



# Privacy Policy

## 1. About this policy

MND NSW values and respects the privacy of the people we deal with. MND NSW is committed to protecting the privacy of participants, their families, staff, volunteers, supporters and business contacts.

MND NSW aims to only collect the personal or sensitive information it requires to carry out its services and functions. This privacy policy describes how MND NSW collects, handles, uses and discloses your personal and sensitive information.

This policy applies to all people who 'do business' with or for MND NSW and includes participants, their families, staff, volunteers, supporters and business contacts.

We may update this privacy policy from time to time, including when our information handling practices change. Updated versions will take effect when they are published on our website at [www.mndnsw.org.au](http://www.mndnsw.org.au)

## 2. Overview and definitions

MND NSW is subject to the requirements of the Australian Privacy Principles (APP) that represent the minimum privacy standards for handling personal information. Relevant Acts include the [Privacy Act 1988](#), [Privacy Amendment \(Private Sector\) Act 2000](#), [Privacy Amendment \(Enhancing Privacy Protection\) Act 2012](#) and the [Privacy And Other Legislation Amendment Act 2024](#)

The NSW State Government also has privacy requirements defined in [Privacy and Personal Information Protection Act 1998 No 133 - NSW Legislation](#), [Health Records and Information Privacy Act 2002 \(NSW\) \(HRIP Act\)](#), [Health Records and Information Privacy Regulation 2022 \(NSW\) \(HRIP Regulation\)](#) and [Health Records and Information Privacy Code of Practice 2005 \(NSW\)](#)

The Australian Capital Territory has privacy requirements defined in [Information Privacy Act 2014 \(ACT Legislation Register\)](#).

The Northern Territory has privacy requirements defined in [Information Act 2002 \(Northern Territory Legislation\)](#)

MND NSW is subject to the requirements of [Federal Register of Legislation - Spam Act 2003](#) (as amended 2016).

MND NSW is not a prescribed agency under the Freedom of Information Act.

## 3. What information does MND NSW collect and why?

Generally, to provide you with our services, MND NSW needs to collect personal information.

You may choose not to identify yourself or may choose to not provide certain personal and/or sensitive information when interacting with MND NSW. However, it may not be practicable for MND NSW to provide some services to you when you do not provide sufficient personal and/or sensitive information for MND NSW to provide the service.

The services you require determines the personal and sensitive information we collect. For example:

- when contacting the MND NSW Infoline with a general question you will not be required to provide personal information such as your name and contact details. However, if you request information be emailed to you, MND NSW records your name, contact details and the request for this service to be provided
- a program participant needs to provide sufficient personal and/or sensitive information for MND NSW to provide the service
- a donor needs to provide contact details if they require MND NSW to issue a receipt for a deductible gift
- a volunteer or staff member may be requested to provide police check information
- a board member may be requested to provide credit information such as personal insolvency information
- a voice message left by you may be electronically stored.

### Personal and sensitive information

**Personal information** collected and stored may include:

- name, signature, address, phone number, email address, date of birth
- gender
- communication preferences, such as
  - preferred day-to-day communication method, for example, phone, SMS, email, mail, video chat
  - types of news you would like to receive from us
- information about your family and other related persons (such as any partners, children, dependents, carers, nominees, authorised representatives or service providers)
- employee record information
- sensitive information (see below)
- credit information
- photographs
- internet protocol (IP) addresses
- voice print and facial recognition biometrics
- location information from a device
- feedback, complaint or application related information.

**Sensitive information** collected and stored may include:

- health information or genetic information
- racial or ethnic origin
- religious or philosophical beliefs
- sexual orientation
- criminal record.

#### 4. Automated decision-making about you

MND NSW does not use any ‘computer program’ (encompassing pre-programmed rule-based processes, AI and machine learning processes) to make decisions that could reasonably be expected to significantly affect your rights or interests.

We do use third-party payments industry services for the processing of financial transactions. These services are global services and have embedded fraud protection/risk algorithms and are commonly used by merchants who accept credit card and debit card payments.

