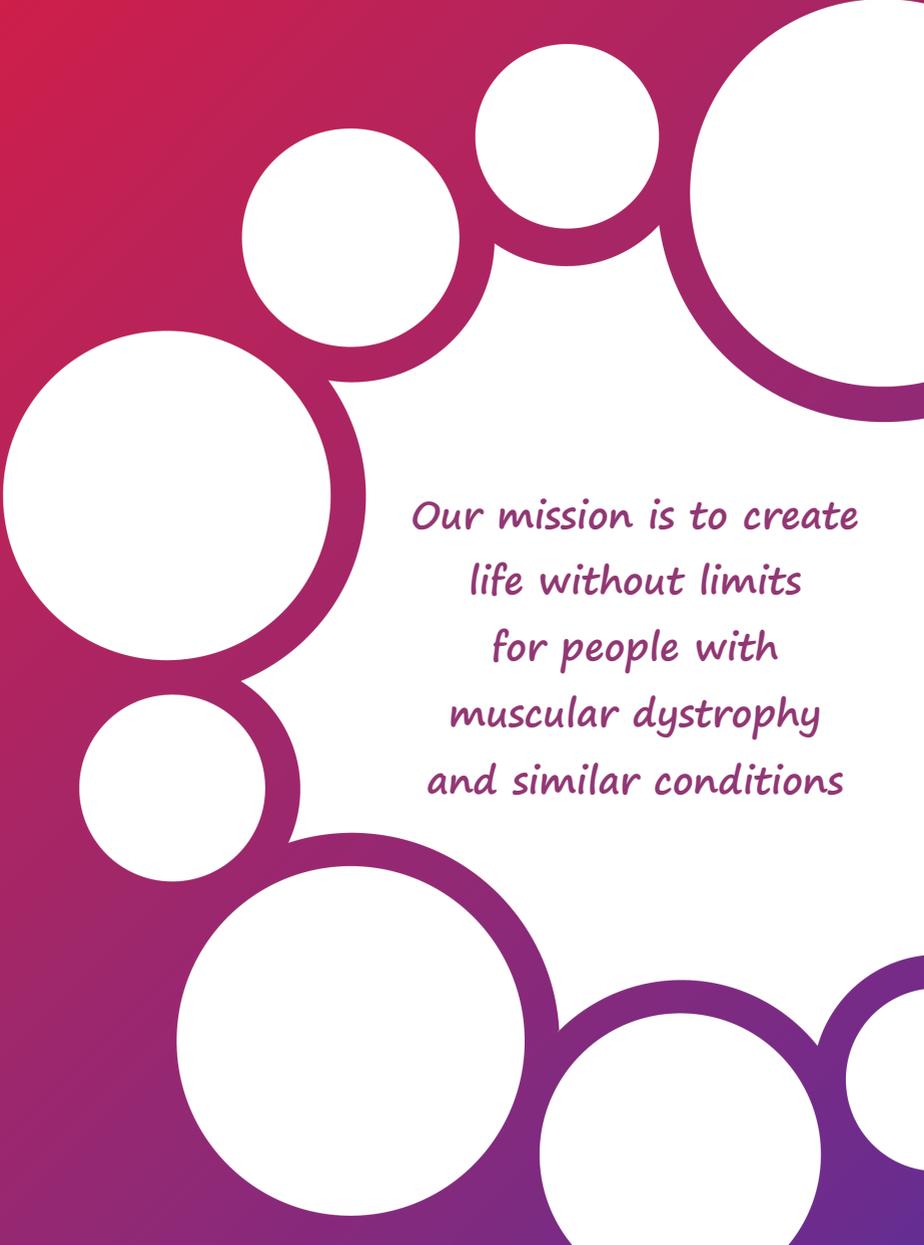


Muscular Dystrophy Queensland
client guide



*Our mission is to create
life without limits
for people with
muscular dystrophy
and similar conditions*

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About this guide

The purpose of this guide is to provide you with brief but important information about Muscular Dystrophy Queensland (MDQ) and our services. For further details please contact our friendly staff, browse our website or follow our Facebook page.

Our contact details are:

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Nundah Qld 4012

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Eagle Farm BC Qld 4009

Reply Paid Address: Reply Paid 66034
Eagle Farm BC Qld 4009

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07 3243 9700

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Email: info@mdqld.org.au

Web: www.mdqld.org.au

Facebook: www.facebook.com/mdqld.org.au

Disclaimer: The 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 on the basis of the information contained in this guide alone.

Version: Updated September 2020

Acknowledgement of Country

Muscular Dystrophy Queensland acknowledges and pays respect to the past, present and future 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

MDQ welcomes all groups within the Australian community. We will deliver equitable access to services, ensuring that they are respectful of the values, customs, cultures and beliefs our clients, no matter what their cultural or societal background. We can arrange for interpreters (including sign language interpreters) in circumstances where clients are unable to communicate easily in English

Privacy

MDQ is committed to respecting the privacy of personal information provided to us. Our privacy policy, available in this handbook, explains how we do this.

NDIS Services

Free services related to the NDIS

- Help to register with the National Disability Insurance Agency (NDIA)
- Assistance to prepare for your NDIS Planning Meeting
- Advice if you are experiencing problems obtaining eligibility for the NDIS or in implementing your Plan

Our Services Funded by your NDIS Plan

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

- Support Coordination
- Plan Management
- Allied Health services (initially for people living in south east Qld) including:
 - Individual Counselling
 - Social Work
 - Occupational Therapy
 - Physiotherapy
 - Programs delivered by an Allied Health Assistant

MDQ's prices and conditions are aligned with the NDIS Price Guide and Support Catalogue. The NDIS updates prices from time to time and when this happens MDQ will also adjust prices accordingly.

Support Coordination

When you employ us as your Support Coordinator, we can provide the following:

- With our experience we assist you to get the most out of your NDIS Plan
- We will develop an Individual Support Plan with you to work towards achieving your goals, manage risks and prepare a budget
- We help you to engage service providers, develop service agreements and build your informal supports
- We assist you to resolve issues e.g. problems with your service providers
- We help you if there is a change in your condition and you need to apply for an NDIS Plan review
- We build your confidence and skills to manage your plan independently

You can ask for Support Coordination to be included in your plan when you are having your planning meeting. If your planner refuses to include Support Coordination in your plan, MDQ may be able to give you advice on how to challenge this decision.

