

Privacy Policy

Approved by Board on	27 October 2025	Last Reviewed	October 2025
Version	2	Review frequency	Annually
Responsible person	CEO	Scheduled review date	October 2026

1. Policy Statement

MND Australia (referred to as “MND”, “we”, “our” or “us”) is committed to protecting the privacy and security of your personal information. This Privacy Policy outlines how we collect, use, manage, disclose and secure your personal information in compliance with the Australian Privacy Principles (APPs) under the Privacy Act 1988 (Cth) (the Privacy Act). It also outlines how you can apply to MND to access and correct personal information that we hold about you.

Good data and privacy governance is critical to meeting ACNC Governance Standards and meeting the expectations and maintaining the trust of donors, supporters, stakeholders and the community.

2. Scope

This policy applies to all individuals in relation to whom MND collects or holds personal information. All employees, volunteers, Board members and Committee members must adhere to this policy.

This policy should be read in conjunction with MND’s *‘Website Terms and Conditions’*.

3. Policy details

What type of personal information might we collect or hold?

“Personal information” is defined in the Privacy Act. It means information or an opinion, whether true or not and whether recorded in a material form or not, about an individual who is identified or is reasonably identifiable.

We collect personal information that is reasonably necessary for the performance of our functions and activities as a health promotion charity with the objective of preventing and controlling Motor Neurone Disease (MND) and as a peak body for the State MND Associations.

An individual’s personal information may be collected in a variety of ways. This includes in paper or online forms, in correspondence to and from the individual, as well as via email, in person, or over the telephone. Information is collected directly from individuals unless it is unreasonable or impractical to do so. An example of where it may be impracticable to do so is where a carer communicates on behalf of an individual who is not readily able to communicate due to the impact of MND or other circumstances. In such circumstances we will endeavour to confirm with the relevant individual, that he/she has given authority to the carer to provide information to MND on their behalf.

We may also collect personal information about you from other third parties, however only if you have provided prior consent (written or verbal) or where collection is required or authorised by law.

The information we collect depends on the type of dealings we have with you.

The type of personal information we might collect includes:

- Contact details (such as name, address, email address, and telephone number)
- Information relevant to our programs and services (such as date of birth, gender, location)
- Preference on receiving updates or promotional materials (such as newsletters).
- Financial information (Note: Credit Card or banking details are only stored for the processing of any required payment and will be deleted once payment is processed.)

“Sensitive information” is a subset of “personal information” that is generally afforded a higher level of privacy protection. “Sensitive information” is defined in the Privacy Act and includes information about an individual's racial or ethnic origin, political opinions, professional or political or religious affiliations or memberships, sexual orientation or practices, criminal record, health, genetics and/or biometrics.

We only collect sensitive information where it is reasonably necessary for the performance of our functions or activities and either:

- the individual has consented (in writing or verbally); or
- we are required or authorised by or under law to do so.

Examples of the type of sensitive information we might collect include:

- Health information (such as date of MND diagnosis)
- Ethnic origin.

The MNDA website does NOT collect personally identifiable information from individuals unless they provide it to us voluntarily and knowingly. When you view the MNDA website, information is collected about your browser and whether you have visited the MNDA website before. It does not extract any personal information about you from your computer.

We use programs that place cookies on your computer to collect information about your browsing history (including on external websites). This information, which does not identify you personally, is collected to improve your online experience by customising the content you see to your interests. You can opt out of these programs at any time by clicking [here](#).

Use and disclosure of personal information

We use personal (including sensitive) information for the purposes for which it was collected, including:

- To respond to your requests or enquiries
- Managing memberships or subscriptions
- Communicating with individuals about our activities, events, or programs
- Delivering or evaluating our programs or services
- Raising awareness in relation to MND

- Performing research and statistical analysis, including for service improvement purposes
- Processing donations
- Obtaining products and services for our business
- Recruiting staff and contractors
- Complying with our legal obligations.

We may also use personal information for other purposes, but only with your prior consent, or as permitted or required by law.

Direct marketing

We may use or disclose your personal information to let you know about us and our activities (including fundraising initiatives or events), either where we have your express or implied consent, or where we are otherwise permitted by law to do so. We may contact you for these purposes in a variety of ways, including by mail, email, SMS, telephone, or online advertising.

Opting out

Where you have consented to receiving marketing communications from us, your consent will remain current until you advise us otherwise. However, you can opt out at any time, by:

- contacting us (details below)
- advising us, if you receive a marketing call, that you no longer wish to receive these calls
- using the unsubscribe facility that we include in our electronic messages (such as emails, SMS and MMS)

Do we share your personal information with others?

In some circumstances, we may *ask your consent* to share your personal information with other individuals, organisations, or agencies, within Australia to:

- respond to your request or an enquiry
- assist us in delivering or evaluating our services and programs
- provide you with goods or services.

We do not provide personal information to overseas recipients unless the consent of the individual is obtained before any transfer of information is undertaken.