MND NSW uses several cloud security products that use machine learning processes and AI to detect and block cyber threats. These assist us to protect your personal information.

#### 5. How do we collect personal information and where is it stored?

##### Where you will not be identified, or reasonably identifiable from the information collected

MND NSW collects some personal information during your interactions with an MND NSW online product or service where you will not be identified, or be reasonably identifiable from the information collected.

##### Google Analytics

MND NSW uses Google Analytics to collect data about how you interact with MND NSW online products and services, including:

- device IP address
- search terms and pages visited on the sites
- date and time when pages were accessed
- downloads, time spent on page and bounce rates
- referring domain and out link, if applicable
- device type, operating system and browser information
- device screen size and
- geographic location (city)

This information is stored on Google’s servers outside of Australia. View [Google Analytics privacy policy - external site](#). When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

##### Google reCAPTCHA

MND NSW uses Google reCAPTCHA as a means to eliminate spam attacks and to be able to

distinguish users from bots. The tool may collect data about how you interact with the website’s forms, including:

- mouse movements
- device IP address
- date and time when pages were accessed
- device type, operating system and browser information
- device screen size
- geographic location (city)

This information is stored on Google’s servers outside of Australia. Content that you enter in MND NSW’s web forms will not be collected through the use of this tool. View Google’s [Cloud Data Processing Addendum - external site](#) and [Google’s privacy policy - external site](#). When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

##### Cookies

Cookies are small data files transferred onto computers or devices by websites for record-keeping purposes and to improve your website user experience.

Most browsers allow you to choose whether to accept cookies or not. If you do not wish to have cookies placed on your computer, you can set your browser preferences to reject all cookies before accessing an MND NSW website. Please note however, that some data may still be collected separately by tools such as Google Analytics, even though you may have set your browser preferences to reject all cookies.

##### Tracking pixels

A tracking pixel is a piece of code generated by a third-party provider that can be placed on an organisation’s website to collect information about a user’s activity. When a user visits a webpage with a tracking pixel, the pixel loads and sends certain types of data to the server of the third-party provider.

MND NSW uses tracking pixels for counting events to measure marketing effectiveness. These counting events include:

- clicks on links/button
- number of submit events on forms (but not the form information)
- number of visits to pages

When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

##### Social networking services

MND NSW uses Twitter, Facebook, Instagram, YouTube and LinkedIn to communicate with the public about its work. When you communicate with MND NSW using these services, MND NSW collects the personal information you provide to it by engaging in that communication.

[Twitter - external site](#), [Facebook - external site](#), [Instagram - external site](#), [YouTube - external site](#) and [LinkedIn -](#)

[external site](#) each have their own privacy policies. When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

## Where you will be identifiable from the information collected

### Consent considerations

MND NSW may collect your identifiable **personal** information:

- when reasonable and practicable, directly from you, for example, when you provide information to MND NSW:
  - in person, by phone, email or other communication method
  - via a web form such as contact, subscription or donation form
- from third parties, for example, from a person who cares for you, a direct relative, a service provider, a club or association of which you are a member.

MND NSW may collect your identifiable **sensitive** information, including health information from:

- you, if you give consent openly and obviously, either verbally or in writing, when you provide information to MND NSW:
  - in person, by phone, email or other communication method
  - via a web form such as online intake form, service agreement, online referral from health care provider
- another source, if there are reasonable grounds for collecting that information from that source.

Reasonable grounds for collecting identifiable sensitive information, including health information, from another source include but are not limited to:

- consent from you to collect that information from the other source
- where your capacity to consent is restricted
- via a referral from a health care provider or organisation including service providers, NDIS and My Aged Care, that has been made with your consent.

If a person's capacity to consent is restricted, support and/or additional resources (such as an interpreter or alternative communication methods) will be offered.

Where the person does not have the capacity to consent even with such support and resources, consent can be obtained from a person with the legal capacity to act on your behalf such as someone with enduring power of attorney.

