

The Motor Neurone Disease Association of New South Wales (MND NSW) recognises that many people are concerned about information provided to MND NSW, and how that information is treated.

In accordance with the Australian Privacy Principles within the Privacy Act 1988 and the Health Privacy Principles outlined in the Health Records and Information Privacy Act, this policy outlines how MND NSW manages privacy protection of your personal information.

Information MND NSW collects

When you deal with MND NSW the personal information collected about you may include details of your name, date of birth, sex, current and previous addresses, telephone/mobile phone number, email address, next of kin details, disease status and other health and treatment information and credit card details. It may also include details of the services or products provided to you by MND NSW, as well as the status of those services or products.

This information is collected so that MND NSW can:

- provide relevant services and products to you, including dealing with any enquiries or complaints;
- raise funds for purposes related to the aims of the association;
- provide advice and information that MND NSW believes will be of direct benefit to you in terms of assisting you to manage your disease;
- administer and manage the delivery of those services and products; and
- improve the services offered to members, donors and participants.

Sources of information

MND NSW may collect your personal information with your consent:

- when reasonable and practicable, directly from you, for example, when you provide information to the Association over the phone or in documents such as an application, donation form or referral from a health care provider;
- from third parties, for example, a person who cares for you, a direct relative, a club or association of which you are a member, the Department of Education or teachers; or
- from the other organisations identified under 'Disclosing your information' overleaf.

Health information

MND NSW only collects health information about you with your consent or if required or authorised by law.

We treat health information on a strictly confidential basis and do not disclose it to third parties without your consent unless disclosure is required by law.

Storage of your information

All your personal details and information are only accessible by authorised personnel who are fully aware of your rights and the MND NSW Privacy Policy. Personal details and information are either:

- destroyed or returned to you if no longer needed; or
- stored securely in either paper or electronic form.

MND NSW website

The MND NSW website does not collect personally-identifiable information from individuals unless they provide it to the Association voluntarily and knowingly. This means MND NSW does not require you to register or provide information to the Association in order to view the site.

If you join the Association online or provide information for another purpose, we use the information you supply online for the purpose of providing the services you've requested. If you specifically agree to follow-up contact by MND NSW or ask to be put on the MND NSW mailing list, MND NSW may contact you from time to time.

You can always change your preference for follow-up contact by contacting MND NSW at any time. However, please be assured that MND NSW does not share any information you give the Association with anyone outside of the Association, other than as set out in this Privacy Policy.

When you view the MND NSW website, information is collected about your browser and whether you have visited the MND NSW website before. The MND NSW website does not extract any personal information about you from your computer.

To update, correct or delete your information

If you would like to know, update, correct or delete the personal information MND NSW holds about you contact the MND NSW Privacy Officer at the address overleaf.

Disclosing your information

MND NSW understands how important it is to keep your information private, and so the Association only discloses your personal information to third parties in certain limited circumstances. These disclosures will be made subject to appropriate privacy and confidentiality protection.

Organisations to which MND NSW may disclose information include:

- outsourced service providers who manage the services MND NSW provides to you;
- government and regulatory authorities and other organisations, as required or authorised by law;
- professional advisers of MND NSW, including accountants, auditors and lawyers associated with MND NSW;
- your representatives, for example, your doctor or other health professionals with your consent;
- any partner with which MND NSW participates in a joint promotional activity, for example, another motor neurone disease association; and
- any 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.

If something goes wrong

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 our Privacy Officer at admin@mndnsw.asn.au, phone or write to MND NSW.

Motor Neurone Disease Association of New South Wales Inc.

Mission

To provide and promote the best possible support for people living with motor neurone disease, their families and carers, to advance research and to raise awareness.

MND NSW is committed to providing appropriate support and information to people with MND and their families.

MND NSW welcomes your feedback to assist in the improvement of services.

Motor Neurone Disease Association of New South Wales Inc

Gladesville Hospital, Victoria Road
Gladesville NSW 2111
Locked Bag 5005, Gladesville NSW 1675
Ph **02 8877 0999** or **1800 777 175**
Fax 02 9816 2077
admin@mndnsw.asn.au
www.mndnsw.asn.au

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Privacy

**Motor Neurone Disease Association
of New South Wales**