

PRIVACY POLICY

About Our Policy

Muscular Dystrophy NSW (MDNSW) (We/Our/Us) is committed to protecting any personal information We hold and manage about You.

We operate in accordance with the laws that relate to how We collect, manage and use Your personal information, including:

- Privacy Act 1988 (Cth)
- Health Records and Information Privacy Act 2002 (NSW)
- Privacy and Personal Information Protection Act 1998 (NSW)
- National Disability Insurance Scheme Act 2013 (Cth)

Is this Policy relevant to me?

We are a not-for-profit charity that provides NDIS services and supports to Our clients and members. As part of Our activities, We may need to collect certain personal information about You:

- where reasonably necessary to manage Your membership or inquiries or provide services and programs to You;
- as part of supporter programs, including donor and fundraising activities;
- to comply with regulatory requirements, including reporting to relevant regulators, including as a NDIS provider and charity;
- if you visit our website; and
- if otherwise required by law.

What type of information do We collect?

Personal information

We only collect Your personal information in fair and lawful ways, and we won't ask for anything that we don't genuinely need to provide you with support, run our programs, or stay connected with our community.

Most of the time, we collect information directly from you, because it's important you stay in control of your own details. In some situations—like when a parent, carer or authorised person speaks with us on your behalf—we may collect information from them if that's the most practical or appropriate way to support you. This may include:

- Your name and preferred contact details
- some demographic information where relevant, for example, gender, date of birth
- information on key client supports, including carers and/or family contact information
- payment information where relevant for a service or a donation
- Information in an employment application sent in response to an advertised role or expression of interest

Sensitive information

We will only collect sensitive information with Your consent and where reasonably necessary to provide services and supports to You unless otherwise required by law. This may include:

- health information, for example, a client's disability and related information about functional capacity and required supports
- information about a client's cultural background and/or religious beliefs
- certain government identifiers, for example, Medicare, NDIS or concession numbers
- information generated by a health service provider, for example, reports, advice or recommendations about an individual's health
- information included in mandatory credential verification, such as police checks and WWCC (or equivalent)

We do not use or disclose Medicare, NDIS numbers unless required by law, or You have consented to disclose this information to a third party.

How do we collect your information?

We collect Your information directly from You in most cases, including:

- from Our website, when You sign up for an event or activity, or donate to MDNSW
- from surveys and evaluations, You complete (unless You chose to be anonymous)
- from social media, such as interactions on Our Facebook page or community fundraising pages
- over the phone or in person as part of Our client services and supports
- over the phone or in person as part of Our fundraising activities
- from an application form for a MDNSW event or program
- from a MDNSW Service Agreement

You may choose to interact with Us without identifying yourself, or using a pseudonym, where it is practicable and lawful to do so. However, We may not be able to provide You with access to various services, or the same level of service, if You choose not to identify Yourself.

What happens if we can't collect Your personal information?

You can choose whether or not to provide Us with information. However, if You elect not provide information to Us, We may not be able to provide You with the service or support You requested or respond to Your inquiry.

For what purposes do We collect, hold, use, and disclose Your personal information?

We collect personal information about You where it is reasonably necessary for Our activities and functions or otherwise required or permitted by applicable law. This may include collecting and using Your personal information:

- to provide services to You and to send communications requested by You
- to keep Your personal details up to date
- to distribute information about fundraising events and opportunities to donors and supporters

- to maintain accurate records about MDNSW membership, including payments
- to inform You about MDNSW's programs, supports, and events that might be of interest
- to process and respond to any complaint made by You
- to comply with any applicable law, direction or requirement of a regulator or governmental authority

Automated decision-making

We do not use automated systems, including artificial intelligence, to make decisions about You or to materially influence decisions about You.

This includes decisions about eligibility, access to services, prioritisation, allocation, suspension or withdrawal of services, and decisions affecting donors, supporters, staff, volunteers or other individuals.

Any decisions that may significantly affect You are made by appropriately authorised MDNSW personnel through existing human decision-making processes.

