

# 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:

Street Address:	1149 Sandgate Rd Nundah Qld 4012
Mailing Address:	Locked Bag 3000 Eagle Farm BC Qld 4009
Reply Paid Address:	Reply Paid 66034 Eagle Farm BC Qld 4009
Telephone:	Freecall 1800 676 364 07 3243 9700
Fax:	07 3123 6606
Email:	<a href="mailto:info@mdqld.org.au">info@mdqld.org.au</a>
Web:	<a href="http://www.mdqld.org.au">www.mdqld.org.au</a>
Facebook:	<a href="http://www.facebook.com/mdqld.org.au">www.facebook.com/mdqld.org.au</a>

Privacy: Muscular Dystrophy Queensland is committed to respecting the privacy of personal information provided to us. Our Privacy Policy, available in this handbook, explains how we do this.

Disclaimer: The Client Guide outlines the obligations and responsibilities of Muscular Dystrophy Queensland Ltd (MDQ), 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 liable for any action or decision made on the basis of the information contained in this guide alone.

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## Who are MDQ's clients?

Muscular Dystrophy Queensland (MDQ) provides whole-of-life support and services for Queenslanders living with muscular dystrophy and similar conditions. Sometimes we use the term, 'muscle wasting conditions'.

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

- muscular dystrophies, such as Duchenne, Becker, FSH & Myotonic
- diseases of the motor neuron, such as Spinal Muscular Atrophy
- neuromuscular junction diseases, such as Myasthenia Gravis
- peripheral nerve disease, 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](http://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, children, unpaid carer. We also provide information to the people who are working with our clients e.g. paid support workers, educators, 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. For example this might include other progressive neurological conditions such as multiple sclerosis. (See *NDIS Services* discussed later in this guide.)

## Becoming a Client of Muscular Dystrophy Queensland

We request that any person wishing to receive services from Muscular Dystrophy Queensland 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.

The process involves welcoming you, helping you make a decision about whether MDQ is a suitable service provider, and provides information and answers to your questions. This entire process should take no more than a week.

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've decided our services might benefit you, there are usually just two steps more steps:

- Offer from MDQ to the person wishing to become a client
- Completion of intake forms (sometimes called registration forms), which include:

### **A client details form**

This includes your personal details and some information about your condition and how it affects your life.

### **A client consent form**

This is your consent (or that of your authorised guardian) for MDQ to work with you. It also allows to give consent (or to decline consent) for MDQ to:

- Provide services
- Disclose and collect information
- Communicate with guardians and carers
- Capture and use photography, videos and other media

### **Additional forms**

- For people using MDQ's NDIS services we ask you to complete an MDQ Service Agreement and Schedule of Supports. These documents are required by the National Disability Insurance Agency.
- Forms for specific programs, e.g. People wishing to access one of our equipment loan programs, would 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 will suggest other appropriate service providers.

Be reassured 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 this process has been completed we consider you to be a client of MDQ. 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*, later in this section of the guide).

Being a client of MDQ has the following benefits:

- Quarterly Client Update magazine and access to the organisation's Facebook page where latest information is shared
- Access to our client services team: They understand your condition more than most and can answer your questions and work with you to solve problems
- Assistance with understanding the NDIS and specialist NDIS related services

Muscular Dystrophy Queensland is a small organisation doing a big job throughout Queensland. This means we will not be able to keep in frequent contact with you unless you have active needs. We do try to keep in touch with every client by making a call at least once per year but, from time to time this cannot be achieved. (For example the introduction of the NDIS in 2018 and the need to support so many people making the transition into new services, meant we were not able to make our annual catch up calls.) We apologise for not being able to call you as often as we would like.

The good news is that our organisation welcomes your calls – with questions; requests for assistance; need for advice and support – and will respond to your needs as best we can.

We understand that the nature of living with a muscle wasting disease means that your needs will change over time. Please keep in contact with us and let us know if there's any way we can assist you.

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 unsubscribe from our communications.

- You would like MDQ to remove your personal details from our records.

## Exiting MDQ's services

People can also easily exit Muscular Dystrophy Queensland when they do not want to continue as a client. They may do so for a number of reasons, for example:

- Their needs change
- They are not satisfied with the services MDQ is providing
- They move interstate or overseas. (If you move within Australia, we may be able to refer you to the state based organisation in the state you are moving to.)

