Muscular Dystrophy Queensland

Client Guide

Registered NDIS Provider

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About **this guide**

This guide is designed to help clients, potential clients and their families learn more about Muscular Dystrophy Queensland (MDQ) and the services we offer.

For more information, please contact our team, visit our website or follow us on social media. We are open Monday to Friday, 9am to 4:30pm.

Our contact details are:

Office Address:	Unit 5 Portal Office Park 2996 Logan Road Underwood QLD 4119
Mailing Address:	Locked Bag 3020 Springwood QLD 4127
Reply Paid Address:	Reply Paid 66034 Springwood QLD 4127
Telephone:	1800 676 364 (free call) 07 3243 9700
Email:	info@mdqld.org.au
Website:	www.mdqld.org.au
Facebook:	www.facebook.com/mdqld.org.au

Disclaimer
Muscular Dystrophy Queensland's Client Guide outlines the obligations and responsibilities of Muscular Dystrophy Queensland Limited, the service provider, and you, the service user. The Client Guide is neither complete nor exhaustive, and MDQ takes no responsibility and cannot be held accountable for any action or decision made based on the information contained in this guide alone.

Updated September 2025

Acknowledgment **of Country**

Muscular Dystrophy Queensland acknowledges and pays respect to the past and present Traditional Custodians and Elders of this nation and the continuation of cultural, spiritual and educational practices of Aboriginal and Torres Strait Islander peoples.

Diversity **and cultural inclusion**

Muscular Dystrophy Queensland is committed to welcoming and supporting all groups within the Australian community.

We provide fair and inclusive access to our services, ensuring they are respectful of each client's individual values, customs and beliefs, regardless of their cultural or social background.

If a client finds it difficult to adequately communicate, we can arrange interpreters, including sign language interpreters, to assist.

Who **we are**

Guiding Principles

Vision

A life without limits for people with muscular dystrophy and similar neuromuscular conditions.

Mission

To empower individuals living with muscular dystrophy and similar neuromuscular conditions to make the most of life's opportunities and live the life they choose.

Objectives

To be a professional, adaptable, efficient and financially sustainable organisation, providing high-quality services across Queensland.

These values guide our Board and staff in the planning and delivery of all MDQ services.

Our Structure

Muscular Dystrophy Queensland:

- Is a public company limited by guarantee, operating under the *Corporations Act 2001* and regulated by the Australian Charities and Not-for-profits Commission (ACNC)
- Is governed by a voluntary Board of Directors
- Provides user-pay services under the NDIS and other schemes
- Offers free services funded through grants, donations and fundraising events

We are proud to have the generous support of individuals and organisations who believe in improving the lives of people with muscular dystrophy and similar neuromuscular conditions.

Our History

Founded in 1978 by a group of parents concerned about the lack of support for their children, Muscular Dystrophy Queensland (MDQ) began as a grassroots organisation focused on education, advocacy and mutual aid.

More than 45 years later, we continue their legacy, offering support services, raising awareness and working with the national Muscular Dystrophy Foundation Australia to

advocate for people living with neuromuscular conditions in Queensland.

MDQ is the only Queensland organisation focused solely on supporting people with muscular dystrophy and similar neuromuscular conditions. We are proud to be here for you as an advocate, a peak body and a service provider, supporting Queensland's neuromuscular community in all aspects of life.

Our Team

MDQ is led by a passionate Board and committed staff. Specialised teams conduct our work in:

- Management
- Client Services
- Allied Health Services
- Plan Management Services
- Finance
- Fundraising and Marketing

Information about our Board of Directors and staff members is available on our website.

Our clients

MDQ provides whole-of-life support and services for Queenslanders living with muscular dystrophy and similar conditions. Sometimes we use the broader term **neuromuscular condition(s)** to describe the range of diagnoses we support.

Commonly supported conditions

Most of our clients live with one of the following neuromuscular conditions:

- **Muscular dystrophies** – including Duchenne, Becker, FSHD and Myotonic dystrophy

- **Motor neuron diseases** – such as Spinal Muscular Atrophy (SMA)
- **Neuromuscular junction disorders** – including Myasthenia Gravis
- **Peripheral nerve diseases** – such as Charcot-Marie-Tooth Disease (CMT)
- **Mitochondrial diseases** – including Friedreich's Ataxia
- **Myopathies** – such as Inclusion Body Myositis
- **Ion channel diseases** – including Myotonia Congenita

If a condition is not listed above, we may still be able to provide support.

To help guide our decisions, we refer to the Muscular Dystrophy Association (USA) website, which offers a comprehensive list of muscular dystrophy and neuromuscular conditions: www.mda.org/disease/list

Who We Support

Our primary client is the person living with a neuromuscular condition. However, our support also extends to:

- Immediate family members (e.g. spouses, parents, children and/or unpaid carers)
- Paid disability support workers
- Educators and school staff
- Allied health professionals and other service providers

We are here to assist people **at any life stage and any level of disability**, ensuring that support is responsive, relevant and tailored to each person's needs.

Any person wishing to receive services from MDQ will undergo a simple intake process to become a client. Our Intake Officer will guide you through this. If they are not available, another member of the client services team will help you. There is no cost involved in becoming a client of MDQ.

The process involves welcoming you, helping you decide whether MDQ is a suitable service provider and providing information and answers to your questions or concerns. For people who have difficulty in understanding processes or language, we can accommodate you bringing a support person of your choice or a language interpreter.