### Email sends and mailing lists

Information about you is also collected by MND NSW when you open, click on links or download any image in an email sent to you via an MND NSW mailing list. The information collected includes:

- whether you have opened an email sent to you
- which links were clicked in those emails
- your mail client (e.g. 'Outlook' or 'iPhone')

- if interactions with those emails occurred on a mobile or desktop environment
- the country geolocation of your IP address (the IP address itself is not stored).

## Storage considerations

Generally, identifiable information collected by MND NSW from the information collected, is stored in Australia. For example, information collected in person, by phone or on MND NSW web forms that enable you to subscribe to a mailing list, express interest in volunteering, provide consent for family member or friend, request intake, be referred from a service provider, accept a service agreement and respond to a survey, is collected and stored in Australia.

However, there are some exceptions and some information is not initially transacted and/or stored in Australia, as detailed below. MND NSW endeavours to minimise these exceptions where possible.

### Event registrations

For some events, MND NSW may use a third-party service to manage event registrations. When registering for an event, you may be required to provide your personal information including your name, address, telephone number and email address, which may not be stored in Australia. When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

### Online education

MND NSW uses a third-party online education platform to manage online delivery of education programs. When enrolling into an online training, you may be required to provide personal information including your name, workplace, address, telephone number and email address, which may not be stored in Australia. Credit card or other payment information is processed by the payment processor nominated by MND NSW on the site and identifiable credit card details are not stored by MND NSW. When MND NSW outputs reports and summaries of this information, and this information is stored, it is stored in Australia.

### Online payments

MND NSW uses third-party payments industry services for the processing of financial transactions. These services are global services and have embedded fraud protection/risk algorithms and are commonly used by merchants who accept credit card and debit card payments. During an online payment transaction data sent to this service may include data entered by you during the transaction such as first and last name, email address, postal address, billing address, and phone number. Other data related to the transaction sent to these services includes device identifiers such as IP address; device information, including browser language, time, session age, user agent, etc; payment information, including partial credit card numbers such as the issuer ID number (IIN) and the last digits of a credit card (but not a full credit card

number). Credit card information is not stored by MND NSW.

### Job applications

MND NSW collects your personal information when you provide it via a job application by either

- directly emailing the relevant Manager or
- via third party-platforms where you have submitted your information through the third-party's website, for example SEEK or Ethical Jobs. You may choose to instead submit your application by email directly to us.

When MND NSW stores this information, it is stored in Australia

### Mailing lists

For some mailing lists MND NSW uses a third-party mailing list management system. Information stored with this third-party provider is very limited and generally includes email address and name.

### Peer to peer and online fundraising platforms

Peer to peer and online fundraising platforms are third-party providers where you can donate towards a cause. These can be categorised into two types:

*Type 1 - MND NSW has engaged the services of the provider*

On registering on the platform you will be asked to consent to the platform's privacy policy. Information entered by you during the transaction such as first and last name, email address, postal address, billing address and phone number may be collected and used by the provider according to their and MND NSW privacy policy. When MND NSW outputs and stores this information, it is stored in Australia. Credit card or other payment information is processed by the payment processor nominated by MND NSW on the site and identifiable credit card details are not stored by MND NSW. MND NSW verifies the PCI compliance of these platforms annually.

*Type 2 - Where the third party provider is not engaged by MND NSW, but MND NSW may receive donations via the platform.*

It is not uncommon for MND NSW to receive funds as donations, which have been collected by fundraising platforms that MND NSW has not engaged. These may include donations from supporters who have participated in a community event, such as a marathon, where the donor has nominated MND NSW as the recipient of their donations. Information entered by you during the transaction such as first and last name, email address, postal address, billing address and phone number may be collected by the provider and MND NSW. When MND NSW stores this information, it is stored in Australia.

Please contact MND NSW [fundraising@mndnsw.org.au](mailto:fundraising@mndnsw.org.au) to verify known peer to peer and online fundraising platforms used by MND NSW.

