

MND Victoria's Guide to Confidentiality, Feedback, Privacy, Rights and Responsibilities



MND Victoria is an organisation dedicated to the support of people living with motor neurone disease (MND).

Our vision: The best care until the world is free of MND.

Our mission: To provide and promote the best possible care and support for people living with MND. We aim to:

- Ensure the availability of a broad range of high-quality services and supports for people living with MND.
- Advocate for the needs of people impacted by MND to be fully and equitably met.
- Promote, support and deliver research into care, treatment and cure for MND.
- Increase awareness and support for MND Victoria.
- Underpin our strategy by remaining sustainable.

We have been delivering supports and services to people impacted by MND since 1981.

- Our direction is governed by a State Council of twelve members of the Association. Six members must be people with MND, carers, or close associates.
- Professional staff are employed to provide services to people living with MND, their families, community workers, service providers and health professionals.
- More than 100 generous and dedicated volunteers support our activities and service provision.

We have regular contact with similar organisations in other states through the Motor Neurone Disease Association of Australia (MNDA), a peak body that serves as a forum for national communication and cooperation. Through its membership of MND Australia, the Victorian Association participates in an International Alliance of ALS/MND Associations and the global effort to conquer MND.

Research

Through donations and fundraising activities, MND Victoria supports research into the causes, cure, treatment and management of MND both directly and through Motor Neurone Disease Australia's Research Grants Program.

Administration and Funding

MND Victoria is primarily supported by its own fundraising activities and, in part, by grants from the Commonwealth Department of Health, the Victorian Government

(Department of Health and the Department of Families, Fairness and Housing) and the NDIS. Other funds are raised through donations, events, merchandise, bequests, support from service clubs and from philanthropic trusts and company sponsorship. Donations are tax-deductible.

Standards MND Victoria Adheres To

MND Victoria complies with the requirements of the NDIS Quality and Safeguards Commission and the Aged Care Quality and Safety Commission.

The NDIS Quality and Safeguard Commission is an independent agency established to ensure NDIS supports and services are delivered to a high standard. The Commission regulates NDIS providers, provides national consistency, promotes safety and quality services, resolves problems, and identifies areas for improvement. MND Victoria is accredited by the Commission to provide support coordination and equipment services. MND Victoria needs to maintain up-to-date accreditation to provide these services.

The NDIA Commission considers that all clients can be approached for consultation during the accreditation process unless they opt out. Please advise the Association if you would like to opt out. Our staff adhere to MND Victoria's Code of Conduct (available on our website) and the NDIA's code of conduct (available on the Commission's website).

The Aged Care Quality and Safety Commission are the national regulator of aged care services. MND Victoria receive funding to provide some Commonwealth Home Support Program (CHSP) services. These services are Specialised Support Services and Home Modifications. MND Victoria are required to adhere to the CHSP guidelines when delivering these services (available on the Commission's website).

Contact Details

For further information please contact MND Victoria Head Office. Contact with State Council members should be directed through the CEO or through correspondence marked 'confidential' addressed to the Association and the relevant State Council Member.

Head Office

Address: 265 Canterbury Road (PO Box 23), Canterbury, Victoria 3126

Telephone: (03) 9830 2122

Email: info@mnd.org.au

Website: <https://www.mnd.org.au/>

MND Victoria is committed to protecting your personal and health information. We need to follow Australian laws when handling your health information. These laws are outlined in:

- The Privacy Act 1988 including the Australian Privacy Principles in the Act
- The Health Records Act 2001 (Vic) including the Health Privacy Principles in the Act.

These laws apply when we collect, hold, use and share personal information, including sensitive and health information.

1. Collecting Personal Information

The types of personal information that we collect depends on the nature of your dealings with us. We collect necessary information to provide you with our services or to manage and inform our relationship.

For example, we collect personal information to make sure we provide adequate, appropriate, and safe services, communicate appropriately with members, supporters, and health professionals, and meet reporting requirements.

The kinds of personal information we collect may include:

- your name, date of birth and gender
- your contact information including address, postcode, email, telephone number / mobile number, next of kin details
- your country of birth, whether you are an Aboriginal or Torres Strait Islander and your language spoken at home
- MND and other health, social and treatment information
- details of the services or products we and other agencies provide you.
- A factual record of interactions which occur between you and MND Vic staff.

2. MND Victoria's use of personal information

The personal information that we collect is used to:

- provide our services.
- manage and inform our relationship with clients and their significant others, members, volunteers, donors and supporters.

Privacy Statement

- establish and maintain proper business and health records.
- refer to and initiate services from other care providers.
- meet quality and accreditation requirements.