Once you have decided to become a client of MDQ, our Intake Officer will ask you to complete the following forms:

- **Client Details Form:** this includes your personal details and some information about your condition
- **Client Consent Form:** this records your consent (or that of your authorised guardian) for MDQ to:
    - Provide services
    - Disclose and collect information
    - Communicate with guardians and carers
    - Capture and use photography, video and other media

If you are accessing MDQ's National Disability Insurance Scheme (NDIS) services, you will also need to complete a **Service Agreement** and **Schedule of Supports,** as required by the National Disability Insurance Agency (NDIA).

Accessing Specific Programs

If you wish to access a specific program, such as our equipment loan service, you will be asked to complete a **Loan Agreement.**

If, for any reason, MDQ is unable to accept you as a client, we will explain the reason to you and, where possible, recommend alternative service providers that may be able to assist.

Your Privacy

All personal information collected by MDQ is protected by our Privacy Policy and Procedures, the *Privacy Act 1988,* and *National Privacy Principles 2014.* Your privacy is important to us, and we are committed to safeguarding your information.

Becoming a Client

Once you have completed the intake process, you are considered a client of MDQ. We offer whole-of-life support, which means you will remain a client until you choose to leave or are formally exited from our services *(see Exiting MDQ's Services on page 10).*

As a client of MDQ, you have access to:

- Regular updates and information about our services and upcoming events
- NDIS and fee-based services delivered by experienced and specialised staff
- Charitable services, such as our Equipment Loan Program and Social Work Program, depending on your eligibility and our capacity

Our team has a thorough understanding of neuromuscular conditions and is here to answer your questions and support you in navigating challenges throughout your time with us as a client.

Keeping your Information Up-to-Date

Please let us know if:

- You move or change your contact details
- You want to update your communication preferences (e.g. subscribe or unsubscribe to our emails)
- You would like us to remove your personal information from our records

Exiting a MDQ Service

MDQ provides a range of supports including NDIS Support Coordination, Allied Health, Plan Management and charitable programs. Each service is managed separately so exiting one will not affect your eligibility for others.

As a client you have the right to discuss ending your Service Agreement with MDQ at any time. When your goals are achieved or if you decide to move to another provider we will support you through the transition. For some funded services a notice period may apply and this will be explained in your Service Agreement.

If at any time you no longer wish to remain an MDQ client just let us know and we will update our records accordingly.

In some circumstances MDQ may also end a service. This may occur if we cannot contact you for an extended period or if the service is no longer suitable for your needs. If this happens we will always communicate with you, explain the reasons and if you wish help connect you with another provider.

Staying connected

MDQ is a small organisation doing big work across Queensland. While we provide regular Client Updates, we may not be able to stay in personal contact all the time. However, we always welcome your calls and emails. We understand that your needs may change, and we are here to support you, so please reach out whenever you need assistance.

For the latest news and community stories, we encourage you to follow our social media pages.

About the NDIS

What is the NDIS?

The National Disability Insurance Scheme (NDIS) provides funding to eligible Australians or permanent residents with a disability, including those living with neuromuscular conditions. This funding is designed to help people:

- Spend more quality time with family and friends
- Increase their independence
- Learn new skills
- Access employment or volunteering opportunities
- Improve their overall quality of life

In addition to individualised funding, the NDIS also helps people with disability connect with supports in their local communities. These might include doctors, schools, libraries, community groups, sporting clubs and other support services.

The NDIS also provides information about supports that are available through state and territory governments.

Currently, the NDIS supports more than 500,000 Australians. As an NDIS provider, we can help you understand the NDIS and connect with the services and supports that are right for you.

Applying to the NDIS

To be eligible for the NDIS, you will need to:

- Be aged under 65 when you apply
- Be an Australian citizen or permanent resident
- Have one or more impairments that are likely to be permanent
- This/these impairment/s impact your ability to do daily life activities, including your social life, your ability to work and/or your ability to study

Once the NDIA decides you are eligible, you will become a participant of the NDIS, and they will start collaborating with you to create your NDIS plan.

What is an NDIS Plan?

An NDIS Plan is a personalised document that outlines your goals and the supports you need to help achieve them and live as independently as possible. Your plan is as individual as you, and with your *Participant's Statement of Goals and Aspirations*, the NDIA creates your plan based on your support needs.

Your plan will include:

- Your NDIS number
- Your "My NDIS" contact
- Your NDIS plan start date
- Your NDIS plan reassessment date
- Your total budget amount
- Your NDIS supports
- Funding component amounts
- Funding periods
- Information about you
- *Participant's Statement of Goals and Aspirations*, i.e. your goals, or things you want to work towards
- How you can use your NDIS funding
- Who will manage your NDIS funding
- Your supports outside of the NDIS, for example, information supports (such as family or friends), as well as mainstream and community supports
- What to do if something changes

Your NDIS plan is a living document that works alongside you to support your goals and aspirations. It provides a framework for accessing supports and services and ensures that any changes in your circumstances or condition can be addressed promptly.

By understanding your plan and how to use it effectively, you can make informed decisions and get the most out of the supports available to you.

Our **NDIS services**

NDIS Support Coordination and Plan Management Provision (PMP)

If you have these services approved in your NDIS plan, we can provide:

- NDIS Support Coordination
- Plan Management Provision (PMP)
- Allied Health services (currently offered for clients living within southeast Queensland) including:
    - Occupational therapy (OT)
    - Physiotherapy

NDIS Support Coordination

When you engage MDQ as your Support Coordinator, you are accessing professional support tailored specifically to the needs of people with neuromuscular conditions.