If you do longer wish to have contact with Muscular Dystrophy Queensland (MDQ), just let us know and we will remove your contact details from our active client list. Letting us know really helps us to keep our records up-to-date.

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
- Your needs don't meet our ability to provide services
- If you move interstate or overseas.

Again, 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.

# NDIS Services

## Free services to prepare you for your NDIS Plan

Through MDQ's NDIS Readiness Program, we can:

- Help you to register with the National Disability Insurance Agency (NDIA)
- Assist you to prepare for your NDIS Planning Meeting
- Advise you if you are experiencing problems in implementing your Plan

## Our Services Funded by your NDIS Plan

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

- Coordination of Supports
- Plan Management
- Allied Health services (initially for people living in the south east corner of Qld)
  - Individual Counselling
  - Occupational Therapy
  - Physiotherapy
  - Programs delivered by an Allied Health Assistant

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

## Coordination of Supports

When you employ us as your Coordinator of Supports, we can provide the following assistance:

- Using our knowledge of you as our client, we assist you to get the most out of your NDIS Plan
- We analyse your NDIS Plan with you 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
- Over time, we build your confidence and skills to manage your NDIS plan independently

If you feel *Coordination of Supports* will assist you, You need to make a specific request of your NDIS Planner for funds for this service to be included in your NDIS Plan and



in some cases, to argue a need for this service to be included in your NDIS Plan.

### **Plan Management Provision**

When you have an NDIS Plan, you are responsible for organising and paying suppliers of services by submitting payment claims to the National Disability Insurance Agency. 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.

As your Plan Management Provider, MDQ offers assistance in:

- Setting up the financial management of your NDIS plan
- Creating service bookings on the NDIA on-line provider portal for spending your funds
- Reviewing supplier invoices to ensure they're correct and then claiming payments from the NDIA on-line portal and paying your providers
- 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 funds 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 this service.

### **Allied Health Services**

MDQ offer a range of allied health services for people to access via their NDIS plans. Currently these services include Counselling, Occupational Therapy and Physiotherapy. 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.

*Note: At this early stage of development, allied health services are available in Queensland's south east corner. This may change as the services develop. You can see our allied health team at our Nundah office; 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.

## *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 if you have had 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

At this stage, MDQ will refer to specialised providers for some other services within Occupational Therapy e.g. for major home modifications or driving assessments.

## *Physiotherapy (PT)*

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*

MDQ also employs Allied Health Assistants who provide individual sessions to carry out programs which have been developed by the physiotherapist or occupational therapist. The allied health assistant may also:

- Assist the therapist with groups e.g. hydrotherapy, life skills, land-based exercise groups and
- Make minor equipment adjustments under the direction of the physiotherapist and occupational therapist

### **Accessing our NDIS 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 applies); 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 the south east corner of Queensland and is not able to offer free allied health services.

# General Services

MDQ's ability to provide these free services depends upon available funds and capacity. There may be a short waiting time for services, however any waiting lists will provide 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](http://www.mdqld.org.au)), Facebook page and other social media outlets.

The Helpline is a phone (during office hours: phone 1800 676 364) or email service ([info@mdqld.org.au](mailto:info@mdqld.org.au)) where any question can be put to our trained and knowledgeable staff. We may be able to answer straightaway or consult our global networks for an answer. This is a free service, available to our clients of course and to any member of the public.

## Individual services

If you are a Client of MDQ (see Who are MDQ's Clients in this handbook) and are not eligible for 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 any incident which makes you feel unable to cope without urgent advice and help.

If you are funded under the NDIS client, 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. 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 which people may need advocacy support include:

- Getting a fair deal in an NDIS Plan
- Being a more independent decision maker within their family
- Not having their condition understood at school or at work

## Extended care

When a person lives with muscular dystrophy or a similar condition sometimes unforeseen problems 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 support you by helping 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 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 usually:

- 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 provides some level of independence.

This equipment can be included in an NDIS plan, therefore our clients eligible for NDIS funding cannot be assisted through this loan program. (Will will assist you to seek funding for the equipment and it's ongoing maintenance in your if you want us to help you.)

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*, 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 one of the 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.

Our Breathe Well Program focuses 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.

All clients have access to MDQ's free, short term 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.



# Peak body Services

As a recognised peak body, Muscular Dystrophy Queensland 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).