## 6. Use

### Primary purpose uses

We collect, hold, use and disclose your personal information for the following purposes:

1. To deliver MND NSW services, which include:
  - responding to enquiries and feedback you have submitted to us either in-person; by phone, email, SMS or post; or via an online form or other communication method
  - providing relevant services and products to you including, for example, dealing with any enquiries or complaints and the organising of equipment delivery, repair and collection
  - to generate alerts to you, for example, notifications on office closure and change in an MND NSW key contact (for example, change in MND Advisor).
  - providing you with information about other services we offer that you may find interesting, in which case you will be offered an opportunity to opt out of receiving further information
  - providing advice and information that MND NSW believes will be of direct benefit to you
  - providing education, training and resources
  - raising funds for purposes related to the aims of the organisation
  - administering and managing the delivery of services and products.
2. To conduct the operation of MND NSW, including general business functions, such as
  - evaluating the effectiveness of the services that we provide, which may include providing you with information about research partner invitations you may choose to respond to or not
  - consolidating statistics for internal reviews and analysis
  - improving the services offered to members, donors and participants, including dealing with complaints (including privacy complaints), feedback or enquiries made to MND NSW
  - to comply with our legal obligations and for purposes related to legal matters, which may include obtaining legal advice from internal and external lawyers and fraud and compliance investigations
  - recruitment and management of prospective and current staff (including ongoing employees, non-ongoing staff, volunteers, suppliers and contractors)
  - managing contracts and funding agreements and audits (both internal and external)
  - managing, advising and reporting on the financial sustainability of MND NSW.

### Secondary purpose uses

Generally, information is used solely for the purpose for which it was collected or for a closely related secondary purpose, where your needs have changed or become extended. For example, you may provide information when joining a particular service. Later you may join a different service within MND NSW which may better meet your needs.

## 7. Disclosure

MND NSW may disclose your personal information to:

- our employees, contractors or service providers for the purposes of delivering our services and conducting our operations, fulfilling requests by you, and to otherwise provide information, products and services to you including, without limitation, IT systems administrators, cloud computing services, mailing houses, couriers, payment processors, network administrators, web hosting providers, and professional advisors such as accountants, solicitors, business advisors and consultants. For example, personal information may be included in an internal alert from our business systems ordinarily generated for staff safety or systems security. These alerts may take a number of forms, including text messages to staff phones, emails or reports.
- suppliers and other third parties with whom we have commercial relationships, for business, marketing, research and related purposes or program
- any organisation for any purpose with your consent.

If you are a competition winner, we may disclose your personal information to an organisation which publishes competition winners' names and/or photos in accordance with the NSW Department of Gaming and Racing conditions (Lotteries and Art Unions Act 1901 (NSW)) or equivalent legislation in other states or territories.

Your personal information will not be shared or disclosed other than as described in this privacy policy unless:

- you consent
- where a permitted general situation exists, such as if MND NSW reasonably believes that the disclosure is necessary to lessen or prevent a serious threat to the life, health or safety of you or the public
- the disclosure is authorised or required by or under an Australian law or court/tribunal order, for example Reporting a reportable incident to [Aged care Quality and Safeguards Commission](#), [NDIS Quality and Safeguards Commission](#) or [SafeWork NSW](#)
- disclosure is otherwise permitted under the Privacy Act.

## Complaints and reviews

Feedback is responded to in a timely manner. Wherever possible this resolution is done at the most immediate level with appropriate support offered to those involved.

If the complaint is about a staff member s/he has the right to be informed of the nature of the complaint. However, confidentiality is a prime consideration during the complaint process for both complainant and any staff members involved.

The handling of any complaints is in accordance with the requirements of legislation and any relevant accreditation or funding body standards including Privacy Act 1998, Ombudsman Act 1974 and the NDIS Practice Standards and NDIS (Complaints Management and Resolution) Rules 2018.

### Disclosure to the media

The Chief Executive Officer (CEO) delegates what information is released to the media

The CEO will make statements and respond to issues in the media relating to the work of MND NSW and the sector in general. This is also the case in relation to critical incidents or complaints that may come to the attention of the media.

### MND NSW does not sell, trade or rent your personal information

MND NSW does not sell, trade or rent personal information it collects under any circumstances.