Our experienced coordinators can assist with:

- Getting the most out of your NDIS plan
- Creating an **Individual Support Plan** to help you achieve your goals, manage risks and set a budget
- Connecting with service providers, setting up service agreements and strengthening informal support networks
- Resolving issues, such as challenges with service providers
- Supporting you through changes in your condition, including applying for a plan review
- Building your confidence and skills to manage your plan independently

You can request Support Coordination at your NDIS planning meeting. If your planner does not include it in your plan, MDQ can provide advice on how to challenge this decision.

Plan Management Provision (PMP)

When you have an NDIS Plan, you receive funding to purchase disability-related goods and services. By engaging a Plan Management Provider, you gain more flexibility: you can use both registered and non-registered providers. It also takes the stress out of

managing your plan's finances.

As your Plan Management Provider, MDQ helps in:

- Setting up the financial management of your NDIS plan
- Creating service bookings in the NDIA portal
- Reviewing invoices for accuracy
- Claiming payments from the NDIA and paying your suppliers
- Providing monthly statements to track spending and available funds

The NDIS encourages participants to build independence in areas like budgeting, planning and decision-making. If you would like your plan managed, **you must ask your NDIS Planner to include it in your plan**. Once requested, the planner is required to allocate funding for this service.

Free Services Related to the NDIS

MDQ offers free support to help you access and get the most out of the NDIS. Our team can assist with:

- **Registration support -** helping you register with the National Disability Insurance Agency (NDIA), the government body that administers the NDIS
- **Planning preparation -** assisting you to prepare for your NDIS planning meeting so you can clearly communicate your needs and goals
- **Eligibility advice -** providing guidance if you are experiencing difficulties with NDIS eligibility or the application process
- **Plan implementation -** offering advice on how to activate and use your NDIS plan once it has been approved

Allied Health Services

MDQ provides allied health services that can be accessed through your NDIS plan. Our current services include **Physiotherapy** and **Occupational Therapy.** To access your supports, you will need to speak with your NDIS planner to ensure the right funding is included in your plan under the *Improved Daily Living* category. Note that this service is currently only offered in Southeast Queensland.

Once funded, our allied health professionals will work with you to develop an **Individual Support Plan** tailored to your needs, helping you work toward your NDIS goals and manage any identified risks.

We have a physiotherapy team based in Brisbane and the Gold Coast, with regular

visits to Toowoomba, the Sunshine Coast and the occasional outreach to Cairns. You can access therapy at our Underwood office, in your home, school or at your workplace, whatever suits you best.

Occupational Therapy (OT)

Occupational therapists help people participate in everyday activities that are meaningful and important to them, at home, at work and in the community. For people with neuromuscular conditions, our occupational therapists focus on maintaining independence, safety and quality of life through practical supports and strategies.

Occupational therapists provide specialist assessments and use evidence-based techniques to support needs arising from your condition. Under the NDIS, an initial OT assessment is usually completed to help determine your ongoing support requirements.

Working with an MDQ Occupational Therapist means you are supported by someone who understands neuromuscular conditions and the challenges that come with them. Our team draws on experience with other clients to recommend supports and strategies that may also be helpful for you.

Your OT support may include:

- Setting goals to support positive life changes
- Prescribing equipment such as hi-lo beds and pressure-relieving mattresses
- Addressing safety concerns, particularly following changes in physical ability
- Supporting life transitions (e.g. leaving school, retiring from work)
- Recommending minor home modifications and improving home access
- Assessing and introducing smart technology and environmental control systems
- Promoting access to the community and social participation
- Supporting employment related goals
- Addressing cognitive needs, such as memory and decision-making
- Assessing eligibility for Specialist Disability Accommodation (SDA)

Physiotherapy

Physiotherapy focuses on helping people improve movement, manage physical symptoms and maintain functional independence. At MDQ, our physiotherapists

understand the unique challenges of neuromuscular conditions and work with you to support your health, mobility and quality of life.

Our physiotherapists can provide:

- Physical and functional assessments including gait, balance, posture, range of movement, muscle strength, timed tests and outcome measures
- Advice and treatment for symptom management, e.g. stretching and light exercise programs, pain management, balance and fatigue
- Equipment prescription, e.g. manual and powered wheelchairs, scooters, pressure-relieving cushions, water wheelchairs and walkers
- Assessment and referral for custom-made orthotics
- Specialised seating assessment and recommendations
- Individual and group hydrotherapy sessions
- Liaison with other healthcare professionals, medical specialists and educational settings to provide coordinated care
- Advocacy related to your mobility and assistive technology needs

Accessing our Allied Health Services without an NDIS plan

MDQ also offers the allied health services described above in a **user-pay basis**. If you are not accessing services through the NDIS, we can provide support through your **private health insurance** (subject to your policy) or under **Medicare's Chronic Disease Management Plan** (a gap payment may apply).

Our allied health team can provide current pricing and written quotes upon request to help you explore your options.

Social Work

MDQ currently offers up to **four (4) free counselling sessions** with a qualified social worker. This service is available to individuals, parents and caregivers experiencing the day-to-day challenges of life with a neuromuscular condition.