In 2018, we were thrilled to receive funding under the NDIS for a two year program to develop a National Digital Resource which when developed, will be an online resource providing trustworthy information and support for all Australians living with muscular dystrophy and similar conditions.

MDQ is enthusiastically involved in developing the resource and would welcome any suggestions from you about how you would like the resource to be developed and which information to be provide and/or topics to be discussed.

## 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 are aligned with the prices in the NDIS Price Guide. The NDIS Price Guide is updated from time to time and with that, prices increases will apply. 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 is MDQ?

## Vision, mission and objectives

Muscular Dystrophy Queensland's 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.

This statement guides our board and our staff, in planning and each and every operational task we undertake.

## 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 related Quality and Safeguarding Commission when it is commenced in Queensland later in 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 and 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.

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.



# Meet Our Team

## Patron



**Emeritus Professor John Pearn AO, RFD, MD, PhD, D Sc, M Phil, FRHSQ, FFAHS**

Prof. Pearn is a senior paediatrician at Lady Cilento Children's Hospital. For many years he served as Professor of Paediatrics and Child Health at the University of Queensland and the Royal Brisbane Women and Children's Hospital. His research publications in international literature have contributed to child safety and welfare, clinical genetics, neuromuscular disease and medical ethics. He has received numerous awards including the Order of Australia for service to medicine, to medical history, and to the community.

Prof. Pearn played an integral role when our organisation was founded in 1978 and we are delighted he continues his association with MDQ through his Patronage.

## Board & Executive Members

### *Chairperson*

e: [chairperson@mdqld.org.au](mailto:chairperson@mdqld.org.au)



Victor brings to the board his extensive leadership experience in the public sector and also he also lives with a neuromuscular condition. Victor was a member of Ipswich City Council from 2000 and Deputy Mayor from 2004 until his retirement from politics in 2016. At the age of 21 Victor was diagnosed with Charcot-Marie-Tooth disease, a neuromuscular condition. Victor has served on the board since 2016 and has been chairperson since 2017.

### *Directors*

Ken Robertson, Tony Biggar, Peter Jeffris, Natasha Taylor, Cullen O'Gorman

**Company Secretary** Helene Frayne

### *Chief Executive Officer and Client Services Manager*

**Helene Frayne**

e: [helenef@mdqld.org.au](mailto:helenef@mdqld.org.au)



For many years, Helene practised as a speech pathologist and manager of allied health services. In both roles, Helene worked with people with muscular dystrophy and similar conditions. Helene has been at MDQ since 2014.

## Client Services & Allied Health Team



### *Client Services Team Leader*

**Kim McNab**

[kimm@mdqld.org.au](mailto:kimm@mdqld.org.au)

Kim has worked at MDQ since 2013, in various roles. She currently coordinates services, is our NDIS specialist, our project officer, as well as providing NDIS Support Coordination services. Kim comes from a health promotions background and, as a family member, has lived experience of muscular dystrophy.

### *Support Coordination & General Client Services*



**Maryanne Dover**

e: [maryanned@mdqld.org.au](mailto:maryanned@mdqld.org.au)

Through building positive relationships, Maryanne works with our eligible clients to fully embrace their NDIS funded services. Using MDQ's free services, Maryanne advocates for client needs and links them into services within the community. Maryanne joined MDQ in 2012 and has met or worked with most of our clients.



**Pushya Rai**

e: [pushyar@mdqld.org.au](mailto:pushyar@mdqld.org.au)

Pushya joined MDQ in 2018 with eight years of prior experience in supporting people and families living with muscular dystrophy and similar conditions. Our clients are benefiting from Pushya's commitment, energy and enthusiasm in supporting our clients.



**Agnes McGauley**

e: [agnesm@mdqld.org.au](mailto:agnesm@mdqld.org.au)

Joining our team in 2019, Agnes has previous experience supporting people with physical and intellectual disabilities. She is passionate about helping our clients reach their goals.





***Social Worker and Intake Officer:*** Lindell De Marte

e: [lindelld@mdqld.org.au](mailto:lindelld@mdqld.org.au)

Lindell enjoys working with clients and families to help them achieve short and long term goals. She uses her experience as a social worker to assist people to navigate the NDIS system. Lindell has extensive experience in working with people with disabilities and also the knowledge of muscular dystrophy and similar conditions to understand the challenges of living with them – ideal skills to build NDIS funded counselling services at MDQ.