2.1 Use of Information for research and service improvement.

To support continuous improvement in services and to improve the evidence base, we may use your name and contact details to ask you to participate in client surveys, quality improvement activities, clinical trials or research. We may share de-identified demographic and clinical outcome data with third-party service providers such as university research partners. This process ensures that individual identities are protected through industry-standard anonymization before any data leaves our internal systems.

All such use will comply with the Privacy Act 1988, the Health Records Act 2001 (Vic), and relevant ethical and privacy requirements.

2.2 Direct marketing purposes

We may use personal information, including your name, phone number, address and email address, to send MND Victoria marketing and promotional information by post, email, social media or telephone including SMS.

You may opt-out of receiving direct marketing communications by contacting us at any time. If you do not opt-out, we will assume that you agree to receive information and communications.

3. Restrictions on use of personal information by MND Victoria

We will not sell, rent or trade personal information about you to, or with, third parties. All personal information that we collect, will only be made available to authorised individuals who need to handle that information for the purposes outlined in our Privacy Policy.

4. Personal information may be shared outside of MND Victoria

In some circumstances, we may share personal information, including sensitive information, to third parties where this is related to the supply of our services, for example, to a health professional. We also share information with government departments to comply with auditing and accreditation requirements.

If it is necessary for MND Victoria to make disclosures of this kind, you will be advised at the time you request MND Victoria to provide supports and services to you. If we engage a third party to handle personal information, we require these organisations to comply with the Australian Privacy Principles. They are only authorised to use personal information to provide the services or to perform the functions required by MND Victoria.

Any individual may authorise another person to provide and discuss personal information on their behalf.

Disclosures required or permitted by law

We will only disclose personal information if this is required by law or permitted under the Australian Privacy Principles. This may include disclosures to government departments or agencies, courts, or external advisers. For example, the Australian Privacy Principles allow us to disclose health information where we believe this is necessary to lessen or prevent a serious and imminent threat to an individual's life, health, or safety.

5. Security and quality of personal information at MND Victoria.

We take reasonable steps to protect personal information from unauthorised access, loss, and misuse. Our electronic information system is password protected and protected by multi-factor authorisation and anti-viral software.

All our staff are required to comply with the relevant Acts and to maintain the confidentiality of any personal information held by MND Victoria.

- All staff, students, volunteers, and contractors are required to sign MND Victoria's Confidentiality Agreement
- The CEO will ensure that all MND Victoria staff are issued with computer passwords.

We are committed to ensuring that the data we collect are accurate, complete and up to date. We expect staff, volunteers, and clients to let us know of changes to contact details etc.

6. Accessing and correcting personal information

Under the Privacy Act, individuals have the right to request access to personal information that we hold about them (although there are some exceptions to this). Individuals also have the right to ask us to update or correct their personal information when it is inaccurate, incomplete, or out of date. Contact us if you wish to exercise your right under the Privacy Act to seek access to your personal information.

In the first instance, we will generally provide individuals with a summary of the current information we hold about them. These records will include personal information that is included in our databases and in paper files which we may use on a day-to-day basis.

We will provide a copy of the relevant personal information (ordinarily, a print-out from a database or a photocopy of files recorded only in paper form). If personal information about you (for example, your name and address) is duplicated across different databases or paper files, we will generally only provide one print-out of this information. We will not charge for the cost of providing this type of access to these records.

For legal and administrative reasons, we may also archive non-current records containing personal information. Individuals may seek access to these non-current records, however, a fee may be charged for the cost of providing access.

7. Unique Identifiers

Unique identifiers are created when a new client, member or donor is entered into the electronic management systems. We do not share unique identifiers of individuals.

8. Anonymity

Privacy Statement



All individuals are given the opportunity of not identifying themselves when entering transactions with MND Victoria to the extent that this is lawful and practicable.

However, this may limit our ability to provide services or assistance. It is the responsibility of individuals who require ongoing de-identification of mail to notify us and request that this information is noted on their individual client file.

9. Cross-border data flows

We do not provide information overseas unless the recipient protects privacy under similar standards required in Australia. All reasonable measures will be taken to ensure that the consent of the individual is obtained before any transfer of information occurs.

10. Sensitive Information

We only collect sensitive information where required to ensure effective service provision to meet identified needs.

11. Privacy Complaints

If you have concerns about the handling of your personal information by MND Victoria, you can make a complaint to the Office of the Australian Information Commissioner (**OAIC**). Please see the MND Victoria Complaints Statement for details.

MND Victoria is committed to making sure that all people who use our services have information about their rights and responsibilities. We support the rights of clients in all things that are lawful.

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MND Victoria supports the following statements as outlining the rights of people with MND:

People with ALS/MND (PALS) have the right to:

- the highest quality care available,
- information, resources, education, and training that will lead to health literacy about ALS/MND
- choice with respect to:
 - health and support workers who are providing treatment or advice.
 - the location where care takes place.
 - the type of treatment or support that is provided.