Plan Management Provision (PMP)

When you have an NDIS Plan, you receive funding to pay for goods and services relating to your disability. If you engage a Plan Management provider, you can use suppliers who are not registered with the NDIA, giving you more flexibility and freedom to purchase the services you want. Having a Plan Management Provider also takes the hassle out of managing the business aspects of your plan.

As your Plan Management Provider, MDQ offers assistance in:

- Setting up the financial management of your NDIS plan
- Creating service bookings on the NDIA provider portal
- Reviewing supplier invoices to ensure they're correct and then claiming payments from the NDIA on-line portal and paying your suppliers
- Providing you with a monthly statement, tracking payments made and amounts left to spend

The NDIS requires that you become as independent as possible in practical daily living areas which include making informed decisions, planning and budgeting.

If you feel Plan Management Provision will assist you, you need to make a specific request of your NDIS Planner for this service to be included in your NDIS Plan. Once the request has been made, the NDIS Planner is required to include funds for PMP.

Allied Health Services

MDQ offer a range of allied health services for people to access via their NDIS plans. Currently these services include Counselling, Social Work, Occupational Therapy, Physiotherapy and Allied Health Assistance. You will need to discuss this need with your NDIS Planner so an appropriate allocation can be provided for the therapy and counselling service you need to achieve your individual goals. Once funded in your plan, therapy and social work services are included under the Improved Daily Living section of your NDIS Plan.

Your Allied Health professional will develop an Individual Support Plan with you to work toward achieving the goals set out in your NDIS Plan and manage risks.

At this stage, allied health services are available in Queensland's south east corner. We have a physiotherapist based on the Sunshine Coast and our Brisbane-based team make regular trips to the Gold Coast and Toowoomba. We have also started to make occasional physio outreach trips to Cairns. You can see our allied health team at our client centre in Nundah; at home; at school or at your workplace.

Counselling

We understand how having muscular dystrophy or a similar condition can be emotionally difficult. Having a qualified counsellor to talk to who understands the condition, will listen in a confidential and non-judgemental way and help you explore options to find a resolution to your concerns may be helpful.

MDQ's counsellor has a deep understanding of muscular dystrophy and similar conditions and can help you to look beyond your disability and to set some goals and to plan your life for the future.

Social Work

Social workers work with individuals, families, groups and communities in the context of their physical, social and cultural environments, their past and current experiences, and their cultural and belief systems.

There is a dual focus on both assisting with and improving human wellbeing and identifying and addressing any external issues that may impact on wellbeing or may create inequality, injustice and discrimination. They may undertake roles in casework, counselling, advocacy, community engagement and development and social action to address issues at both the personal and social level. Social workers may also work in areas such as policy development, education and research particularly around issues of social justice, disadvantage and the marginalisation of people in their communities or in society.

Occupational Therapy (OT)

The OT provides specialist assessment and uses treatment techniques to address needs resulting from your disability. Under NDIS there is usually an initial OT assessment to determine your ongoing needs which may include:

- Goal setting to make positive changes to your life
- Equipment prescription e.g. hi-lo beds and mattresses
- Safety, especially after a progression affecting your physical abilities
- Transitions e.g. from school and changes to roles e.g. from worker to retiree
- Minor home modifications and home access
- Smart technology and environmental controls
- Community access and participation
- Employment
- Ability to think (cognition), interpret and remember
- Specialist disability accommodation

Physiotherapy

MDQ's Physiotherapists can provide:

- Physical and functional assessments including gait, balance, posture, range of movement, muscle strength, timed tests and outcome measures
- Advice and treatment regarding symptom management – eg. Stretching and light exercise programs, pain management, balance, fatigue
- Equipment prescription – manual and power wheelchairs, scooters, pressure relieving cushions, water wheelchairs, walkers
- Assessment and referral for custom-made orthotics
- Specialised seating assessment and recommendations
- Hydrotherapy – individual and group programs
- Respiratory assessment and management in the community setting
- Training to family and support workers in home programs
- Liaison with other health care professionals, medical specialists and educational settings to provide co-ordinated care.
- Advocacy regarding mobility issues and assistive technology

Allied Health Assistance (AHA)

MDQ employs Allied Health Assistants who compliment our Allied Health Team. The AHA may:

- Assist the therapist during groups session e.g. hydrotherapy (AHA Level 1)
- Provide individual, unsupervised sessions to carry out programs which have been developed by the physio or OT e.g. prescribed stretching programs (AHA Level 2)

Accessing our Allied Health services without an NDIS plan

MDQ also offers the allied health services described above on a user pays basis. MDQ has processes in place to offer these services under your private health insurance; Medicare's Chronic Disease Management Plans (a gap may apply); and through your private resources.

Our allied health team is able to provide pricing information and written quotes should you require those.

Because of limited resources, MDQ is only able to provide allied health services in south east Queensland and is not able to offer free allied health services.

General Services

MDQ's ability to provide free services depends upon available funds and capacity. There may be a short waiting time for services, however any waiting lists will ensure equitable access and wait times will be explained to you. Because of our supporters' generosity, Muscular Dystrophy Queensland (MDQ) is able to continue to provide the following free services throughout Queensland.

Information and Support

We know that having trustworthy information about all aspects of your condition is vital and that is the reason our clients value our specialist expertise. Information about muscular dystrophy and similar conditions is provided through our helpline, newsletters, website (www.mdqld.org.au), Facebook page and other social media outlets.

If you have concerns about living through the COVID-19 pandemic you can talk to someone through our helpline. We have also collated some relevant information in the [COVID-19 Info Hub](#) on our website.

You can call our Helpline (during office hours) on 1800 676 364 or email info@mdqld.org.au. Any question can be put to our trained and knowledgeable staff. We may be able to answer straightaway or we will consult our global networks for an answer. This is a free service, available to our clients and to any member of the public.

