



Muscular
Dystrophy
Queensland

Registered NDIS Provider

Client Guide

Our vision is for 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 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: 1800 676 364 (freecall)
07 3243 9700

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. Information is correct at the time of publishing, however this guide, and the policies it refer to, may be updated from time to time. The Client Guide is neither complete nor exhaustive and Muscular Dystrophy Queensland 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.

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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

Muscular Dystrophy Queensland 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 of our clients and community members, 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

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.

NDIS Services

Free services related to the NDIS

- Help to apply for an NDIS plan, including advice on how to reapply if you have been previously rejected
- Assistance to prepare for an NDIS planning meeting
- Advice if you need help 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:
 - Occupational Therapy
 - Physiotherapy
 - Programs delivered by an Allied Health Assistant

Muscular Dystrophy Queensland'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 Muscular Dystrophy Queensland 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, Muscular Dystrophy Queensland can 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, Muscular Dystrophy Queensland 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

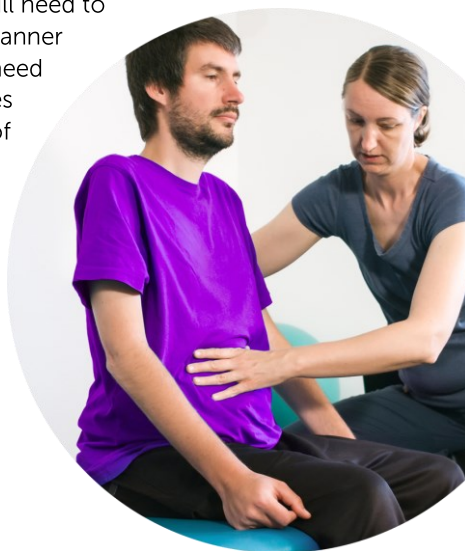
If you feel Plan Management Provision will assist you, you need to make a specific request of your NDIS Planner for this service to be included in your NDIS Plan. Once the request has been made, the NDIS Planner is required to include funds for PMP.

Allied Health Services

Muscular Dystrophy Queensland offer a range of allied health services for people with neuromuscular conditions via their NDIS plans. (See p9 of this guide if you would like to access Allied Health without an NDIS plan)

Currently these services include Occupational Therapy, Physiotherapy and Allied Health Assistance. You will need to discuss your allied health needs with your NDIS Planner so that appropriate funding for the therapies you need will be included in your NDIS plan. Therapy services are included under the Capacity Building section of your plan listed as 'Improved Daily Living'.

At this stage, allied health services are available in Brisbane and surrounding areas with regular trips to the Gold Coast and Toowoomba. We also provide Occupational Therapy and Physiotherapy on an outreach basis to Cairns and the Sunshine Coast. You can see our allied health team at our client centre in Nundah; at home; at school or at your workplace.



Occupational Therapy (OT)

Muscular Dystrophy Queensland's Occupational Therapists provide assessment and use 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

Muscular Dystrophy Queensland'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)

Muscular Dystrophy Queensland employs Allied Health Assistants (AHA) who complement our Allied Health Team. The AHA may:

- Assist the therapist during group sessions e.g. hydrotherapy (AHA Level 1)
- Independently provide sessions to carry out programs developed and monitored by the therapist e.g. prescribed stretching programs (AHA Level 2)

Individual Support Plans

When you receive services funded by an NDIS plan, the staff providing those services will work with you to create an Individual Support Plan. The plan will outline your goals and how we are working towards them. We will discuss risk mitigation strategies and contingencies for what to do in case of an emergency. You should have a disaster and emergency plan in place and our staff can assist you to develop one if you need help.

Using Allied Health services without an NDIS plan

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

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

The safety of our staff

Under Australian law, your home is considered a workplace when we provide services in your home. To ensure safety, our staff will complete a Home Visit Risk Assessment prior to and at their initial visit. In addition to an initial assessment, our staff may also ask you to do a pre-visit health questionnaire to ensure that you and other members of your household are well. This is also very important to minimise the spread of viruses and infections to vulnerable clients.

We respectfully request that you disclose any potential risks to our staff as they complete these assessments.



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 Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland. (See NDIS Services and Accessing our NDIS services without an NDIS Plan in this handbook.

Muscular Dystrophy Queensland's prices and conditions are aligned with [NDIS Pricing Arrangements and Price Limits](#). The National Disability Insurance Agency updates the NDIS Pricing Arrangements and Price Limits from time to time and with each update, price increases may apply and conditions may change.