We may use approved software tools, including artificial intelligence, for limited low-risk internal purposes, such as drafting, summarising, research support and administrative efficiency. These tools are used to support staff and are not used to make decisions about individuals.

Where these tools involve personal information, outputs are reviewed by authorised staff before use and responsibility for decisions and actions remains with MDNSW.

You may contact Us if You have questions about how decisions affecting You are made or how We handle Your personal information.

Fundraising activities

Where permitted by law, We may use personal information We hold about supporters and donors, together with limited publicly available information, for fundraising activities such as analytics, donor profiling and prospect research. We do this to better understand supporter interests, improve Our communications, and use Our fundraising resources responsibly. We take reasonable steps to ensure these activities are proportionate and privacy protective. You may ask Us at any time not to use Your personal information in this way by contacting Us using the details in this Privacy Policy.

Who do we collect Your information from?

Wherever possible, We will collect personal information directly from You. However, We may collect it from a third party:

- if it is unreasonable or impracticable to collect personal information about You from You, taking various factors into account, including the sensitivity of the information and what You'd reasonably expect in the circumstances
- from a parent, legal guardian or authorised nominee, in the case of a minor or other person who may not be able to give informed consent.
- where You have authorised Us to do so. For example, where You have authorised Us to access information necessary to provide support coordination services

- in a permitted general situation, for example, where necessary to manage a health or safety situation where it is impracticable to obtain Your consent
- where otherwise required or authorised by law or a court/tribunal order

Where information is collected from third parties, We will use reasonable endeavours to:

- ensure the information is accurate and up to date
- inform You of the information collected about You, taking reasonable steps to ensure You are aware of who We received information from, Your right to access the information, the purpose for which the information is collected, any law that requires the information to be collected and what will happen if we don't receive this information.

Informed Consent

We provide functions and services for a vulnerable community that includes minors and individuals with reduced decision-making capacity. In these cases, We may take additional steps to:

- verify and where possible, support an individual's decision-making capacity
- ensure that We only collect personal information from a person who is duly authorised or otherwise empowered to provide that information.

In doing so, We will take into account:

- the circumstances at the relevant time, including an individual's unique capacity and the nature of the information
- applicable law and guiding principles under the Convention on the Rights of Persons with Disabilities (CRPD) and the Disability Inclusion Act 2014 (NSW)
- the capacity assessment principles under the NSW Capacity Toolkit

This may include family members, carers, guardians, nominees and authorised service providers.

We encourage family support and communication between family members. However, We will not generally provide personal information about a person over 16 years to family members without the relevant individual's consent.

Use and Disclosure of Your information

We may use and disclose Your personal information for the purpose for which it was collected. This will generally be only those ways You'd reasonably expect, such as providing You with services or supports requested by You or directly related to that purpose. For example:

- We may use or disclose Your information to service providers if, and only to the extent necessary, to perform associated financial, audit and compliance, reporting or administrative functions and to regulators, such as the NDIA and ACNC, if and to the extent necessary to comply with regulatory requirements, with your consent.
- We may also use images of individuals attending Our events as part of Our communications and media activities, including our website, newsletter and social media if You, or your responsible person, have expressly consented or would reasonably expect that use. A Media Consent option and further information is included in all program applications.

We will only use or disclose it for another purpose if You consent to it, or an exception applies. This includes:

- where a permitted general situation exists, for example, if necessary to support the health or safety of an individual participating in one of Our activities, or managing unlawful activity
- where a permitted health situation exists. These are limited and specific situations that generally relate to the health and safety of an individual or the public
- where required by an enforcement body for their activities or required or authorised by law or court/tribunal order.

We will not use or disclose Your personal information that is a government related identifier (such as a NDIS or Medicare number) except:

- where reasonably necessary to verify Your identity or comply with obligations to a government authority
- where reasonably necessary to provide services or activities You have requested, such as NDIS support coordination or participation in [overnight programs](#)
- where otherwise permitted or required by law We will not disclose information to third parties for statistical, research or service improvement purposes unless permanently and irretrievably de-identified.

Unsolicited information

From time to time, We may receive personal information that is unsolicited, that is, without requesting it, nor having taken active steps to collect it.