Sessions can focus on personal or family mental wellbeing and provide a confidential space to talk about things like daily stress, relationships, health challenges, life changes, grief, loss and building better coping skills.

Counselling is available by phone, video call or in person. You do not need an NDIS plan to access this service - it is provided at no cost to you, thanks to funding from our

generous supporters and the NDIS Peer Support and Capacity Building Grant. MDQ is also working to expand our social work program, with the goal of offering it as an NDIS-funded service in the future.

Our General Services

MDQ's ability to offer free services depends on available funding and service capacity. While there may sometimes be a short waiting period, we maintain fair and equitable access through waitlists, and any expected delays will be clearly explained.

Thanks to the generosity of our supporters and donors, Muscular Dystrophy Queensland is proud to continue offering the following free services:

Infoline, Information and Support

We understand how important it is to have reliable, accurate information about your condition. That is why our clients value the specialist expertise MDQ provides. You can access trusted information about muscular dystrophy and related neuromuscular conditions by calling our Infoline, reading our newsletters, visiting our website (www.mdqld.org.au) or following us on social media.

You can reach our Infoline during office hours on **1800 676 364** or by emailing info@mdqld.org.au. Our trained and knowledgeable staff are here to help, whether by answering your question on the spot or consulting our networks to find the right information for you.

This is a free service available to all MDQ clients and members of the public.

Individual Services

MDQ offers specialist expertise and practical support to help you navigate living with muscular dystrophy and related neuromuscular conditions. Whether you are seeking

information, personalised advice or advocacy, we are here to support you at every stage of life.

Even if you are not currently receiving NDIS funding, MDQ can help in times of change or need, such as:

- When you are newly diagnosed or navigating the pre-diagnosis stage
- During life transitions, such as leaving school, starting a new job or retiring
- If your condition progresses and your support needs change
- When you are facing a crisis and require urgent assistance

We can also help you understand the NDIS, guide you through the application process and assist with eligibility requests.

For those with NDIS funding, MDQ can support you in a variety of ways:

- Acting as your Support Coordinator, Plan Management Provider or delivering Allied Health Services
- Connecting you with other funded providers
- Advocating for adjustments to your NDIS plan when required

You can access information and advice via our Infoline, newsletters, website (www.mdqld.org.au) or social media. Our trained staff are available during office hours to provide timely, accurate information and connect you with the right supports.

Advocacy

We understand that people with a disability may sometimes need a strong voice to support them in reaching their personal goals. MDQ offers **free individual advocacy** for clients on relevant issues or concerns. Our advocacy is respectful, appropriate and focused on your needs.

In some cases, where more specialised or independent support is needed, we can also refer you to an external advocacy organisation.

Examples of situations where you might benefit from advocacy support include:

- Securing fair and appropriate outcomes in your NDIS plan
- Becoming a more confident decision-maker within your family
- Helping friends, colleagues or employers better understand your condition

If you need advocacy support or advice, MDQ is here to help guide and support you.

Extended Care

Living with muscular dystrophy or a similar neuromuscular condition can sometimes bring unexpected challenges. These might include a sudden progression of symptoms, the breakdown of essential equipment, a carer becoming unavailable or unforeseen changes in housing or support arrangements.

When a critical incident occurs, MDQ can help you manage the immediate situation and work with you to reduce the risk of future crises. Depending on your needs, we may:

- Contact the NDIS to request a **Change of Circumstance Review** and assist you with lodging the request
- Connect you with relevant community services, such as the Department of Housing, Centrelink or the Taxi Subsidy Scheme
- Provide advocacy support for you and your family

Equipment Loan Program

MDQ's equipment loan programs are made possible through the generous support of our donors. As these programs are entirely donor-funded, availability is subject to current funding levels.

Access is offered through a straightforward application and assessment process. If you are interested in our Equipment Loan program, please ring or email us.

We currently offer the following equipment loan programs:

Cough Assist Machine Loan Program

The Cough Assist machine is a specialised respiratory device that supports people with weakened breathing muscles by simulating a natural cough. It works by delivering positive air pressure, followed by a rapid shift to negative pressure, generating a strong expiratory flow to help clear the airways.

MDQ's Cough Assist Machine Program is designed to support clients experiencing an acute respiratory infection, helping to prevent complications and promote faster recovery. The program is also available to those wishing to trial a machine before purchasing one.

All MDQ clients, and others living with a neuromuscular condition, are eligible for this free, short-term loan program. We provide full training to ensure the machine is used safely and efficiently, and machines can be delivered anywhere across Queensland.

Wheelchair Loan Program

MDQ's Wheelchair Loan Program offers **short-term loans of powered and manual mobility chairs** for individuals living with neuromuscular conditions. This free program is designed to support people recovering from illness, travelling or waiting for their own equipment.

Our team will work with you to ensure the right equipment is provided, along with guidance for safe and effective use. If you need a wheelchair on a short-term basis, please contact us so we can assist you promptly.

Other Equipment

MDQ may be able to assist with a short-term loan or a lease of essential equipment such as hoists, shower commodes, wheelchair cushions and padding, and other mobility aid items we have available.

Access to this equipment is subject to availability, and your support coordinator or allied health professional can help you determine what is needed and guide you through the process.

