
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. National MND 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'?

MND Australia (ie. MNDA) connects members of the National MND LEN with organisations or groups 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.

People living in any State or Territory of Australia can join, if they are:

- living with MND
- carrying a positive genetic mutation
- currently caring for someone living with MND, or
- previously cared for someone living with MND.

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

- MND Australia
- State MND Associations
- Other not-for-profit organisations
- Researchers
- 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 or committee (usually online)

- Give feedback on information materials that educate people about MND
- Help to design a new project or program
- Participate in a clinical drug trial or other research study (if eligible)
- Participate in a focus (discussion) group on a given topic
- Complete a survey

What does the National MND LEN hope to achieve?

We hope that the National MND LEN contributes to:

- More lived experience voices being included in activities and decisions that affect people impacted by MND.
- Members feeling empowered to get involved in activities that help the MND community.
- 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 more relevant, readable and understandable for people impacted by MND.
- 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.

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 send regular emails about any new requests from organisations or groups, including a short explanation of the activity and any requirements. Emails may be sent to all members listed in the network or matched with specific groups. For example, emails may be sent only to people living with MND, or people living within a specific state. This will depend on the type of request.

Members who are interested in a listed activity should let MNDA know. If too many people express interest in an activity, MNDA will select the number of people needed in the fairest way possible.

MNDA will email members matched with an activity asking to share their contact details and any support needs with the requesting organisation or group. The requesting organisation or group will then contact each member to introduce themselves and discuss the arrangements.

Reimbursement and Remuneration

The requesting organisation or group is required to reimburse any out-of-pocket expenses incurred by a member, as well as an accompanying carer, to participate in an activity. Some organisations or groups may also be able to offer some form of remuneration (i.e. payment) to officially thank members for their time and input. Others may not have the funds available to provide a payment. This will be made clear to members before accepting a request. Members are free to accept or decline any offers of remuneration 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

Members are required to:

- Participate in an online introduction session with MNDA staff, following registration. Any form of assistance that might help a person to participate in the session will be considered.
- Abide by the values of MNDA including: collaboration, empathy, inclusion and quality.
- Maintain a harmonious, courteous, and respectful attitude towards all people and organisations.
- Be open to sharing their insights and personal experiences with MND.
- Not feel pressured to talk about topics that they have little experience or knowledge of.
- Consider the needs of others impacted by MND, but be aware that members are not expected to speak on behalf of all people impacted by MND.
- Read emails shared by MNDA and consider whether they would like to participate in a listed activity.
- Respond to requests in as timely a manner as they are able.
- Understand that expressing interest to participate in a listed activity does not mean that they will be automatically matched to that activity.
- Understand that if too many people express interest in an activity, MNDA will select the number of people needed in the fairest way possible.
- Never promote commercial products or services.
- Avoid endorsing MND-related therapies or treatments during activities.
- Avoid providing medical, health, counselling, spiritual, or professional advice, to others.
- Understand that their opinion/s will be listened to and considered, knowing that suggestions may not always be followed.
- Treat all information provided to them by another member, organisation, or group as confidential and not disclose this information to a third party.
- Inform MNDA if contact details change.
- Notify MNDA if choosing to become involved in any 'subgroups' related to the National MND LEN.

Members are encouraged to:

- Participate in scheduled online group forums related to the National MND LEN.
- Be prepared to meet other people living with MND, with varying levels of disability, or other carers.
- Respond to 'check-ins' from an MND Australia staff member (twice per year).
- Submit a short 'Final Feedback Report' to MNDA following completion of an activity, for evaluation purposes.
- Contact MNDA regarding any issues or concerns related to the National MND LEN.

All members are expected to fulfil their roles and responsibilities as outlined above. If a member does not fulfil the listed roles and responsibilities, MNDA staff will make contact to discuss the concerns, provide support and determine the best way forward.