Individual services

If you are a Client of MDQ and are not receiving funding from the NDIS, we can provide practical support, advice, and individual advocacy, especially at critical times in your life:

- Pre-diagnosis or at diagnosis
- When you (or a loved one) are making a transition in life e.g. leaving school; retiring
- If there is a progression in your condition and you need more services
- If there is an incident which makes you feel unable to cope without urgent advice and help

We can also help you with information about the NDIS, including how to apply and assisting your with your application for eligibility.

If you are funded under the NDIS, we have some options which we can work through with you:

- You may employ Muscular Dystrophy Queensland as a support coordinator or plan management provider or use our allied health services
- We may be able to direct you to the appropriate funded provider within the system or advocate on your behalf for a change in your NDIS Plan.

Advocacy

We recognise that people with disability may need a strong voice to support them in achieving their individual goals. MDQ is able to provide free, appropriate individual advocacy for its clients about relevant issues or concerns. From time to time, this might not be adequate and referral to an external advocacy organisation may be appropriate. MDQ can assist you with these referrals.

Some of the issues for which people may need advocacy support include:

- Getting a fair deal in an NDIS Plan
- Being a more independent decision maker within their family
- Getting help so friends and workmates can better understand your condition

Extended care

When a person lives with muscular dystrophy or a similar condition, unforeseen problems can occur. This might be a rapid progression and loss of ability, a carer suddenly falling ill or becoming unable to provide care, equipment breakdown, or an unplanned and unwelcome change in housing or support arrangements.

When such a critical incident occurs we can help you resolve immediate issues. We can also help reduce the impact of a similar event reaching a crisis point in the future by doing one or more of the following:

- Contact the NDIS for a Change of Circumstances Review of your NDIS Plan and help you to lodge that request
- Link you into an appropriate community service e.g. Housing, Centrelink, taxi subsidy scheme
- Advocate for you and your family

Unfortunately, MDQ cannot:

- Pay debts or bills e.g. electricity, rent, flights, transport
- Purchase any resources e.g. equipment for your disability

Equipment loans

MDQ's equipment programs are 100% funded by our generous donors so allocation of loans depends on available funding. For both programs there is a simple application and assessment process. These programs include:

Rest Well Hi-lo Bed loans

The hi-lo electric bed resembles a bed found in any home but functions similarly to a hospital bed - offering adjustable positioning via a hand control, of the head and foot rests, and of bed height. This functionality contributes to a person's health, well-being and independence.

This equipment can be included in an NDIS plan, therefore our clients eligible for NDIS funding cannot be assisted through this loan program.

For clients who are not eligible for an NDIS plan, MDQ provides free, long term loans and maintenance of electric hi-lo beds for those who need them. There is often a waitlist for the Rest Well Program, so we encourage you to consider your needs and let us know if you feel these beds would assist you.

Breathe Well Cough Assist machine loans

The Cough Assist machine is a respiratory machines that promotes the health and well-being of members of our community with compromised breathing muscles. The machine works by applying positive air pressure to the airway and then rapidly shifting to negative air pressure. The resulting high expiratory flow simulates a deep, natural cough.

MDQ's Breathe Well Program focuses on assisting people who are in the acute phase of a respiratory infection, to prevent the infection settling in and/or to recover from an infection more quickly. The loans are also available for people who wish to trial the machine before purchase.

All MDQ clients and others with muscle wasting conditions have access to MDQ's free, Cough Assist machine loan scheme. Machines are delivered on short term loan. Training is provided so that the machine can be used safely and effectively. If you have a respiratory infection, please let us know urgently so that we can arrange for a machine to be delivered to you, anywhere in Queensland.

The MDQ Breathe Well Cough Assist Program is generously supported by Queensland Health.

Peak body Services

As a recognised peak body, MDQ invests time in the following tasks aimed at improving the quality of life for members of our community:

- Advocating to government - writing letters, having meetings - about the particular causes identified by our people or by the organisation
- Making submissions to government consultations e.g. mobility scooter consultation
- Writing funding applications for programs and equipment which support members of our community, especially people not eligible for an NDIS Plan
- Working with MD organisations in other states to provide national advocacy for Australians living with muscular dystrophy and similar conditions

National Projects

Many of the state based organisations providing services to people living muscular dystrophy and similar conditions are members of our national organisation called Muscular Dystrophy Foundation Australia (MDF).

The Loop: Your Neuromuscular Resource Hub

In 2018, we were thrilled to receive an NDIS ILC funding grant to develop a National Digital Resource to provide trustworthy information and support for all Australians living with muscular dystrophy and similar conditions.

The Loop was launched in May 2020 and is a fantastic resource featuring information on health and wellbeing, living life and how to support people living with a neuromuscular condition. You can:

- Find information about your condition
- Customise your very own condition guide that you can share with others
- Find out about medical and allied health supports, equipment, finding support workers and creating an accessible home
- Get advise on other life stuff like travel, education, relationships & transport
- Get advise on caring for someone with a neuromuscular condition
- Chat to other people who understand what you are going through on the secure forum

You can find the Loop at www.theloopcommunity.org and download the app from the App Store or Google Play.

Fees and Charges

The introduction of the National Disability Insurance Scheme (NDIS) has made a huge difference to the way disability organisations are funded. Now, if the person is eligible for an NDIS Plan, they;

- choose their services,
- buy them from their chosen supplier,
- pay for the service with the funds from their NDIS Plan.

Organisations like MDQ no longer receive funds from government to provide your services, so we have had to re-establish ourselves as businesses. As a result, fees and charges now apply for many services offered by MDQ. (See NDIS Services and Accessing our NDIS services without and NDIS Plan in this handbook. Our General Services, also discussed in the handbook remain free.)

MDQ's prices and conditions are aligned with the NDIS Price Guide and Support Catalogue. The NDIS Price Guide is updated from time to time and with that, prices increases will apply and conditions may change.

People without NDIS Plans can also access MDQ's allied health services at a cost e.g. through private health insurance or a Medicare program. Or you can pay from your funds for these services. Call MDQ if you would like to enquire further about payment methods.