Peak **body services**

As Queensland's recognised peak body for people living with neuromuscular conditions, MDQ works to improve the quality of life for our community through a range of strategic and advocacy-based strategies, including:

- **Government Advocacy:** Engaging with government through written submissions, letters, grants and meetings on key issues identified by our community or the organisation

- **Policy Input:** Contributing to government consultations, such as the mobility scooter review, to ensure the voices of people with neuromuscular conditions are heard
- **Funding and Program Development:** Writing grant applications to secure funding for vital programs and equipment, especially for those who are not eligible for an NDIS plan
- **National Collaboration:** Partnering with neuromuscular organisations in other states to strengthen national advocacy efforts for all Australians living with muscular dystrophy and similar neuromuscular conditions.

National Projects

Many of the state-based organisations supporting people living with muscular dystrophy and similar neuromuscular conditions are members of our national body, **Muscular Dystrophy Foundation Australia** (MDFA). Through MDFA, we collaborate on national initiatives that benefit the broader neuromuscular community across Australia.

The Loop: Your Neuromuscular Resource Hub

In 2018, MDQ was proud to receive an NDIS Information, Linkages and Capacity Building grant to create a national digital resource. The result was **The Loop**: a trusted, easy-to-use online hub launched in May 2020, designed to support all Australians living with neuromuscular conditions.

The Loop offers a wealth of practical and reliable information topics including health, daily living and supporting others. Through the website or mobile app, you can:

- Learn about your specific condition
- Customise and share your own condition guide
- Explore medical and allied health supports, equipment, and home accessibility
- Get advice on everyday life, from travel and education to relationships and transport
- Access support and tips for carers
- Connect with others through a secure, moderated online forum

Visit **www.theloopcommunity.org** for more information.

Fees **and charges**

If you are an NDIS participant, your plan will include funding that you can use to pay for your services with MDQ. If you are self-funded, we will provide you with a clear outline of our fees. Our fees and service conditions align with the current NDIS Price Guide and Support Catalogue. As the Price Guide is updated from time-to-time service prices and conditions may also change in line with these updates.

Accessing Services Without an NDIS Plan

MDQ's allied health services are also available to individuals who do not have an NDIS plan. These services can be funded through:

- Private health insurance
- Medicare programs (where applicable)
- Personal (self-funded) payments

If you would like to discuss payment options, please contact MDQ for further information.

Funding Responsibilities

If there is a shortfall between available funding and the cost of a service, the participant is responsible for paying the gap. It is also the participant's responsibility to make sure there is enough funding in their NDIS plan before engaging MDQ as a service provider.

Our **Policies and Processes**

At MDQ we are committed to meeting our legal obligations and providing high quality services to the people we care for. To support this commitment, we follow a set of policies and processes that guide every aspect of our work with clients and their families. This section outlines some of the key policies you should be aware of:

- Our Privacy Policy
- Our Complaints Policy, and
- Our Diversity and Inclusion Policy

These are just some of the policies we have in place to ensure safe, respectful and effective support for everyone we look after. From time to time, we may also publish new or updated policies on our website. If you would like to know more about or discuss any of our policies in detail, please do not hesitate to contact us.

Principles of Practice

MDQ is guided by key legislation and strategic plans that protect and promote the rights of people with a disability, including:

- United Nations Convention on the Rights of Persons with Disabilities
- Queensland Disability Services Act 2006
- National Disability Insurance Scheme (NDIS) Act 2013
- National Disability Strategy
- All Abilities Queensland Plan (2017-2020)

We also align our practice with the **Social Model of Disability**, which recognises that disability is shaped by societal barriers, not just medical conditions. Our goal is to help remove these barriers and support inclusion in all areas of life.

Our Guiding Principles and Priorities

Our service delivery is underpinned by the following principles:

- A person- and family-centred approach
- Strengths-based practices
- Self-management principles
- Diversity and inclusion
- Equitable access to MDQ's charitable services
- Promoting choice and control for individuals

Our Commitment to NDIS Principles

We follow the principles outlined in **Section 4 of the NDIS Act 2013**, which affirm that:

- People with disability have the same rights as all Australians to:
    - Reach their full potential

    - Be treated with dignity and respect
    - Live free from abuse, neglect and exploitation
    - Pursue grievances and have their voices heard
- People with a disability should be:
    - Supported to participate in social and economic life
    - Given choice and control over their supports and goals
    - Encouraged to take reasonable risks in pursuit of their aspirations
    - Assisted in communicating in ways that suit their needs and culture
    - Supported in interactions with the NDIS and are free to exercise choice and control over their supports
- Families, carers, and advocates:
    - Play a vital role and should be respected and acknowledged
    - Help promote independence, community inclusion and self-determination
- MDQ also upholds principles that guide the delivery of high-quality, future-focused services, including:
    - Early intervention
    - Positive development for children and young people
    - Innovation, continuous improvement and best practice

Rights **and responsibilities**

At MDQ we are committed to upholding the rights of our clients, families, staff and volunteers. We strive to foster a safe, respectful and inclusive environment for everyone connected to our organisation.