People without NDIS Plans can also access our allied health services at a cost e.g. with Aged Care package funding, through private health insurance or a Medicare program, or you can pay from your funds for these services. Call us 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 they have adequate funding available before engaging Muscular Dystrophy Queensland as a service provider.

General Services

Thanks to the generosity of our donor and supporters, Muscular Dystrophy Queensland is able to provide some programs at no cost to the person who is accessing them. There may be a short waiting time for services, however any wait times will be explained to you.

Information and Education

We know that having trustworthy information about all aspects of your condition is vital and that is the reason our community members value our expertise.

Information about muscular dystrophy and similar conditions is provided through our Infoline, newsletters, website (www.mdqld.org.au), Facebook page and other social media outlets. Our website also includes a range of webinars from created by our Allied Health professionals.

If you have concerns about living through the COVID-19 pandemic you can talk to someone through our Infoline.

You can call our Infoline (Mon-Fri 9:00am to 4:30pm) on 1800 676 364 or email info@mdqld.org.au.

Any questions about living with muscular dystrophy or similar conditions 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 community member registered with Muscular Dystrophy Queensland, 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
- Help to apply for an NDIS plan, including advice on how to reapply if you have been previously rejected
- Assistance to prepare for an NDIS planning meeting
- Advice if you need help implementing your plan

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.

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
- Work through issues with you

Advocacy

We recognise that people with disability may need a strong voice to support them in achieving their individual goals. Muscular Dystrophy Queensland is able to provide free, appropriate individual advocacy for its community members about relevant issues or concerns. From time to time, this might not be adequate and referral to an external advocacy organisation may be appropriate. Muscular Dystrophy Queensland 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

Equipment loans

Muscular Dystrophy Queensland's equipment programs are funded by our generous donors so allocation of loans depends on available funding. For both programs there is a simple application and assessment process.

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, Muscular Dystrophy Queensland 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 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.

Muscular Dystrophy Queensland'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 Muscular Dystrophy Queensland clients and others with muscle wasting conditions have access to our free, Cough Assist machine loan scheme. Machines are delivered on short term loan anywhere in Queensland. Referral must be made by a respiratory physiotherapist. Conditions apply, please contact us if you need more information about this program.

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

Community Leadership

As a recognised leader in the Queensland community of service providers, 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 muscular dystrophy organisations in other states to provide national advocacy for Australians living with muscular dystrophy and similar conditions

National Projects

Several 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

Our group of organisations developed a National Digital Resource to provide trustworthy information for all Australians living with muscular dystrophy and similar conditions.

The Loop features 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 advice on life issues like travel, education, relationships & transport
- Get advice on caring for someone with a neuromuscular condition

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

Who are Muscular Dystrophy Queensland's clients?

Muscular Dystrophy Queensland provides whole-of-life support and services dedicated solely 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 community is for people who live with muscle wasting conditions, their families and carers. 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 Muscular Dystrophy Queensland's support at whatever life stage or level of disability they are experiencing.

Muscular Dystrophy Queensland 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.

Becoming a client

Any person wishing to receive services from Muscular Dystrophy Queensland undergoes a simple intake process to become a client. Our Intake Officer or another member of the client services team will help you. There is no cost involved in registering as a client.

The process involves welcoming you, helping you make a decision about whether Muscular Dystrophy Queensland is a suitable service provider, and providing information and answers to your questions. You always have a choice about whether you wish to register with us and the level of engagement you want.

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. We can also spend some time answering your question and providing extra explanations.

Once you have made the decision to become a client of Muscular Dystrophy Queensland, 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 Muscular Dystrophy Queensland 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.

People wishing to use our NDIS services will also be required to complete a Service Agreement and Schedule of Supports prior to receiving your service. These documents are required by the National Disability Insurance Agency.

If you are wishing to access an equipment loan, you will be asked to complete a Loan Agreement.

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

Being a client

Once the intake process has been completed we consider you to be a client of Muscular Dystrophy Queensland. We provide a whole-of-life service, so you will continue to be a client until you wish to exit our services (see *Exiting Muscular Dystrophy Queensland's Services*).

Clients of Muscular Dystrophy Queensland have access to:

- regular Client Updates and information about services and events that may interest you.
- NDIS and chargeable services
- General free 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.