Where there is a gap between the level of funding provided and the total cost of the service we provide, the payment of the gap is the responsibility of the client. It is also the client's responsibility to check that there is adequate funding in his/her NDIS Plan before engaging MDQ as a service provider.

Who are MDQ's clients?

MDQ provides whole-of-life support and services for Queenslanders living with muscular dystrophy and similar conditions. Sometimes we use the terms, 'muscle wasting conditions' or 'neuromuscular conditions'.

Most commonly, our clients live with one of the following conditions:

- Muscular dystrophies, such as Duchenne, Becker, FSHD and Myotonic
- Diseases of the motor neuron, such as Spinal Muscular Atrophy
- Neuromuscular junction diseases, such as Myasthenia Gravis
- Peripheral nerve diseases, such as Charcot Marie Tooth disease
- Mitochondrial diseases, such as Friedreich's Ataxia
- Myopathies, such as Inclusion Body Myositis
- Ion channel diseases, such as Myotonia Congenita

When deciding whether a person can benefit from our services, particularly when their diagnosis isn't included in the list above, we refer to the Muscular Dystrophy Association USA website which provides a comprehensive list of types of muscular dystrophy and neuromuscular conditions: www.mda.org/disease/list.

Our client is the person living with the condition. We also extend support and services for that person's immediate family members e.g. spouse, parents, children or unpaid carer. We also provide information to the people who are working with our clients e.g. paid disability support workers, educators and allied health professionals. It is our aim to be available for all Queenslanders who need MDQ's support at whatever life stage or level of disability they are experiencing.

MDQ is committed to providing equal access to our services for people from all cultural, language and religious backgrounds. We will do our best to tailor our services to meet the specific needs of our community members and to seek the support of interpreters and cultural mentors to ensure we are providing the best possible service.

We can, at our discretion, provide our NDIS services for people living with other disabilities if we believe our knowledge, expertise and service will benefit them (see *NDIS Services* discussed later in this guide)

Becoming a client of MDQ

Any person wishing to receive services from MDQ undergoes 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 make a decision about whether MDQ is a suitable service provider, and providing information and answers to your questions.

For people who have difficulty in understanding processes or language, we offer help for you e.g. a support person of your choice or an interpreter.

Once you have made the decision 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 and how it affects your life.
- **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

These forms can be completed and submitted electronically, or we can send you a paper copy in the mail with a reply paid envelope.

For people using MDQ's NDIS services, you will also be required to complete a Service Agreement and Schedule of Supports. These documents are required by the National Disability Insurance Agency.

If you are wishing to access a specific program e.g. equipment loan, you will be asked to complete a Loan Agreement.

If, for any reason, MDQ cannot take you as a client, we will make those decisions objectively, explain the reason to you, and suggest other appropriate service providers.

Be assured that all of the personal information that is collected by MDQ is subject to the *MDQ Privacy Policy* and procedures, the *Privacy Act 1988* and *National Privacy Principles 2014*.

Being a client

Once the intake process has been completed we consider you to be a client of MDQ. We provide a whole-of-life service, so you will continue to be a client until you no longer wish to be a client or are formally exited from our services (see *Exiting MDQ's Services*).

Clients of MDQ have access to:

- regular Client Updates and information about services and events that may interest you.
- NDIS and chargeable services delivered by dedicated, specialist teams of professional staff
- Charitable services (subject to eligibility and capacity)

Our client services team understand your condition more than most and can answer your questions and work with you to solve problems.

MDQ is a small organisation doing a big job throughout Queensland. While you will receive our regular Client Updates, we don't always have the capacity to keep in regular personal contact. We do, however, welcome your calls and emails. We understand that the nature of living with a muscle wasting disease means that your needs will change over time. Please contact us and let us know if there is any way we can assist you.

You might like to follow our Facebook page for regular update about what is happening in the MDQ community.

And, don't forget to let us know if you:

- Move or change your contact details
- You wish to change your instructions to us about anything e.g. you want to subscribe or unsubscribe from communications
- You would like MDQ to remove your personal details from our records

Exiting an MDQ service

MDQ offers a range of different services including:

- Support Coordination
- Allied Health
- Plan Management
- Charitable Services

These services are provided by different departments of MDQ and your decision to exit one service will not impact your eligibility to receive other services. MDQ supports your right to freedom of choice.

We work with you to achieve your goals and as these goals are reached we will support you in the process of exiting a service.

If you decide to choose another service provider for a particular service, MDQ will support your transition. We do ask for a notification period for certain funded services, this would be outlined in your Service Agreement.

People can easily exit Muscular Dystrophy Queensland when they do not want to continue as a client. If you no longer wish to have contact with MDQ, just let us know and we will remove your contact details from our active client list.

From time to time, MDQ may exit clients from our services if:

- We haven't heard from you for a very long time and cannot get in contact with you
- Our ability to provide services does not meet your needs

We will try to communicate with you and let you know the reasons for not continuing to provide services to you and we will help you to look for another suitable service provider if that is what you would like us to do.

Who is MDQ?

Vision, mission and objectives

Our vision is for life without limits for people with muscular dystrophy and similar conditions. We work to the mission of empowering people living with muscular dystrophy and similar conditions to make the most of opportunities and live the lives they choose with the objective of achieving success by being a professional, adaptable, efficient, and financially sustainable organisation.

Our Mission, Vision and Objectives guide our board and our staff, in planning and delivery of our services throughout Queensland.

Structure

Muscular Dystrophy Queensland

- Is a public company limited by guarantee and accountable under the Corporations Act 2001 and to the Australian Charities and Not-for-profits Commission (ACNC)
- Is led by a board of directors, who volunteer their time
- Provides user pays services under the NDIS and other schemes
- Provides some free services, under specified terms and conditions. Our free services are funded through some government grants, but mostly through donations, events and other fundraising activities. Our supporters give generously knowing that they make a difference to the lives of people with muscular dystrophy and similar conditions.