We recognise that families, carers, and advocates:

- Play a vital role in supporting individuals with neuromuscular conditions
- Should be acknowledged and treated with respect
- Support independence, community inclusion and self-determination

MDQ's Client Responsibilities

In line with the NDIS Code of Conduct, the Queensland Disability Service Standards, and the NDIS Quality and Safeguarding Commission, MDQ commits to the following:

Rights and Inclusion

- Respecting the rights and dignity of all clients, staff and volunteers
- Providing safe, equitable access to MDQ's services
- Delivering culturally sensitive services for:
    - Aboriginal and Torres Strait Islander people
    - People from culturally and linguistically diverse (CALD) backgrounds
    - LGBTIQ+ individuals
    - Individuals who may require interpreter, communication assistance or other access support
    - Other underrepresented or marginalised groups in Australian society

Privacy and Confidentiality

- Keeping all personal information secure and comply with the Australian Privacy Principles
- Ensuring clients and stakeholders have access to their personal records upon request

Access and Referrals

- Assisting clients in accessing relevant services
- If MDQ cannot provide a service, providing help identifying and referring to alternate suitable providers

Feedback and Complaints

- Encouraging open feedback without fear of retribution
- Addressing concerns and complaints promptly and fairly

Client Safety and Program Quality

- Ensuring all MDQ programs are safe, effective and continuously improved based on client needs

- Promoting active contribution to client safety and service design
- Taking all reasonable steps to prevent and respond to any form of abuse or harm to clients and their families
- Preventing staff or volunteer misconduct
- Providing timely updates regarding significant changes to MDQ's services or practices

Responsibilities of MDQ Clients and Customers

Clients and customers engaging with MDQ have a role in supporting a safe and respectful service environment:

- Treat MDQ staff and volunteers with respect and fairness
- Respect the scope and limits of the services MDQ offers
- Respect the professional nature of the relationship
- Respect staff and volunteer privacy outside of working hours
- Provide a safe and healthy environment for staff and volunteers, particularly when home visits are required
- Provide your MDQ service provider with adequate notice of any change in circumstances that may affect service provision, including appointment changes and cancellations *(Please note: there may be a cancellation fee charged as per the NDIS Price Guide if the appointment has been cancelled without the required notice)*
    - **Allied Health cancellation and change notice period:** please provide your service provider with at least two (2) business days prior notice before your appointment.

      This means if your appointment is at 10AM on a Monday, you must let your provider know, at the latest, 10AM Thursday to avoid a Short Notice Cancellation Fee.
    - **Support coordination cancellation and change notice period:** please provide your service provider with at least two (2) business days prior notice before your appointment.

      This means if your appointment is at 10AM on a Monday, you must let your provider know, at the latest, 10AM Thursday to avoid a Short Notice Cancellation Fee.
- In emergencies, clients should only contact emergency services
- Speak respectfully about MDQ within the community and direct concerns through MDQ's feedback and complaints process

MDQ Staff and Volunteer Responsibilities

MDQ values its staff and volunteers and recognises their right to:

- Work in a safe and respectful environment
- Be free from discrimination, abuse, neglect and harassment
- Fulfil their roles in line with the organisation's purpose and policies
- Raise concerns or complaints without fear of retribution

All MDQ representatives must act in accordance with the organisation's Code of Conduct and uphold the rights of clients, including their right to provide feedback or make complaints. Alleged breaches of the Code of Conduct are investigated and addressed appropriately, which may include disciplinary action or involvement of external authorities.

Home Risk Assessment

Before delivering services in your home, MDQ may conduct a risk assessment to identify and address any potential safety concerns for clients, staff and volunteers. These assessments ensure that the environment supports safe service delivery for everyone involved.

MDQ will:

- Explain the purpose of the risk assessment to you
- Involve you in identifying and mitigating potential hazards
- Record any risks and safety measures in your client file

We aim to work with you respectfully and collaboratively to ensure the safety of all parties.

Feedback and Complaints

At MDQ we welcome your feedback as an important way to understand your level of satisfaction with our services and to help us improve. Your feedback may take the form of compliments, suggestions or complaints.

We are committed to ensuring that everyone is treated fairly, respectfully and without fear of retribution when providing feedback. You have the right to speak up without it affecting your access to services, and you are welcome to involve a support person or advocate of your choice. All feedback will be handled confidentially.

Who can provide feedback?

Feedback is welcome from:

- People who use MDQ's services or attend our events
- Family members or carers
- People working in the sector
- Members of the public

What can I provide feedback about?

You can provide feedback about:

- Our programs, including NDIS-funded and charitable services
- Our processes and the way we work
- Our events and how they are run
- The conduct of our staff
- Our general performance

How can I provide feedback?

There are several ways to give feedback or make a complaint:

- **Speak with a MDQ Staff Member** – they will either try and resolve the issue immediately or refer it to a manager. They can help you summarise your feedback in writing if needed.
- **Submit the online feedback form** – available at www.mdqld.org.au/contact-us
- **Email the CEO –** email pennyd@mdqld.org.au
- **Write to us –** Locked Bag 3020, Springwood, Queensland 4127
- **Respond to surveys and evaluations such as**
    - Our annual client surveys
    - Workshop and program evaluations
    - Occasional phone surveys

You may choose to provide feedback anonymously. If so, we will make every effort to respect your wishes.

If you feedback directly relates to the CEO, or if you prefer not to share it with staff, you can contact the Board Chair directly by emailing chairperson@mdqld.org.au

Can I have a support person?

Yes. We want you to feel comfortable throughout the feedback or complaint process. MDQ can support you by involving:

- A support person of your choice
- An interpreter or communication assistant
- A cultural ambassador

What happens after I submit feedback or complaint?

We aim to respond to all feedback with a constructive and objective approach, especially in the case of complaints.