(The International Alliance of ALS / MND Associations fundamental rights for people with ALS / MND (PALS), revised January 2024).

As a client of MND Victoria or MND Tasmania you have the right to:

Access to

- complimentary membership of MND Victoria and/or MND Tasmania
- a prompt and responsive service
- open and honest communication
- accurate, relevant information, including information about the types of supports being provided
- an interpreter
- health professionals who provide best practice management of MND.

Freedom from discrimination

- Be treated in a professional, courteous, and caring manner that respects and appreciates differences related to race, ethnicity, national origin, gender, sexual orientation, right to intimacy and sexual expression, religion, personal values, age, disability, economic or veteran status.

Choice

- Be actively involved in discussing and making decisions about your current / future care needs.
- Involve an advocate of your choice (family member, friend) at meetings with our staff and/or ask them to act on your behalf.
- Choose to use, or not use, our services and to decline services offered to you.
- Choose to leave our service and request a referral to another service.
- Request a change of MND Advisor/Support Coordinator

Privacy

- Expect that your personal privacy will be respected, and confidentiality protected to the greatest extent permitted by law according to MND Victoria's Privacy Statement (REF-003=MND Privacy Statement).
- The law allows us to disclose health information where we believe disclosure is necessary to lessen or prevent a serious and imminent threat to an individual's life, health, or safety.
- Expect to have clear and up to date record of supports kept on your behalf.

Access to read your care records upon application as per our Privacy Statement (Ref-030).

Feedback and complaints

- Provide feedback about the conditions under which our services are delivered and have problems addressed quickly.
- Make a complaint about our services and expect that this complaint will be heard and dealt with in a fair, objective and confidential manner without fear of it affecting decisions relating to the assistance you receive. Refer to MND Victoria's Complaint Statement (REF-039)

Client responsibilities - As a client of MND Victoria or MND Tas you have a responsibility to:

- Be respectful of our staff, volunteers and other clients
- Provide relevant information to your MND Advisor/Support Coordinator and care team of any changes to your situation that may impact on the supports you receive
- Complete and return documents relevant to the provision of support services
- Work cooperatively and be actively involved in decisions regarding your care needs
- Raise any concerns that you may have in a timely manner
- Provide reasonable notice, in accordance with service or other agreements you have with us, should you wish to change your supports or services
- Respect the rights of others including their rights to confidentiality and privacy
- Take responsibility for the outcomes of your decisions
- Seek a fair resolution of any complaints. Refer to MND Victoria's Complaint Statement (REF-039).

We recognise, support and encourage the right of clients, members and others to offer feedback or make a complaint regarding our service provision and operations. We are committed to making sure that all complaints and concerns are investigated and resolved quickly and fairly and without retribution. **People making a complaint will be dealt with sensitively, objectively, confidentially, promptly and in accordance with relevant legislation.** However, there is no guarantee of a successful resolution of any issue or complaint: the policy and procedure exist as a guide for complaint processes.

We recognise that feedback and complaints are an important element of quality improvement.

1. Definitions

What is a complaint?

A complaint generally refers to issues which are perceived to have a negative impact. This can relate to staff, services provided, or the terms of engagement or contract with the organisation.

Complaint resolution

A complaint is resolved when both parties reach agreement. The parties will be informed, in writing, of the complaint outcome and agreement.

Vexatious grievances

Where complainants use the complaint/grievance resolution process without reasonable cause, the processes as outlined will still be adhered to. If complaints are malicious or vexatious and therefore not made in good faith, the complainant may be referred to the General Manager Support Services (GMSS) or Chief Executive Officer (CEO) to take appropriate action.

2. Informal complaints

If a person expresses dissatisfaction with any aspect of our services, personnel, or programs, they have the right to lodge a complaint. Firstly, they are encouraged to discuss the issue with the staff member they have most contact with. Staff are encouraged to address and resolve issues immediately at a local level whenever possible. The concern will be noted, and the General Manager Support Services (GMSS) informed.

Where a complaint relates to one of the following, the CEO will be notified immediately:

- Criminal behaviour
- A breach of the Code of Conduct
- A breach of MND Victoria Policy
- An action which intentionally puts a person or staff member at risk

- An action which intentionally intimidates a person or staff member.

3. Lodging complaints

If the matter of concern is unable to be resolved at the local or informal level the matter becomes a formal complaint. Formal complaints should be lodged with the General Manager of Support Services (GMSS). They can be forwarded by mail, email, or any other form of electronic communication, or by speaking to the GMSS. You can ask for assistance to write your complaint.

The GMSS will contact the complainant within 5 working days of receiving the complaint, provide advice about the complaints process and organise a meeting with the complainant to review the complaint and address the issues of concern. Usually the meeting includes any other people involved, but separate interviews can also be arranged if the complainant prefers.