Muscular Dystrophy Queensland has a structure which ensures that we remain a relatively small, specialist service provider focussed on:

- Becoming recognised as a leader in our field and a peak body
- Developing and maintaining the skills and knowledge required to support people with muscular dystrophy and similar conditions
- Creating and continually improving the services which our community members need and want
- Standing out as a quality service provider.

Muscular Dystrophy Queensland is preparing to be accredited under the NDIS Quality and Safeguarding Commission which was introduced to Queensland in July 2019. Currently MDQ is accredited under the Human Services Quality Framework (HSQF) and the Queensland Quality Standards.

Strategic Direction 2018-2022

MDQ has developed a Strategic Plan 2018 – 2022 in line with our vision, mission and objectives. It was created through consultation with a group of clients, our members, staff and Directors. The complete plan is available for you to read (please let us know if you'd like us to send you a copy) but is summarised into the following key strategic goals:

- Provide relevant, specialised information and services which result in positive impact
- Raise awareness of all aspects of muscular dystrophy and other similar conditions in the Australian community
- Form positive partnerships, collaborations and alliances
- Build a secure and sustainable future for Muscular Dystrophy Queensland
- Promote a culture of agility, deep expertise and innovation

History

MDQ was established in 1978 by a group of parents who were concerned about the lack of assistance for their children. Without clinical or public recognition of the conditions, the group began the challenging process of community education and fundraising while continuing to provide support to each other.

More than forty years later, MDQ continues to build upon the hard work of those early volunteers. We remain committed to their original goals and extend this work by working with the national Muscular Dystrophy Foundation Australia, to advocate and to build a strong voice for all Australians living with muscular dystrophy and similar conditions.

MDQ is the only Queensland organisation who focusses solely on the needs of people with muscular dystrophy and similar conditions. We aim to be a peak body, an advocate and a service provider for Queensland's neuromuscular community.

Our Board and Staff

Muscular Dystrophy Queensland is fortunate to have a dedicated Board and staff members, who ensure the organisation remains focused on achieving our vision.

We have teams dedicated to:

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

You can find information about our Board and staff members on our website or in our 'Meet the Team' brochure.

Policy Statements

Muscular Dystrophy Queensland is committed to complying with legislation and also to being a high quality service provider, so we live by a set of policies and processes which we would like to let you know about. In this Client Guide, we have included some information about our privacy, feedback and complaints and diversity policies. We also have policies and processes which cover all of our work with clients and families. From time to time, we may post new and relevant policies on our website. If you would like to discuss our policies and processes further, do not hesitate to contact us.

Principles of Practice

Muscular Dystrophy Queensland is committed to legislation which emphasises the rights of people with disabilities and their families:

- UN Convention on the Rights of People with Disabilities
- Qld Disability Services Act (2006)
- NDIS Act 2013 (Cth)
- National Disability Strategy
- All Abilities Queensland Plan (2017 – 2020)
- Client safety and minimisation of client risk

MDQ is guided by the principles of the Social Model of Disability (which contrasts with and builds upon the medical model of disability).

Current MDQ priorities and Principles of Practice follow:

- Person and family centred approach to service provision
- Strengths based practice
- Self-management principles
- Diversity and inclusion
- Equitable access to MDQ's free services
- Choice and control

MDQ is also committed to the Principles of the National Disability Insurance Scheme (outlined in Section 4 of the NDIS Act 2013) to guide our practice. They are outlined below:

- People with disability have the same right as other members of Australian society to realise their potential for physical, social, emotional and intellectual development
- People with disability should be supported to participate in and
- contribute to social and economic life to the extent of their ability
- People with disability and their families and carers should have certainty that people with disability will receive the care and support they need over their lifetime
- People with disability should be supported to exercise choice, including in relation to taking reasonable risks, in the pursuit of their goals and the planning and delivery of their supports
- People with disability should be supported to receive reasonable and necessary supports, including early intervention supports
- People with disability have the same right as other members of Australian society to respect for their worth and dignity and to live free from abuse, neglect and exploitation
- People with disability have the same right as other members of Australian society to pursue any grievance.
- People with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity
- People with disability should be supported in all their dealings and communications with the Agency so that their capacity to exercise choice and control is maximised in a way that is appropriate to their circumstances and cultural needs
- People with disability should have their privacy and dignity respected

- Reasonable and necessary supports for people with disability should:
 - Support people with disability to pursue their goals and maximise their independence;
 - Support people with disability to live independently and to be included in the community as fully participating citizens; and
 - Develop and support the capacity of people with disability to undertake activities that enable them to participate in the mainstream community and in employment
- The role of families, carers and other significant persons in the lives of people with disability is to be acknowledged and respected
- The role of advocacy in representing the interests of people with disability is to be acknowledged and respected, recognising that advocacy supports people with disability by:
 - Promoting their independence and social and economic participation;
 - Promoting choice and control in the pursuit of their goals and the planning and delivery of their supports; and
 - maximising independent lifestyles of people with disability and their full inclusion in the mainstream community
- People with disability should be supported to receive supports outside the National Disability Insurance Scheme, and be assisted to coordinate these supports with the supports provided under the National Disability Insurance Scheme
- Innovation, quality, continuous improvement, contemporary best practice and effectiveness in the provision of supports to people with disability are to be promoted.
- Positive personal and social development of people with disability, including children and young people, is to be promoted.

Rights and Responsibilities

As with any professional relationship, best outcomes are achieved if each party understands their rights and responsibilities in that relationship. In the relationship between MDQ and its clients, each party has rights and responsibilities as follows.