***Physiotherapist:*** Lynne Borgert

e: [lynneb@mdqld.org.au](mailto:lynneb@mdqld.org.au)

Lynne Borgert has been working with people with muscular dystrophy and similar conditions for most of her career and has experience of physiotherapy needs across the whole lifespan. Lynne has particular expertise in physical assessments and equipment prescription including complex seating and specialised devices such as standers, walkers and modified bikes. Lynne is also providing individual and group hydrotherapy services at selected locations.



***Physiotherapist:*** Karen Dines

e: [karend@mdqld.org.au](mailto:karend@mdqld.org.au)

Karen Dines has over 40 years' experience as a physiotherapist, much of which has been in rehabilitation and disability. Karen will work alongside Lynne Borgert in providing physio services. She strongly believes in equal opportunity for all and is looking forward to meeting our clients and helping them meet their goals.



***Occupational Therapist:*** Isabella Bolton

e: [isabellab@mdqld.org.au](mailto:isabellab@mdqld.org.au)

Early in her career, Isabella has made a commitment to providing specialist services to our community. Her special interests include equipment prescription, collaborative goal setting and problem solving. Isabella is looking forward to being able to learn and grow professionally as part of the MDQ team.



***Allied Health Assistant:*** Robbie Clark

e: [robbiec@mdqld.org.au](mailto:robbiec@mdqld.org.au)

While on a soccer scholarship in the USA, Robbie completed a degree in Clinical Health and Human Performance. He is enjoying introducing allied health assistant services to MDQ. What he like best about the role is assisting clients with their exercise and hydrotherapy programs.

## Finance and Administration Team



### *Plan Management Services*

Arlie Arcayan

e: [services@mdqld.org.au](mailto:services@mdqld.org.au)

As finance officer, Arlie leads our Plan Management program and is committed to providing a smooth and efficient service.



### *Administration, Database & Client Communications*

Suzi Zahnow

e: [suziz@mdqld.org.au](mailto:suziz@mdqld.org.au)

Suzi leads MDQ's administration and data services and writes some of our client communications, including our much valued Client Update newsletter.



### *Reception & Administration*

Ondrea Hornsby

e: [info@mdqld.org.au](mailto:info@mdqld.org.au)

Ondrea is probably the first voice that callers hear as she supports our reception service and our client services team.



# 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 [www.mdqld.org.au](http://www.mdqld.org.au) as well. 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 & 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 purposes
- 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 Profile**

MDQ also has a duty of care to all of our clients, so the staff will be developing and reviewing a Client Risk Profile which is included in your confidential client file at MDQ. From that Risk profile, the staff have a duty to implement plans to lessen the risks to you.

It would be ideal if you were to develop your client risk profile in partnership with your MDQ staff member so you will be informed when your Client Risk profile is being developed or reviewed and invited to participate.



## Feedback and Complaints

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.

### *How can I provide feedback?*

Feedback can be provided through the following:

- Verbally to an MDQ staff member – either via the telephone or face-to-face. The staff member will ask you whether you want the feedback to be reported and assist you in writing a summary of your feedback
- The MDQ Feedback form is available on [www.mdqld.org.au](http://www.mdqld.org.au)
- You can email or write a letter to the Business Operations Manager, Kerry Atkins
- Periodic evaluations i.e. responding to our annual client survey, workshop and program evaluations, phone surveys
- You can lodge your feedback with your contact details included or you may wish to lodge it anonymously.

Feedback is also provided by the MDQ Client Consultation Committee and other groups of clients formed for a specific purpose.

### *What happens to my feedback?*

Feedback is collected and recorded on a register. Each month, it is included in a report to the MDQ Board. The leadership team and board use the feedback- compliments, suggestions and complaints - to address issues raised and to continually improve MDQ's services and programs.

### *How does MDQ handle my complaint?*

MDQ undertakes to provide a timely, objective and positive response to any feedback, especially to any complaints. All complaints will be investigated, discussed with the complainant and resolved within 28 days if possible. All people involved in the complaint i.e. both the complainant and the person against whom the complaint has been made, will have the right to have the complaint handled respectfully,

confidentially and in a timely manner. For the well being of all parties involved in the complaint, It is vital that its resolution is prioritised.