## 8. Cross-border disclosure of personal information

MND NSW does engage contractors or service providers located overseas to perform services on our behalf.

Where we have engaged a third party to provide a service that is not hosted in Australia, for example our online education platform for the delivery of education programs, only information you provide to the site is stored by the site. You will provide your consent separately to the site in accordance with their privacy policy.

MND NSW uses third-party payments industry services for the processing of financial transactions. These services are global services and have embedded fraud protection/risk algorithms and are commonly used by merchants who accept credit card and debit card payments. MND NSW conducts checks to ensure payment processors used for MND NSW transactions have an externally verified Payments Card Industry (PCI) compliant status.

Where MND NSW provides access to personal information held in Australia to contractors or service providers engaged by MND NSW who are located overseas, MND NSW takes reasonable steps to ensure that the contractor or service provider does not breach the APPs in relation to the personal information through, for example, the signing of a confidentiality agreement, limited access provisions and access alerts.

## Reasonable steps to protect personal information

Generally, MND NSW takes reasonable steps to protect the security of the personal information it holds from both internal and external threats through access security and monitoring controls, including:

- regularly assessing the risk of misuse, interference, loss and unauthorised access, modification or disclosure of that information
- taking measures to address misuse, interference, loss and unauthorised access, modification or disclosure of that information, For example, by privileged access controls.
- reviewing information so it is retained for the length of time that is reasonably necessary for the purpose for which it was collected, and as necessary to comply with our legal obligations, resolve disputes, prevent fraud, and enforce our agreements.
- implementing and regularly updating MND NSW's data breach response plan to ensure that MND NSW meets its obligations under the notifiable data breach (NDB) scheme under the Privacy Act
- conducting checks to ensure payment processors used for MND NSW transactions have an externally verified PCI compliant status.

## 9. Your access to and correction of personal information held by MND NSW

### Rights to information

MND NSW gives you a right of access to your personal information so that you can review and correct details.

Access to information will be supervised so the content of the information can be explained.

Access will not be permitted where a legislative exemption overrides the right to access such as where access is not permitted by any law or court order. A written notice will be given outlining the reasons for refusal if access is refused for any reason.

You only have the right to access your own records or information. You cannot access records or information of any family or friends. If providing you access to their information will breach the privacy of another individual, the other individual's information will be removed before access can occur.

Reports from other agencies (including neurologists, general practitioners etc.) are seen as being the property of the originating agency and the inquirer should be referred back to that agency. If the agency no longer exists and has no obvious successor, then the material/report may be released to you by MND NSW.

### Access by you

You can request access by contacting the Manager, Support Services or program or any senior MND NSW staff member.

You will be asked to verify your identity so that MND NSW can be satisfied the request comes from you, or a person authorised to make a request on your behalf, for example, as a legal guardian or authorised agent.

MND NSW will strive to provide access as quickly as possible. Access will be provided no later 30 calendar days from the receipt of the request. If for some reason this timeframe is not practical (for example, there is a justifiable need to clarify the scope of your request, or to locate and assemble the requested information, or to consult a third party), approval will be obtained from the CEO to contact you to explain the delay and provide an expected timeframe for finalising the request.

The information will generally be made available under the supervision of a Support Service staff member or an intermediary agreeable to the person making the request and MND NSW. As all records are electronic a paper print out of the record will be provided.

Where there is a legislative exemption overriding the correction, a written notice will be given to you outlining the reasons for refusal to correct information and the complaint mechanisms available to you.

### Access by relatives/descendants of deceased clients

All inquirers must put their request for information in writing to the CEO and include their relationship to the client and the reasons for the request. If MND NSW is not aware of the client's death, the inquirer must provide evidence that the client has died.

If the CEO approves making the file available, the record will be made available in accordance with procedures listed above in the section 'Access by you'.

### Correction of personal information

If you think the personal information MND NSW holds about you is incorrect, inaccurate, incomplete, irrelevant, out-of-date or misleading for the purpose for which it is held contact MND NSW Privacy Officer at [admin@mndnsw.org.au](mailto:admin@mndnsw.org.au), phone or write to MND NSW using the Contacting MND NSW information at the bottom of this policy.

