

MUSCULAR DYSTROPHY ASSOCIATION OF NSW

PRIVACY POLICY

Definitions

- The Muscular Dystrophy Association of NSW is hereinafter referred to as the *Association*.
- *Personal information* identifies an individual, e.g. name, address and telephone number.
- *Health information* is that personal information which is specific to an individual's health or disability. This may include information about health services, referrals and advocacy.
- *Sensitive information* is that personal information which may also be collected where relevant. This may include information such as health, ethnic origin, religious beliefs, membership of a political or professional or trade association, political opinions, sexual preferences or criminal record.
- A *Client* is a person who approaches the Association seeking information, support, referral, membership, advocacy or other services.

Preamble:

This policy is based on the National Privacy Principles as outlined in the *Guidelines on Privacy in the Private Health Sector* (08 November 2001).

The Association accepts these privacy principles and this privacy policy conforms to them. While each principle contained in the guidelines is covered, many of the sub clauses do not apply to the Association's role and operations. If a situation arises that is not covered within this policy *The Privacy Amendment, Private Sector, Act 2000* and other relevant legislation will take precedence over this policy.

This policy does not apply to employee records when that information collected is for employment purposes, as this is covered by separate legislation and policies.

This policy applies should the Association provide advocacy services on behalf of any individual, including an employee.

1. Consent

- 1.1 The Association will obtain consent from individuals before personal information is collected.
- 1.2 The Association has internal policies and procedures to ensure that this policy is adhered to.

2. Collection Use and Disclosure

- 2.1 The Association collects personal information:

- 2.1.1 To facilitate the distribution of information about neuromuscular disorders and relevant services.
- 2.1.2 To keep accurate financial records of Association membership.
- 2.1.3 To keep accurate records of individuals when the Association provides advocacy services on their behalf.
- 2.1.4 Prior to employment or volunteer selection.
- 2.2 The Association undertakes to keep confidential any personal information collected and to use or disclose such information only for the primary purpose for which it was collected or as may be agreed by or on behalf of the individual.
- 2.3 Information about services and agencies is collected by the Association and is given to clients, where appropriate, for referral purposes.

3. Data Quality

- 3.1 The Association undertakes to ensure that the information collected is maintained in an accurate and complete manner.

4. Data Security

- 4.1 The Association undertakes to keep the personal information it collects in a secure place.
- 4.2 The Association will grant access only to those staff and authorised volunteers who require that personal information as part of their job requirements.
- 4.3 The Association undertakes to destroy all personal information when it is no longer required by statute or the Association's constitution. All personal records are kept for six years.

5. Openness

- 5.1 This policy is also displayed in the Association offices and copies are available on request.
- 5.2 The Association has in place a grievance policy and procedure that can be used for breaches of this privacy policy .

6. Access and Correction

- 6.1 Apart from relevant staff who access information in the performance of their duties, personal information can be accessed and/or changed only by the person to whom it relates.

- 6.2 A copy of personal information collected by the Association can be obtained by contacting the Association's Chief Executive Officer via:
- a) telephone, quoting membership number and address, or other means of verifying membership status.
 - b) a request in writing, quoting membership number and address.
- 6.3 When requested, a copy of personal information held will be posted within 5 working days of the request being received.
- 6.4 Personal information can be amended via:
- a) telephone, quoting membership number and address, or other means of verifying membership status.
 - b) a request in writing quoting membership number and address, or by completing a membership renewal form.
- 6.5 Health and sensitive information may be withheld from clients in situations where it is considered by the Association that this information will cause serious threat to the psychological and/or physical health of the client.
- 6.6 Health and sensitive information will be supplied under the direction of an appropriate Association staff member. This information will not be unreasonably withheld.

7. Identifiers

- 7.1 The Association does not use the identification or reference numbers of other organisations.
- 7.2 The Association does not release clients' personal information to other organisations or people without written consent from that client.

8. Anonymity

- 8.1 The Association undertakes to maintain clients' anonymity where practicable.

9. Trans-border data flows

- 9.1 The Association will not transfer or send any personal information outside Australia without prior written consent from the client.