### *What happens if I am not happy with the complaints investigation?*

At MDQ, we aim to investigate the complaint and resolve it through positive negotiation with all parties. Some of the following may happen as a result:

- An apology in appropriate circumstances
- Clarification through information provided to the complainant
- Changes in the processes which MDQ follows
- Staff training
- Reallocation of complainant to another team member for service provision

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

There may however be some circumstances where the complainant is not satisfied with the outcome. Should you be dissatisfied, you have the right to take the complaint to MDQ's board of Directors for review. Email: [president@mdqld.org.au](mailto:president@mdqld.org.au)

If you are not satisfied with the board's decisions, you also have the right to take your complaint to some of the following entities:

- The Queensland Ombudsman
- The Australian Charities and Not-for-profit Commission
- The Queensland legal system.

### *What happens after the complaint has been resolved?*

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.

### *Contact details for feedback*

- MDQ website: <https://www.mdqld.org.au/contact-us/>
- Email to the Business Operations Manager: [feedback@mdqld.org.au](mailto:feedback@mdqld.org.au)
- Post to: Ms Kerry Atkins  
Business Operations Manager  
Locked Bag 3000  
Eagle Farm BC Qld 4009



## Privacy Policy

Muscular Dystrophy Queensland (MDQ) is committed to compliance with the Privacy Act 1988 (Cth)\*, which incorporates the 13 Australian Privacy Principles (APPs). This is the legislation governing the collection, use and disclosure of personal information, including sensitive information. \* You can find out more about the principles by calling the office of the Australian Information Commissioner on 1300 36 39 92, or through their website at <http://www.oaic.gov.au/>

### *Who does the MDQ Privacy Policy apply to?*

To provide programs and services, MDQ needs to collect and store some relevant personal details about stakeholders. The MDQ Privacy policy and procedures apply to our stakeholders as follows:

- Clients and customers (including Helpline callers) of MDQ services and their families
- Customers of MDQ's fundraising programs e.g. donors, and event attendees
- Members of Muscular Dystrophy Qld
- Staff and volunteers

### *Why MDQ collects and holds personal information*

MDQ collects only the necessary, personal information that is required for its operating purposes and depends on the nature of the person's association with MDQ. Some of the purposes for which information is collected are outlined below:

- To enable MDQ to provide support and services to our clients and their supporters
- To enable our donors and supporters to participate in funding our services, including processing donations, memberships and issuing receipts
- To enable us to communicate with all of our stakeholders
- In the engagement of employees, volunteers and contractors
- Dealing with suppliers and with funding providers e.g. government

MDQ may also be required by law to disclose personal information and would be obliged to do so.

To ensure a high quality of service provision, especially to clients who receive services such as physiotherapy, MDQ sometimes needs to hold personal and sensitive information, which may include health information.

### *Consent*

At MDQ, express consent is obtained from people receiving client services, via a consent form completed by a client, guardian, or nominee. This also occurs for

the collection of images, especially those used by MDQ for public purposes e.g. fundraising and education. Express consent is obtained for each public use of personal details and images e.g. for fundraising purposes.

Personal information may also be collected at Muscular Dystrophy Qld with implied consent e.g. where people voluntarily share information during conversations which may be relevant in service provision. Attendees at public events may be photographed however, where practicable, MDQ would seek to obtain consent prior to using the image obtained.

### *How MDQ collects personal information*

Specific instances where personal information is collected may include:

- Through a call to MDQ's Helpline, email asking for assistance, conversations
- Information provided by care givers, health professionals, or referral agencies
- Marketing and mailing lists
- Responses to MDQ's hard copy or electronic fundraising campaigns
- Through fundraising events

For fundraising and marketing purposes, MDQ may purchase commercial lists or source personal information from public documents e.g. phone directory. When asked, MDQ will disclose the source of the personal information that MDQ has obtained. MDQ does not sell, or share our database information e.g. for fundraising or to gain income.

### *How MDQ stores personal information*

MDQ stores personal information in secure formats, accessible only via password including:

- In secure databases,
- In hard copy files and
- On portable devices including laptop computers.

The security of your personal information is of primary importance to MDQ and we take all reasonable steps to protect the information from loss, misuse, authorised access or disclosure.