Only you or a person you have authorised, such as a legal guardian or authorised agent, can request the correction of your personal information.

MND NSW must be satisfied the request came from you or the person you authorised. You may be asked to put your request in writing or for information that identifies you.

## 10. How to make a complaint

If you have any questions about the MND NSW Privacy Policy or would like to discuss any issues in relation to your personal information, you can contact the MND NSW Privacy Officer at [admin@mndnsw.org.au](mailto:admin@mndnsw.org.au), phone or write to MND NSW using the Contacting MND NSW information at the bottom of this policy.

All feedback, complaints and incidents are recorded and used to help us improve our services. MND NSW will respond to, and investigate, any complaints made within one week and aim to resolve all issues within one month. The CEO and Support Services Manager are responsible for ensuring all complaints are managed within our policies and procedures. You will be kept updated throughout the process and advised of how we are resolving your issue. You will also be provided with the outcomes in writing once all actions have taken place

You can find out more information in the MND NSW Rights, Responsibilities, Feedback and Incidents policy at <https://mndnsw.org.au/quality/749-rights-and-responsibilities-and-feedback.html>.

If you are not satisfied with the outcome of any complaint you can contact the following for more advice:

- NSW Health Care Complaints Commission Ph. 1800 043 159. TTY 02 9219 7555  
<http://www.hccc.nsw.gov.au>
- NSW Ombudsman (about services funded by Dept of Family and Community Services) Ph. 1800 451 524. TTY 02 9264 8050  
<https://www.ombo.nsw.gov.au>
- ACT Disability and Community Services Commissioner. Ph. 02 6205 2222.  
<http://hrc.act.gov.au>
- NDIS Quality and Safeguards Commission (about NDIS providers) Ph. 1800 035 544.  
<https://www.ndiscommission.gov.au>
- NT Health and Community Services Complaints Commission Ph. 1800 004 474 08 8999 1969  
<https://hccsc.nt.gov.au/>
- NT Ombudsman Ph. 1800 806 380 or 08 8899 1818 <https://ombudsman.nt.gov.au/>
- the Office of the Australian Information Commissioner (OAIC). Further information about how to do this is available on the [OAIC website](#). OIAC is independent of MND NSW and has the power to investigate complaints about possible interferences with a person's privacy.

## 11. Contacting MND NSW

If you have any questions about the MND NSW Privacy Policy or would like to discuss any issues in relation to your personal information or would like to request a copy of this Policy in another format (e.g. hard copy) contact the MND NSW Privacy Officer at:

MND NSW  
Locked Bag 5005  
Gladesville NSW 1675  
Email: [admin@mndnsw.org.au](mailto:admin@mndnsw.org.au)  
Phone: 02 8877 0999 or 1800 777 175

### Contact using accessibility services

#### National Relay Service (NRS)

The [National Relay Service](#) is a service provided by the Australian Government to assist people who are Deaf or have a hearing or speech impairment.

If you are d/Deaf, hard-of-hearing or are experiencing changes to your speech and find it hard to speak to hearing people on the phone and need assistance, contact MND NSW through call 1800 555 660 or 1800 555630 TTY (Speak and Read).

#### Translation and Interpreting Service (TIS)

If you need an interpreter to assist you to contact MND NSW you can access services through [Translating and Interpreting Service \(TIS National\)](#) or phone 131 450 (within Australia) +613 9268 8332 (outside Australia)

## 12. Privacy policy update

This privacy policy is effective as of 1 October 2025.

MND NSW may update this privacy policy from time to time. MND NSW will notify you by other means (for example, by placing a notice on its website) if it makes material changes to this policy.

## 13. Information sources used in the development of this policy

In developing this policy MND NSW reviewed publicly available information at:

- Office of the Australian Information Commissioner  
<https://www.oaic.gov.au/>
- NDIS Quality and Safeguards Commission  
<https://www.ndiscommission.gov.au/>
- Department of Industry Science and Resources  
<https://www.industry.gov.au/>