All formal complaints will be investigated by the GMSS or delegate. The GMSS or delegate will inform all people involved in the dispute that a formal complaint has been lodged.

Where a complaint is received in relation to the operations or services of another organisation that is delivering services for a MND Victoria client, the client will be referred to that organisation to lodge a complaint. Where appropriate, the client will be supported by their MND Advisor.

4. Resolving complaints

The GMSS or delegate will review the terms and background of the complaint, seeking input from relevant MND Victoria staff and the complainant. At the first formal meeting, the complainant will be provided with every opportunity to state their views, the circumstances leading up to the complaint and their suggested course of action. All relevant discussions and investigations will be documented. Based on all the information, the GMSS will negotiate a plan of action to resolve the matter in a way which is acceptable to everyone involved. An action plan will be documented and shared with the complainant and any other involved parties.

Where the complaint is unable to be resolved, or where the complaint relates to actions or decisions taken by the GMSS, the complaint will be referred to the CEO for resolution. The CEO will, within five business days, discuss the issues making up the complaint; review the information supporting the complaint, and the actions of MND Victoria subject to the complaint and the actions and decisions of the GMSS in attempting to resolve the complaint. The CEO will resolve the complaint within the existing MND Victoria policies and procedures. From the Association's perspective, the CEO's decision is final.

5. Use of a support person

We aim to complete the above steps within no longer than 28 working days after receiving the complaint. Complainants have the right to have a support person and/or interpreter present during any discussions and meetings. The role of the support person is not to mediate between complainant and MND Victoria or to arbitrate in a dispute, but to speak and act on behalf of the complainant.

6. Other resources and organisations

If the complaint cannot be resolved to the satisfaction of the complainant other options which may help to resolve the complaint or provide advice, include the following:

a) **NDIS Quality and Safeguards Commission**

<https://www.ndiscommission.gov.au/>

The NDIS Quality and Safeguards Commission is an independent agency set up to improve the quality/safety of NDIS supports and services. The Commission works with NDIS participants, service providers, workers and the community to provide consistent access to services/supports that promote choice, control and dignity.

b) **Aged Care Quality and Safety Commission**

<https://www.agedcarequality.gov.au/>

The Aged Care Quality and Safety Commission monitors the quality and compliance of Aged Care services and assists with complaints regarding an aged care provider's responsibilities under the Aged Care Act 2024. They cannot assist with complaints about NDIS services provided in an Aged Care setting.

c) **Health Complaints Commissioner**

<https://hcc.vic.gov.au/>

The Health Complaints Commissioner deals with complaints concerning any private or public health service provider, including doctors, nurses, allied health professionals and naturopaths. The Commission aims to mediate and conciliate between parties.

d) **Victorian Ombudsman**

<https://www.ombudsman.vic.gov.au/>

The Victorian State Government Ombudsman deals with complaints concerning actions of government departments. The Ombudsman's office also covers the administrative actions of local government officers. However, it cannot act if the complaint concerns a decision or action of an elected Council or Councillor.

e) **Victorian Equal Opportunity and Human Rights Commission**

<https://www.humanrightscommission.vic.gov.au/>

The Victorian Equal Opportunity and Human Rights Commission deals with complaints concerning discrimination on the grounds of disability, sex, race, age, industrial activity, marital, parental or carer status, political or religious beliefs, sexual orientation or pregnancy. The Commission helps people to prepare statements and lodge complaints and then mediates between parties to reach resolution.

f) Office of the Public Advocate

<https://www.publicadvocate.vic.gov.au/>

The Office of the Public Advocate represents the interests of Victorian people with a disability. It is independent of government and has the power to investigate and take action in situations where people are exploited, neglected or abused. Individual advocacy can also be provided for people with a disability who are being abused or neglected, and where no other advocacy is available. Independent guardians can be provided for people with a disability when the Guardianship and Administration Board make orders.

g) Office of the Australian Information Commissioner (OAIC)

<https://www.oaic.gov.au/>

The Office of the Australian Information Commissioner (OAIC) can investigate privacy complaints about Australian government agencies, and private sector organisations covered by the [Privacy Act 1988](#) (Privacy Act). Complaints are usually resolved through conciliation.

h) Australian Human Rights Commission

<https://www.humanrights.gov.au/>

The Australian Human Rights Commission investigates and resolves complaints of discrimination, bullying and harassment based on a person's age, sex, race or disability. Complaints are resolved through a conciliation process.

7. Use of complaints and feedback

Complaints will be addressed in meetings of staff and volunteers as part of continuous quality improvement and used, if appropriate, to improve training, systems, or services.

For queries relating to any of the information in this guide, please contact us via:

Phone: (03) 9820 2122

Email: info@mnd.org.au

Address: 265 Canterbury Road, Canterbury VIC 3126