Procedures have been established for identifying and managing privacy risk. These include:

- Access to personal information only granted to authorised users
- Password protection on all computer systems, databases, and portable devices



- Staff training on privacy issues
- Securely locked paper based records
- Secure destruction of personal information no longer required for purposes for which MDQ is authorised to use it
- Locked offices and secure monitoring of MDQ premises

We may need to disclose personal information to third parties if permitted by the Privacy Act or, with explicit consent, to other service providers, or to assist MDQ's functions or activities, including:

- Government departments, e.g. National Disability Insurance Agency (NDIA)
- Lawyers, accountants, auditors or business professionals that we engage as consultants
- Printers
- Law enforcement agencies

### *How can I access and/or opt out of sharing personal information?*

You may access your personal information in any of the following ways:

- Update
- Change its status e.g. from identified to anonymous
- Request that it is removed from MDQ records.

These requests are enacted by contacting MDQ's Privacy Officer, whose details are listed at the end of this document. When updating personal information, MDQ may ask questions to establish your identity. Access may be delayed or denied if MDQ cannot satisfactorily verify your identity; if the request is unreasonable; or if there are perceived grounds to refuse access e.g. someone else's privacy is impacted. MDQ does not charge a fee to access, update, remove or opt-out of sharing personal information.

Where practicable, you can deal with MDQ anonymously i.e. without disclosing your identity, or by using a pseudonym. This may give you greater control and you can decide how much personal information will be shared with us. We will explain the options and limitations to MDQ's engagement should you wish to exercise those options. With our help, you may wish to opt-out of allowing your personal information to be collected and held by MDQ.

### *How long does MDQ keep private information?*

As a general rule, MDQ keeps the stakeholder's personal information for seven

(7) years following the last entry into a client file (ref: MDQ Guidelines for Client Records), however we also comply with other legislation e.g. destruction of credit card details after single use.

### *Disclosure of personal information to overseas recipients*

MDQ does not disclose personal information outside of Australia, however, as with most organisations, we store personal information on a Cloud based client database with the usual password access and security measures described above.

### *What happens when I share my personal information on MDQ's website or facebook page?*

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. You may refuse all cookies from MDQ websites however some functions may be unavailable.

By using the MDQ website, Fb or other social media sites, stakeholders provide implied consent on the understanding that:

- The internet is inherently insecure
- They use MDQ's web based products at their own risk
- It is the stakeholder's decision alone to share this personal information and MDQ does not take responsibility for its privacy
- MDQ is not liable for any security breaches, viruses, Trojans or other malicious software that may infect the stakeholder's computer or any loss of data, revenue or otherwise that may occur as a result of using MDQ's web based products.

### *Registering a complaint regarding the breach of an app*

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, whose details are listed at the end of this document. (You can also refer to the MDQ Complaints Policy and information). 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 Office of the Australian Information Commissioner ([www.oaic.gov.au](http://www.oaic.gov.au)).

### *Communicating the MDQ Privacy Policy*

This information document is displayed in the following places where updates are



also displayed.

- On the MDQ website [www.mdqld.org.au](http://www.mdqld.org.au)
- In relevant communications e.g. MDQ client welcome pack.

This policy was last updated in December 2018 and is subject to annual review. MDQ welcomes requests from stakeholders to receive a copy of the MDQ Privacy Policy.

### *Contact Details for privacy enquiries*

Privacy Officer: Business Operations Manager  
Postal address: Locked Bag 3000 Eagle Farm BC 4009  
Telephone: 07 3243 9700 or 1800 676 364  
Email: [privacy@mdqld.org.au](mailto:privacy@mdqld.org.au)

#### **Privacy Policy Footnotes**

<sup>1</sup> Muscular Dystrophy Qld Privacy Policy and Procedures <https://pwd.org.au/resources/social-model-of-disability/>

<sup>2</sup> Accessed on 2019 01 02

<sup>3</sup> Queensland Disability Service Standards

<sup>4</sup> NDIS Principles: <http://www.idfnsw.org.au/images/files/8.-NDIS-Principles-handout-NSW-FINAL.pdf>

<sup>5</sup> Muscular Dystrophy Qld Working with Vulnerable People Policy and procedures

<sup>6</sup> Muscular Dystrophy Qld Feedback and Complaints policy and procedures

<sup>7</sup> You can find out more about the principles by called the office of the Australian Information Commissioner on 1300 36 39 92, or through their website at <http://www.oaic.gov.au/>

**Your Notes:**





