Things you need to know

- For you to get the best from this service it's important that you feel comfortable, are able to exchange information freely and understand the written information you receive
- Please let us know how we can best meet your needs (e.g. if you use Sign Language, want information provided in a certain format, or need an interpreter)
- Fieldworkers can help you with safety planning, as we do not provide an emergency or crisis service.

Giving feedback

MDANZ wants to provide the best possible service to its members. We welcome all feedback as it helps us improve the work we do.

You have specific rights when using this service. You can find out more about these rights at www.hdc.org.nz.

If you think your rights have been breached, you can also contact an independent Health and Disability Advocate on 0800 555 050, or email advocacy@hdc.org.nz

To give feedback to MDANZ contact our National Support Office:

Phone: 0800 800 337 Email: info@mda.org.nz



About us

The Muscular Dystrophy Association of New Zealand (MDANZ) formed in 1959 and supports people with lived experience of a neuromuscular condition, and their support networks. We are a member-led charitable organisation, and our unique governance structure ensures leadership comes from individuals with lived experience of a neuromuscular condition. We rely on grants and donations to continue our work.

What we do

MDANZ provides a free, nationwide fieldworker service, funding for counselling and a range of other benefits for our members.

We promote freedom of choice and support individuals, families and whānau, by:

- Providing specialist information
- Facilitating service access
- Providing resources
- Creating social networking opportunities
- Facilitating research and working with clinicians and researchers to improve care standards
- Linking members with clinical trials and treatment opportunities.

Only members affected by a neuromuscular condition covered by MDANZ can access the



free, professional, fieldworker service. You can become a member by contacting your local branch or the National Support Office.

What does a fieldworker do?

Fieldworkers work alongside you and your community, get to know your strengths, needs and goals and facilitate access to further supports, services or resources as you need them.

Personalised support may include:

- Supporting you and your family through diagnosis
- Walking alongside you during times of grief and change
- Offering information about conditions and how to manage these

- Assisting you to "problem solve" and provide resources to help you achieve your goals
- Providing information on entitlements, community and support services
- Facilitating service access through referrals or advocacy
- Reducing isolation by connecting people to others with a shared experience.

Community education may include talking with teachers, health professionals or disability support staff to improve their understanding of rare, progressive neuromuscular conditions, which enables them to provide even better services and supports for our members.

What can I expect when working with a fieldworker?

We have regional branches in Auckland, Wellington, Christchurch and Dunedin. Fieldworkers are dotted around the regions and may visit different parts of their region only once or twice a year. They will visit you at home or at another convenient place. They also keep in touch by phone, email or video calling.

They work within a practice framework and maintain professional standards of practice.

All information you share with the fieldworker is confidential. You are welcome to have support when meeting with one of our fieldworkers.