Muscular Dystrophy Queensland strives to ensure that it meets its responsibilities to clients and to achieve that, has the following objectives:

- To comply with the NDIS Code of Conduct
- To acknowledge and respect the rights of our clients, customers, staff and volunteers in their engagement with MDQ
- To ensure that MDQ complies with the Qld Disability Service Standards (and in the future with the NDIS Quality and Safeguarding Commission), in that all programs are legislatively compliant and MDQ is accountable
- To treat all MDQ stakeholders with dignity and respect
- To ensure equitable access to MDQ's free services i.e. take reasonable steps to support access to our services; and to provide appropriate and culturally sensitive services for people from the following backgrounds:
 - Aboriginal and Torres Strait Islander and other culturally diverse
 - LGBTIQ
 - Culturally and linguistically diverse
 - Groups with disability who need assistance to access programs, especially those people whose challenges include communication difficulties
 - Other minority groups within Australian society
- To assist our clients to have equitable access to other relevant services
- If MDQ is not able to provide services, to assist enquirers to access alternate, suitable service providers
- To ensure privacy of personal information – personal details are kept secure; held in compliance with Australian Privacy Principles; and clients/ stakeholders have access to personal records
- To facilitate feedback and complaints re all aspects of MDQ's practice – to provide feedback and to complain without fear of retribution
- To ensure that all programs provided by MDQ are safe and to expect to actively contribute to client safety.

Additional MDQ Responsibilities

As an employer and program/service provider:

- To uphold client/customer rights, both within MDQ and in the broader community
- To provide our stakeholders with the opportunity to shape our future services and have input into planning and evaluation of services
- To ensure that MDQ's programs are continually improving, both in quality and relevance to client need
- To promptly act upon concerns re
- Safety about matters that may have a negative impact on the safety of a client/customer; the quality of supports provided
- Staff/volunteer safety
- To take all reasonable steps to prevent and respond to all forms of abuse and/ or harm to clients and/or family members to whom MDQ has a duty of care
- To take all reasonable steps to prevent MDQ staff/volunteer misconduct in any form
- To provide timely information about any significant changes to MDQ's practice or support provision

Responsibilities of MDQ's Clients and Customers

MDQ's clients/customers have responsibilities when engaging with the organisation's staff/volunteers:

- To speak with respect within the neuromuscular community about MDQ as a service provider and to direct any concerns about MDQ to MDQ via the feedback and complaints system
- To provide a safe and healthy environment in which staff/volunteers can work, especially when they are visiting your home for work
- For all members of the client's household to treat MDQ staff fairly and with respect
- To respect that MDQ staff are providing a specific service and cannot provide services beyond the scope of MDQ's practice and/or beyond those specified at the time

- To respect that the relationship between client/customer and MDQ staff/volunteer is a professional one without the expectation that it will become a personal friendship
- To respect MDQ staff's/volunteer's privacy out of hours
- To understand that MDQ provides ongoing rather than emergency services contact emergency providers out of hours and to source alternate services if there is an emergency
- If the client/customer has a complaint, to report it to MDQ directly
- To inform MDQ staff with adequate notice when circumstances change which may affect service provision i.e. providing adequate notice of cancellation of appointments
- To cancel face-to-face appointments if the client/customer or family member has an infectious disease e.g, influenza, conjunctivitis.

MDQ Staff/volunteer Rights

MDQ staff and volunteers have the following rights when engaged in providing MDQ's programs:

- The right to be treated fairly and with dignity and respect by MDQ and by clients/customers
- The right to have the appropriate tools to provide the service which is expected of them
- The right not to be exploited
- The right to feel safe and free from harm, abuse and harassment
- The right to have a workplace (including vehicle, client home, community setting) which is safe and healthy
- The right to have minimal risks when performing duties for MDQ
- The right to be able to perform a specified piece of work efficiently and effectively without undue interruption from people present whilst they are providing services.

Home Risk Assessment

To ensure that MDQ staff/volunteers are able to work in a safe workplace, the organisation has developed a Home Risk Assessment which our staff will complete prior to and at an early visit. We respectfully request that you disclose any potential risks to our staff as they complete the assessment.

Client Risk

Client risk is assessed in consultation with the client during the development of an Individual Support Plan. The likelihood of the risk occurring and the impact it may have will be taken into consideration when developing a risk mitigation strategy.

Your choices are important and may override the level of risk determined. This will be discussed and recorded in the Risk Assessment along with suggestions to reduce risks if you choose to proceed with an identified risk.

Feedback, Complaints and Resolution

Muscular Dystrophy Queensland (MDQ) welcomes your feedback as a way to understand the level of your satisfaction with our service and as an opportunity for us to continue to develop and improve.

Your feedback can be via compliments, suggestions and complaints.

MDQ is committed to upholding your right to be treated fairly and consistently and without fear of retribution when there is a disagreement or complaint. You have the right to complain without affecting your access to services and you also have the right to have an advocate or support person of your choice to assist you when providing your feedback. All feedback will be handled respectfully and confidentially.

Who can provide feedback?

Any person who uses Muscular Dystrophy Queensland's services or participates in our events can provide feedback, make a suggestion or a complaint. Family members, people who work in the sector or members of the public can also provide constructive feedback or make a complaint

What can I provide feedback about?

- Our programs, both NDIS funded and our charitable services
- Our processes and the way we do our work
- Our events and any aspect of them
- Our staff and how they conduct themselves in any situation
- Our performance in general

How can I provide feedback?

You can provide feedback or make a suggestion or a complaint by contacting Muscular Dystrophy or discussing your issues with any one of our staff. Here are a few suggestions:

- Have a conversation with an MDQ staff member who will either try to resolve your complaint on the spot or refer it to a manager for resolution. The staff member will ask you whether you want the feedback to be referred and assist you in writing a summary of your feedback if that is necessary
- The MDQ Feedback form is available on our website: www.mdqld.org.au/contact-us/
- You can email the CEO at helenef@mdqld.org.au or write a letter to: Locked Bag 3000, Eagle Farm BC, Qld 4009
- We have an annual, wide ranging Client Survey which you can use to provide us with feedback
- We have workshop and program evaluations, and occasional phone surveys

You can lodge your feedback or complaint with your contact details included or you may wish to lodge it anonymously. If you wish to remain anonymous, every effort will be made to ensure that your wishes are respected.

If you have an issue with the CEO or one which you do not want to share at staff level, you can provide feedback or make complaints directly to the Board Chair (Email: chairperson@mdqld.org.au)

Can I have a support person?

We would like you to be as comfortable as possible throughout lodging a complaint, having it investigated and resolved so where you have a need, we will assist you in making a complaint. MDQ will also support you to have a support person, an interpreter, a communication assistant, or a cultural ambassador. The support person is there purely to provide support and cannot argue the case on behalf of the person making the complaint

Once my feedback is received, what happens?