If, on review, the unsolicited information, could have been lawfully collected, We may retain the information and manage it in accordance with this policy. This may occur if the information is reasonably necessary for Our functions or activities and, the consents are given for sensitive information.

If, on review, the unsolicited information could not have been lawfully collected, We will destroy or de-identify the information as soon as reasonably practicable provided that it is lawful and reasonable to do so.

Do We disclose Your personal information outside Australia?

Our offices, staff and volunteers are based in Australia. Our contractors and service providers, including Our IT providers, are also based in Australia. In the rare event that We are asked to disclose personal information outside of Australia, We will only do so:

- if we reasonably believe the recipient is subject to a law, binding scheme or contract that provides protection substantially similar to the Australian Privacy Principles and can be enforced
- with Your express and informed consent
- where otherwise permitted or required by law

Direct marketing

We may use Your personal information to send You direct marketing communications and information about Our products and services if You have consented to receive these or would otherwise reasonably expect them. Any communications will be sent in accordance with applicable marketing laws.

You may opt-out of receiving direct marketing from Us at any time by contacting Muscular Dystrophy NSW – PO Box 3071, North Strathfield NSW 2137 Tel: + 612 9888 5711 or via email: info@mdnsw.org.au.

We do not provide Your personal information to other organisations for the purposes of direct marketing.

How can You access and correct Your personal information?

You may request access to any personal information We hold about You by contacting Us. We will ask You to verify Your identity and where possible, describe the scope of information requested.

Where We hold information that You are entitled to access, We will endeavour to provide it to You promptly (generally within 30 days of Your request) and in a suitable form. We reserve the right to impose a reasonable and not excessive charge if the request is complex or involves large amounts.

We may refuse access to personal information held by Us if required or authorised by law. For example, this may occur if access would unreasonably impact another person's privacy or threaten the health or safety of an individual. We will give You written reasons for any refusal.

We are committed to:

- keeping Your personal information up to date, complete and accurate with regard to the purpose for which it is held
- promptly correcting personal information We hold about You if You request us to do so

We may request that You verify Your identity to establish Your authority to correct personal information held by Us.

If We do not hold Your personal information or are not satisfied that the information We hold requires correction, We provide You with reasons for Our refusal in writing and add a note to the personal information stating that You disagree with it.

Security of personal information

We are committed ensuring that Your personal information, in any form, is held securely and protected from misuse, interference and loss as well as unauthorised access, modification or disclosure. We use a range of measures including:

- screening staff in accordance with applicable law and best practice
- training staff and volunteers in applicable procedures
- applying system access controls, such as password protection and authentication
- restricting access to physical premises where records may be held
- utilising secure onshore data storage and back up
- destroying or de-identifying personal information that is no longer required for the purpose for which it was held (unless otherwise permitted or required by law), in accordance with document management policy

- maintaining an up-to-date data breach management procedure

How to contact Us or make a complaint

Please contact Us with any questions regarding Our Privacy Policy, requests to access or correct Your personal information, or concerns or complaints about the management of Your personal information.

Muscular Dystrophy NSW
PO Box 3071 North Strathfield NSW 2137
by phone on 02 9888 5711 (ask for our Office Manager)

by email at info@mdnsw.org.au
or via the [Contact Page](#) on our website.

We are committed to resolving any complaints in a confidential, timely and appropriate manner in accordance with Our complaints procedure/data breach procedure and other requirements where applicable eg, NDIA.

We may ask You to verify Your identity and provide written details of any alleged breach to the extent necessary to investigate and address any complaint. On receipt, We will investigate and respond to You within a reasonable time (usually no more than 30 days) then work with You to explore options and resolution of the matter in a fair and reasonable manner.

You may also contact the Federal Information Commissioner or the NSW Privacy Commissioner if We are unable to resolve Your complaint satisfactorily.

More information on complaints and contacting external bodies to make a complaint is available in [Compliments, Suggestions and Complaints](#).

Changes to Our Privacy Policy

We may change this Privacy Policy from time to time. Any updated versions of this Privacy Policy will be posted on Our website and may be notified in Our member newsletter.