct fundraising activities will be declined, as fundraising is not the LEN's primary focus.

What does the LEN aim to achieve?

The LEN aims to:

- Empower members to contribute to activities and decisions that affect the MND community.
- Amplify lived experience voices to inform research, improve care and influence meaningful change.
- Ensure members feel respected and valued as equal partners.
- Strengthen connections between people with lived experience and professionals across Australia.
- Keep members informed about national developments in care, research and advocacy.

How will MNDA communicate with members?

MNDA emails members at varying frequency about engagement opportunities and national updates. Emails may go to all members or relevant groups. If an activity attracts more interest than places available, MNDA selects participants fairly. Selected members are contacted to confirm their interest and consent to share their contact details and support needs with the professional, who then follows up directly.

How long does membership last?

After registering, there is no minimum or maximum membership term.

Can I cancel my membership?

You can easily cancel your membership at any time by unsubscribing from LEN communications, or contacting the LEN Manager. MNDA understands that changes in health or circumstances may also prevent you from continuing an activity. Where possible, please notify the LEN Manager in writing, yourself or through a nominated carer. MNDA will help the organisation or group explore alternatives.

Payment and reimbursement

Members and their accompanying carers should be reimbursed for out-of-pocket expenses incurred to participate. Some activities also offer payment for members' time and expertise. Payment and reimbursement arrangements will be explained before you accept an activity. You may accept or decline these offers and are encouraged to seek independent advice about any effects on Centrelink payments or tax.

Member roles and responsibilities

To support a respectful, inclusive and meaningful experience, members are expected to:

Required:

- Attend a short introductory meeting with the LEN Manager after registering. Support to participate can be arranged.
- Treat others with courtesy, respect and kindness.
- Read LEN emails and consider opportunities to get involved.
- Consider the input, knowledge and experience an activity requires before expressing interest.
- Understand that expressing interest does not guarantee selection.
- Share MND experiences and insights only if comfortable.
- Decline to speak on topics outside your experience or knowledge.
- Consider the broader MND community without feeling responsible for representing everyone.
- Refrain from promoting products, therapies or services.
- Avoid offering medical, professional or spiritual advice.
- Respect the confidentiality of shared information.
- Notify the LEN Manager of changes to your contact details.

Encouraged:

- Join online discussions related to the LEN.
- Register with the MND Australia Connected Community – online peer chat forum.
- Be open to meeting others affected by MND, including people with diverse experiences.

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

Contact and support

For any questions, concerns, or feedback, please contact the LEN Manager via: len@mndaustralia.org.au