- We will acknowledge your feedback or complaint within three (3) business days
- If a resolution is needed, we aim to achieve this within 21 days of acknowledgement

All complaints will be:

- Investigated appropriately, depending on the nature of the issue
- Discussed with you and any relevant staff
- Resolved respectfully, confidentially and in a timely manner

We will:

- Keep you informed of our investigation process
- Provide clear outcomes
- Act as needed, which may include:
    - An apology
    - Clarifying information
    - Process improvements
    - Staff training
    - Reallocating a team member

All outcomes and actions will be communicated to you in writing.

What if I am not satisfied with the outcome?

If you are not satisfied with the outcome of our internal process, you may:

- Ask the CEO to refer your complaint to the **MDQ Board**, or
- Contact the **Board Chair directly**: chairperson@mdqld.org.au

If you remain dissatisfied, you may escalate your complaint to an external agency, such as:

- NDIS Quality and Safeguards Commission
- Queensland Ombudsman
- Commonwealth Ombudsman
- Australian Charities and Not-for-profits Commission
- The Queensland legal system
- As a whistleblower, if the matter involves public interest or misconduct

How does MDQ use feedback to improve?

After a complaint is resolved, MDQ's management team will:

- Review the issue and resolution
- Make changes to reduce the risk of similar concerns arising again

The CEO providers regular reports to the Board, who monitor:

- Complaint and feedback trends
- Outcomes
- Opportunities for systemic improvement

An end of year report summarises all complaints, their outcomes, and any resulting improvements. The Board uses this data to support ongoing learning and quality improvement.

Need more information? A copy of MDQ's Feedback, Complaints and Resolutions Policy is available upon request.

Privacy and Collection of Personal Information

MDQ is committed to protecting your personal information and respecting your privacy in accordance with the **Privacy Act 1988 (Cth)** and the **13 Australian Privacy Principles (APPs)**.

How MDQ Collects Personal Information

MDQ collects personal information directly from you or other stakeholders, either verbally or in writing. This may also include information provided through MDQ's website or social media platforms. Examples of how we may collect information include:

- Calls to MDQ's Infoline, emails requesting assistance or conversations with MDQ staff

- Information shared by caregivers or external agencies (e.g. NDIA staff, health professionals)
- Data from marketing campaigns, email lists, event attendance or fundraising responses

What Information is Collected and Stored?

We only collect and store the personal information necessary to:

- Communicate with you
- Provide appropriate, tailored services (which may include health-related information)
- Meet reporting obligations for funded programs and services

This information is stored securely in a variety of formats, including secure databases and password protected portable devices. MDQ ensures that any cloud-based systems we use store data on servers in Australia where possible.

How MDQ Handles Your Information

- Access to personal information is restricted to authorised MDQ staff, based on relevance to their role
- Information is protected from loss, misuse, unauthorised access, modification or disclosure
- Sensitive information is safeguarded with additional protective measures
- Personal information is destroyed or permanently de-identified when no longer needed or once legal retention periods have expired
- If a data breach likely to cause serious harm occurs, MDQ will notify affected individuals and the Office of the Australian Information Commissioner (OAIC)

When MDQ May Disclose Personal Information

MDQ will not share your personal information without your consent unless required by law or situations relating to your safety. We may disclose information to:

- Government departments (e.g. QLD Health, NDIA or Education QLD)
- Third parties with your explicit consent for service provision or organisational functions (e.g. legal, accounting or auditing professionals)
- Law enforcement agencies, where legally obligated

MDQ does not sell or share information from its fundraising databases.

Your Rights: Access, Corrections and Opting Out

You have the right to:

- Access and update your personal information
- Request that your information be removed from MDQ's records
- Interact with MDQ anonymously or using a pseudonym (noting this may limit the services we can provide)

MDQ may require you to verify your identity when processing access or correction requests. Access may be denied in limited circumstances, such as when doing so could compromise another individual's privacy.

There is no fee for accessing, updating, or opting out of MDQ's collection or use of your personal information.

Online Privacy and Cookies

The MDQ website may use cookies to enhance your browsing experience (e.g. tracking visits, navigating pages or managing donations). You can configure your browser to notify you about cookies and choose whether to accept them. By using MDQ's website or social media pages, you provide implied consent to these practices.

Privacy Complaints

If you believe your privacy rights have been breached under the Australian Privacy Principles, you can lodge a written complaint to MDQ's Privacy Officer. We will investigate and respond within a reasonable timeframe. If the matter cannot be resolved, you may contact the **Office of the Australian Information Commissioner** via www.oaic.gov.au or call **1300 36 39 92**.

Contact MDQ's Privacy Officer

Muscular Dystrophy Queensland
Locked Bag 3020, Springwood QLD 4127
Phone: 07 3243 9700 or 1800 676 364
Email: privacy@mdqld.org.au

Advocacy and Support

Muscular Dystrophy Queensland (MDQ) is committed to supporting your rights, including the right to access services, be treated fairly and have your voice heard.

Individual Advocacy

You have the right to use an advocate, such as a family member, friend or professional, to support you in making decisions, understanding information or raising concerns. Your advocate can be involved in any part of your journey with MDQ, including:

- Assessments and reviews
- Meetings and planning
- Feedback or complaints

MDQ staff may also be able to provide individual advocacy by:

- Assisting with writing letters of support
- Helping you lodge complaints
- Supporting you to initiate an appeal with the Administrative Appeals Tribunal (AAT)

Please note: While we can support you in lodging an appeal, MDQ is unable to accompany you through the full AAT process. In such cases, we will refer you to an independent advocacy service or Legal Aid Queensland, if appropriate.