MDQ undertakes to provide an objective and positive response to any feedback, especially to any complaints. All complaints will be investigated, discussed with the person making the complaint and resolved as soon as possible i.e. acknowledgement within 3 business days and if possible, resolution within 21 days of acknowledgement

All people involved in the complaint i.e. both the person complaining and any person/s against whom the complaint has been made, will have the right to have the complaint investigated and resolved respectfully, confidentially and in a timely manner

We will aim to:

- Do an investigation which is proportionate to the nature of the complaint,
- Keep you informed about how we investigate
- Provide answers and take remedial action.

One or some of the following may happen once we have all the information:

- An apology. Mistakes are made and it is only when you point those out that MDQ can improve.
- Clarification through information provided to the person complaining
- Changes in the processes which MDQ follows
- Staff training
- Reallocation of a client to another team member for service provision

MDQ will also communicate their actions in writing to the complainant.

What happens if I am not satisfied with the outcome of my complaint?

You may not be satisfied with the outcome of our internal complaint investigation. Should you be dissatisfied, you have the right to ask the CEO to refer your complaint to the MDQ Board or to direct it yourself to the Board Chairperson, via email chairperson@mdqld.org.au

If you are not satisfied with the board's decisions or you wish to refer the complaint to an external agency, you can take your issue to one of the following:

- NDIS Commission www.ndiscommission.gov.au/about/complaints (MDQ has an [information sheet](#) about making a complaint to the NDIS Commission)
- Queensland Ombudsman www.ombudsman.qld.gov.au/how-to-complain
- Commonwealth Ombudsman <https://forms.business.gov.au/smartforms/servlet/SmartForm.html?formCode=oco-complaint-form>
- Australian Charities and Not-for-profit Commission <https://www.acnc.gov.au/contact-us>
- Queensland legal system
- As a whistleblower for matters of public interest or misconduct. (MDQ also has an [information sheet](#) about making a complaint as a whistleblower)

How does MDQ use my feedback to continuously improve its practice?

Following the complaint resolution, the management team will also review all aspects of the complaint and make changes needed to reduce the risk of similar situations arising.

The CEO also keeps the board informed and they analyse trends as well. An end of year report which includes a summary of the complaints, outcomes, and the changes made. The board again discusses any systemic issues and opportunities for improvement.

MDQ's full Feedback, Complaints and Resolution policy is available on request.

Privacy

MDQ is committed to compliance with the Privacy Act and the 13 Australian Privacy Principles (APPs), which is the legislation governing the collection, use, storage, and disclosure of personal information, including sensitive information. You can find out more about the Privacy Act 1988 (Cth) and the Australia Privacy Principles by calling the office of the Australian Information Commissioner on 1300 36 39 92, or through their website: www.oaic.gov.au

To provide programs and services, MDQ needs to collect and store some relevant personal details about stakeholders.

In dealing with personal information, Muscular Dystrophy Queensland will:

- ensure privacy for all stakeholders when they are discussing matters of a personal or sensitive nature
- only collect and store personal information that is necessary for the functioning of the organisation and its activities
- use fair and lawful ways to collect personal information
- collect personal information only by consent from an individual
- protect sensitive information
- ensure that people know what sort of personal information is held, what purposes it is held it for and how it is collected, used, disclosed and who will have access to it
- ensure that personal information collected or disclosed is accurate, complete, and up-to-date, and provide access to any individual to review and/or correct their wrong information
- take reasonable steps to protect all personal information from misuse and loss and from unauthorised access, modification or disclosure
- destroy or permanently de-identify personal information no longer needed and/or after legal requirements for retaining documents have expired
- notify individuals and the Office of the Australian Information Commissioner (OAIC) when there has been a data breach (or suspected breach) of personal information, if it is likely to result in serious harm to individuals whose privacy has been breached

Consent

Personal information is only collected following consent – explicit consent via signed consent form; verbal consent which is documented on the client database, and implied consent when the stakeholder shares the information. All information is treated with respect and according to privacy laws and principles.

For children, MDQ recognises the rights of the parents/guardians to give consent, however, also understands that the Privacy Act sets no minimum age at which an individual can make informed decisions regarding his or her personal information. MDQ acknowledges that the Guidelines to the National Privacy Principles suggest that each case must be considered individually as to when a young person may have the capacity to make a decision on his or her own behalf.

How MDQ collects personal information

MDQ collects personal information directly from MDQ stakeholders, either verbally or in written format. In some cases, we collect personal information through details that have been provided on MDQ's website and Facebook page. Instances where personal information may be collected include:

- Through a call to MDQ's Helpline, email asking for assistance, conversations
- Information provided by care givers or external professionals e.g. NDIA staff, health professionals
- Marketing, mailing lists and records of event attendees and responses to MDQ's fundraising campaigns

What information is stored?

Only personal information that is needed is stored. MDQ requires personal information to:

- Communicate with you
- provide appropriate services (this may include health information)
- meet the reporting requirements of some funded services.

MDQ stores personal information in a variety of secure formats including in secure databases and on portable devices with password control. The security of this personal information is of primary importance to MDQ. We ensure that our cloud-based programs store information on Australian servers and we take all reasonable steps to protect information from loss, misuse, unauthorised access, or disclosure.

MDQ may be obliged by law to disclose personal information. We may disclose personal information to third parties if permitted by the Privacy Act or, with explicit consent, to other entities for service provision or to assist MDQ's functions or activities, including:

- Government departments, namely Qld Health, National Disability Insurance Agency (NDIA), Education Qld
- 'For purpose' disclosure to lawyers, accountants, auditors or business consultants
- Law enforcement agencies
- MDQ does not sell or share our fundraising database information.
- Within the organisation, staff have restricted access to folders which are not relevant to them.

Accessing, correcting or opting out of sharing personal information

It is important that the personal information that MDQ holds is kept up to date and accurate. You may request access to your personal information or request that your personal information is changed or removed from MDQ's records. MDQ may ask questions to verify identity in this process. Access may be denied if MDQ cannot satisfactorily identify the stakeholder; if the request is unreasonable; or if there are perceived grounds to refuse access e.g. if in providing access, there is a risk that the privacy of another party is impacted.