In some circumstances, we may share your personal information with others, for example:

- Financial institutions for payment processing
- Referees whose details are provided to us by job applicants
- Our contracted third-party service providers, including:
 - delivery and shipping providers
 - information technology and data storage providers
 - venues and event organisers
 - call centres
 - mail houses

- external business advisers (such as consultants, recruitment advisors, accountants, auditors and lawyers)
- Regulatory bodies and government agencies as required by law. For example, the Australian Privacy Principles permit MNDA to disclose sensitive information where we believe disclosure is necessary to lessen or prevent a serious and imminent threat to an individual's life, health, or safety.

Third-Party Service Providers

As stated above, MNDA may disclose personal information to our contracted third-party service providers and these service providers may, in turn, provide us with personal information collected from you while they provide the relevant products or services to you on our behalf.

When entering arrangements with third parties, MNDA takes reasonable steps to ensure that the third party's privacy practices meet the expectations of MNDA. MNDA checks the privacy related sections of relevant agreements; conducts periodic reviews of its arrangements with third parties; and seeks to include terms in agreements which ensure that third parties delete any personal information collected under the contract with MNDA, at the end of the contract term.

Security of personal information

We take reasonable steps to protect the personal information we hold from misuse, interference and loss, and from unauthorised access, modification or disclosure. These steps include:

- Implementing physical, technical, and administrative security measures within our organisation
- Hosting electronic information on a secure Australian-based Cloud platform.
- Restricting access to personal information to authorised MNDA employees only.
- Using secure methods to destroy or de-identify personal information that is no longer needed.
- Only retaining personal information where there is an ongoing need to hold this information, not holding information indefinitely. MNDA is developing processes and systems for conducting regular reviews of personal information it holds to determine whether retention of the information is still required or whether the information can be de-identified or destroyed. MNDA is considering whether to specify maximum retention periods for certain types of personal information.

How we manage a breach of privacy

We may need to notify the Office of the Australian Information Commissioner (OAIC) and affected individuals if we become aware of an eligible privacy data breach. We have policies and procedures in place to identify and assess such breaches and will notify the OAIC if required. We will inform the person/s affected by any breach of their personal information including the nature of the information disclosed, level of risk and actions taken to remedy the breach. The incorrect recipient of such information, if known, will be requested to destroy the information and confirm that this has occurred.

Online credit card payment security

We process payments using EFTPOS and online technologies. All transactions processed by us meet industry security standards to ensure payment details are protected.

Website security

While we endeavour to protect the personal information and privacy of users of our website, we cannot guarantee the security of any information that you disclose online: You disclose that information at your own risk. If you are concerned about sending your information over the internet, you can contact us by telephone or post (details below).

Access and correction

Individuals have the right to access and correct the personal information we hold about them (including information that has been provided to us about that individual by a third party, such as a carer). Requests for access or correction should be made in writing to our Privacy Officer using the contact details provided below. We will respond to requests within a reasonable timeframe and provide access or make corrections as required by law.

Generative Artificial Intelligence (AI)

MNDA applies the published Guidance of the OAIC in relation to its use of commercially available Generative AI products.

When considering the adoption of any commercially available Generative AI product, MNDA conducts due diligence to ensure the product is suitable for its intended uses. This includes considering whether the product has been tested for such uses, how human oversight can be embedded into processes, the potential privacy and security risks, as well as who will have access to personal information input or generated when using the product. Where possible, MNDA seeks prior consent to the use of the product from those impacted by its use. For example, if MNDA intends to deploy a Generative AI tool to assist with minute taking at a meeting, the Chair seeks the prior consent of all meeting attendees to such use.

If MNDA decides in the future to adopt any public-facing AI tools (such as chatbots), MNDA will ensure that these are clearly identified to external users and that it develops related policies and systems to ensure compliance with the Privacy Act.

It is MNDA policy that no personal information including sensitive information, be entered into publicly available Generative AI Apps (for example ChatGPT, Claude, Gemini, Perplexity) by employees, volunteers, Board members or Committee members, due to the significant privacy risks involved.

Complaints

If you have a complaint about our handling of your personal information or believe that we have breached the Australian Privacy Principles (APPs), please contact our Privacy Officer in the first instance, using the contact details provided below. We take all complaints seriously and will investigate promptly and impartially. You may also choose to take the

complaint to the Office of the Australian Information Commissioner (OAIC). For more information about this, please visit:

<https://www.oaic.gov.au/contact-us>

Contact us

If you have any questions about our Privacy Policy or practices, or if you would like to request access to or correction of your personal information, please contact our Privacy Officer:

Maddie Catlin

MND Australia

Email: maddiec@mndaust.asn.au

Changes to this Privacy Policy

We will update this Privacy Policy from time to time to reflect changes in our practices, legal requirements, or changed industry standards. Any updates will be posted on our website, and we encourage you to review this Privacy Policy periodically for changes.