If your issue is significant, our CEO may review it for further support. This decision will depend on the nature and urgency of the matter, your circumstances and available MDQ resources.

Systemic Advocacy

MDQ also engages in systemic advocacy to help improve the lives of people living with neuromuscular conditions at a broader level. Our CEO leads this work by:

- Addressing Queensland-based issues directly with government agencies, either independently or in partnership with other disability organisations
- Referring national-level concerns to the Muscular Dystrophy Foundation of Australia (MDFA), where advocacy priorities are determined by the Foundation's Executive Committee

Supporting Advocacy

MDQ respects your right to involve an advocate at any time. We will:

- Support you to connect with an independent advocacy organisation, if needed
- Treat your advocate with the same respect and professionalism as we do you
- Only communicate directly with your advocate when you are not present if

you have given us permission to do so

You may also nominate a Client Representative to act on your behalf. This could be:

- A legal guardian
- An attorney under an enduring power of attorney
- An administrator under the relevant guardianship legislation
- A legally empowered person acting in your best interests

We will ask for proof of the representative's authority and retain this documentation on file.

For more information or to connect with a disability advocacy provider, visit the National Disability Advocacy Program (NDAP) at www.ndap.org.au or call 1800 700 600. If you require more information, our full Providing Client Advocacy and Support Policy is available on request.

Client Risk

Client risk is assessed in collaboration with you during the development of your Individual Support Plan. When assessing risk, we consider both the likelihood of the risk occurring and the potential impact it may have. This assessment guides the creation of a risk mitigation strategy tailored to your needs.

Your choices and preferences are highly valued and may override the assessed level of risk. Any decisions you make regarding identified risks will be discussed thoroughly and documented in your Risk Assessment. We will also provide suggestions to help reduce risks should you choose to proceed despite them.

Informed consent

Muscular Dystrophy Queensland (MDQ) is committed to supporting your right to make informed decisions about your care, personal information and how we communicate with you. Informed consent is essential before we provide any service, collect your personal information, or use media involving you.

What is Informed Consent?

Informed consent means you understand and agree to the supports, services, or actions proposed by MDQ. We will always ensure you are fully informed about:

- The nature of the support or service

- Any potential risks or benefits
- Your right to withdraw consent at any time

Consent can be:

- **Written** – e.g. via a signed consent form
- **Verbal** – discussed and documented in your client file
- **Implied** – when you voluntarily share information or engage with MDQ services

We will always ensure your consent is freely given, informed and voluntary.

Who Can Give Consent?

Consent can be given by:

- You, if you are an adult client
- An informal representative (e.g. a support person), if you are unable to sign, with a declaration that they are acting in consultation with you
- A legal guardian or substitute decision-maker (for example, adults under guardianship or children)

MDQ recognises that the **Privacy Act 1988 (Cth)** does not specify a minimum age for consent. We assess each case individually to determine whether a young person has the capacity to make decisions regarding their own information and services.

What do I Need to Consent to?

- **Provision of services** - We require your consent before delivering services, and we will always explain the purpose and any related costs.
- **Collection, Use and Disclosure of Personal Information** - To provide services, we must collect, store, and sometimes share your personal information, in accordance with the **Australian Privacy Principles** and **Privacy Act**.
- **Communication with others** - If you want us to speak with someone on your behalf, such as a family member or support worker, you must nominate them in writing. You can nominate up to two representatives on your consent form. If you are over 18, we can only speak with others if you have provided permission or they are legally recognised decision-makers.
- **Use of Photos, Video, and Media** - You can choose whether to allow MDQ to use photos or videos of you for:
    - Assessments, therapy or NDIS goals

- Educational materials
- Marketing, advertising and media (including social media)
- Fundraising purposes

Providing this consent is completely optional and does not affect your access to services.

How Long does Consent Last?

Unless you specify otherwise, your consent will remain active for five (5) years. It may be reviewed or updated if:

- You turn 18 and want to give consent yourself
- Your circumstances change (e.g. you add/remove a nominated representative)
- You decide to withdraw your consent

We respect your right to change your mind. For more detailed information, our full Informed Consent policy is available upon request.

Next steps

Thank you for considering Muscular Dystrophy Queensland (MDQ) as your service provider. We would be honoured to support you and your family on your journey.

At MDQ, we are committed to walking beside you with respect, empathy and determination to ensure you can access the services, support and information you need to live life the way you choose.

We hope this guide has been helpful for you to understand your rights, our responsibilities and how we can work together. If you ever have a question, concern, or suggestion, please reach out, we are here to listen.

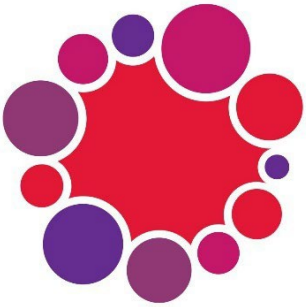
Stay Connected

If you would like to update your information, request a copy of a policy or speak with a team member, please contact us:

Muscular Dystrophy Queensland
Locked Bag 3020, Springwood QLD 4127
1800 676 364 or (07) 3243 9700
info@mdqld.org.au
www.mdqld.org.au

Feedback

Your voice matters. Feedback helps us improve.
You can share your experience with us at any time by phone, email, or through our website.



Muscular
Dystrophy
Queensland

We're stronger **together**