- You can deal with MDQ anonymously or use a pseudonym instead of your personal details when engaging with MDQ, however, there may be limitations to the services we are able to provide.
- You can opt-out of allowing your personal information to be collected and held by MDQ, however, this will impact the services that MDQ will be able to

provide to you. MDQ does not charge a fee to access, update, remove or opt-out of sharing personal information.

- Please contact the Privacy Officer (details below) if you wish to access, update or opt out of sharing information with MDQ.

What happens when you share personal information online?

The MDQ website may use cookies to track site visits, navigate within MDQ sites, and add items while using the donation facilities. If you are concerned about the use of these cookies, your browser can be configured to notify you when you receive a cookie and provide you with the opportunity to accept or reject it. By using the MDQ website, Facebook or other social media sites, you are providing implied consent.

How to register a complaint if you believe your privacy has been breached

You may lodge a complaint regarding a perceived breach of your privacy related to the Australian Privacy Principles. The complaint must be made in writing and addressed to MDQ's Privacy Officer (details below). MDQ will need a reasonable time to investigate and respond to the complaint. In the unlikely event that the privacy issue cannot be resolved, you may take your complaint to the Australian Information Commissioner (www.oaic.gov.au).

MDQ's full Privacy Policy is available on request.

Contact Details

Privacy Officer: Senior Administration Officer

Postal address: Locked Bag 3000 Eagle Farm BC 4009

Telephone: 07 3243 9700 or 1800 676 364

Email: privacy@mdqld.org.au

Advocacy and Support

Muscular Dystrophy Queensland is committed supporting the legal and human rights of individuals and their right to services.

Advocacy is embedded in our work for clients. MDQ also leads systemic advocacy and within our capacity, will use our privately funded resources to advocate for clients' significant needs.

Our organisation also strongly supports the right of clients to use an external advocate of their choice to negotiate on their behalf. This advocate may be used in relation to assessment, reviews, complaints or any other communication between the client and this organisation.

Systemic Advocacy

The CEO leads systemic advocacy. Issues arising within Queensland are addressed to appropriate government agencies, either with MDQ as the sole advocate or in partnership with other Queensland agencies. National issues are taken to the Muscular Dystrophy Foundation where the Executive Committee makes decisions about issues for advocacy.

Individual Advocacy

MDQ staff may be able to provide individual advocacy, for example supporting you to make appropriate complaints, writing letters of support, supporting you to lodge an appeal with the Administrative Appeals Tribunal (MDQ does not have the capacity to support you through the process of an appeal to the Administrative Appeals Tribunal - for this support, MDQ will refer you to an external advocate and if appropriate, to Legal Aid Queensland)

Significant issues are referred to the CEO. Approvals are at the discretion of the CEO who makes decisions based on significance of the issue, urgency, family history, circumstances and availability of MDQ resources.

MDQ Client Services staff can provide you with information about external advocacy agencies.

Supporting Advocacy

We support your right to use an external advocate of your choice to negotiate on your behalf or support you. Your advocate can be present at assessments, reviews, meetings or for any other communication between the you and MDQ. Our staff will not provide any information to an advocate when you are not present unless you have given permission to do so.

Client Representatives

In some circumstances, MDQ may communicate directly with a client representative. Authorised client representatives include:

- Guardians
- Attorneys under enduring powers of attorney
- Agents under the Medical Treatment Act 1988
- Administrators under the Guardianship and Administration Act 1986
- A person otherwise empowered by the consumers to act or make decisions in their best interests.

We will request to see proof of representative authority and will keep a copy of the documentation on file.

Our full 'Providing Client Advocacy and Support' policy is available on request.

Informed Consent:

MDQ is committed to adopting best practices that support and maximise the client's clear decision-making, choice and self-direction. Informed consent is necessary for the provision of all MDQ services and is obtained through the completion of MDQ's Consent Form.

In order to give informed consent, MDQ is responsible for explaining what the consent relates to and why the consent is required.

Who can give consent?

- An adult client of MDQ. If you are physically unable to sign a consent form, you can ask an informal representative to sign it for you. We will ask for their details and a declaration that the form has been signed and submitted in consultation with you.
- The legal guardian of an adult client
- For children, MDQ recognises the rights of the parents/guardians to give consent, however also understands that the Privacy Act sets no minimum age at which an individual can make informed decisions regarding his or her personal information. MDQ acknowledges that the Guidelines to the National Privacy Principles suggest that each case must be considered individually as to when a young person may have the capacity to make a decision on his or her own behalf.

What does MDQ need consent for?

Consent to provide services: MDQ requires your consent before we can provide services. We will explain the services that we offer and any costs involved.

Consent to disclose and collect information: information is disclosed, collected, stored and shared under the Privacy Act and Australian Privacy Principles 2014. In order to provide a service, MDQ must have access to and authorisation to store and share information.

Consent to Communicate with a Guardian/Nominated Representative/Family Member: Under the Australian Privacy Act (1988) MDQ is not entitled to disclose

client information to anyone other than a legally recognised guardian, unless we have your permission. If you are over 18 years old and would prefer that we communicate with a family member or other informal representative, you must give your consent and provide details. The MDQ consent form will allow you to nominate 2 people as your nominated representatives.

Consent to video, photography and media: You can choose to provide consent about how any images and digital media can be used. MDQ may wish to use photos, video and media for:

- assessment, treatment or your NDIS goals
- educational purposes
- client publications, marketing, advertising and media (including social media)
- fundraising publications, marketing, advertising and media (including social media)

You can choose to give consent or decline consent for using video, photography and media and this will not affect your access to services from MDQ.

How long does consent remain in place?

Your consent form will remain in place for three years unless

- You turn 18
- There is a change in your circumstances e.g. you may wish to add or remove a nominated representative
- You ask for it to be revoked – you have the right to withdraw your consent at any time.

Our full 'Informed Consent' policy is available on request.