Muscular Dystrophy Queensland 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 neuromuscular 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 Muscular Dystrophy Queensland to remove your personal details from our records

Exiting a Muscular Dystrophy Queensland service

Muscular Dystrophy Queensland offers a range of different services including:

- Support Coordination
- Allied Health
- Plan Management
- General Free Services

These services are provided by different departments of Muscular Dystrophy Queensland and your decision to exit one service will not impact your eligibility to receive other services. We support 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, Muscular Dystrophy Queensland will support your transition. We do ask for a notification period for certain funded services, this would be outlined in your Service Agreement.

There are no barriers to exit Muscular Dystrophy Queensland if you no longer want to continue as a client. Just let us know and we will remove your contact details from our active client list. There are no hard feelings and you can always choose to come back at any time.

From time to time, we 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. If this happens, we will 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 Muscular Dystrophy Queensland?

Vision, mission and values

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.

We're stronger **together**

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 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 within the disability community in Queensland
- 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 a registered NDIS provider and is accredited under the NDIS Quality and Safeguarding Commission.

History

Muscular Dystrophy Queensland 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, Muscular Dystrophy Queensland 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.

Muscular Dystrophy Queensland is the only Queensland organisation that focusses solely on the needs of people with muscular dystrophy and similar conditions. We aim to be a leader in the Queensland disability community and contribute to the national voice for our community through our involvement with Muscular Dystrophy Foundation Australia.

Our Board and Staff

Muscular Dystrophy Queensland is fortunate to have a dedicated Board that use their combined skills, knowledge and lived experience of neuromuscular conditions to ensure that the organisation remains focused on achieving our vision.

We also have a team of committed staff with 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.

Strategic Plan 2022-2025

Muscular Dystrophy Queensland's Strategic Plan 2022 – 2025 focusses on the organisation we need to be in the future and tells the story about how we are going to strive to achieve our strategic goals to:

Build our community: Muscular Dystrophy Queensland will grow and develop our community services according to the wishes and needs described by its members.

Deliver services of superior quality and value for our clients: We will provide continually improving, dedicated, charitable and user pays services which best meet the unique and complex needs of our clients and contribute to Muscular Dystrophy Queensland being considered a provider of choice by our community members.

Our community benefits from the philanthropy of others: The philanthropic goals of our donors and supporters are met as they understand the benefit of their investment to our community of people and families living with muscular dystrophy and similar conditions.

Grow, develop and empower our workforce: Our staff and volunteers are supported, resourced and empowered to have a balanced work and home life and develop their skills and knowledge.

Strive for excellent organisational performance: Our business practices, innovation and accountability enhance financial sustainability, positive reputation, and ultimately, organisational excellence.

Community Liaison Group

Muscular Dystrophy Queensland's Community Liaison Group is comprised of a diverse group of clients and family members representing different ages, genders, and backgrounds. They are a conduit for communication from community members to the board in an advisory capacity.

The purposes of Community Liaison Group (CLG) are:

- to be the voice of Queensland's neuromuscular community and
- to provide strategic and high-level operational advice to Muscular Dystrophy Queensland's CEO and board on matters relating to our neuromuscular community.



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
- NDIS Act 2013 (Cth)
- All Abilities Queensland Disability Service Plan (2020 – 2023)
- Client safety and minimisation of client risk

Muscular Dystrophy Queensland's priorities and Principles of Practice are:

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

We are 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:

- 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, 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 Muscular Dystrophy Queensland and its clients, each party has rights and responsibilities as follows.

What you can expect from Muscular Dystrophy Queensland

Muscular Dystrophy Queensland will:

- Treat you with respect at all times
- Be transparent and honest in our dealings with you
- Treat you fairly and without discrimination
- Provide you with sufficient information about the service and its terms of use
- Work with you to ensure you have choice and control over your decisions, including your choice of service providers
- Support you to connect with other services if needed
- Inform you of your rights and responsibilities
- Provide a safe and healthy environment within the service and our facilities
- Comply with robust infection control policy, including responsible management of risks relating to COVID-19
- Never subject you to physical, sexual, emotional or verbal abuse or exploitation
- Take all reasonable steps to prevent Muscular Dystrophy Queensland staff or volunteer misconduct in any form
- Take all reasonable steps to prevent and respond to all forms of abuse and/or harm to clients and/or family members to whom we have a duty of care
- Respect your privacy and confidentiality
- Protect your personal information and only use it for the right reasons, after obtaining your informed consent
- Tell you how to provide us with feedback on our service and how to make a complaint
- Ensure your complaints are dealt with fairly, promptly and without fear of retribution. If your complaint cannot be resolved internally we respect your rights to seek advice from an external agency

- Do all that is possible to support access to our programs for all people, including:
 - Our First Nations people
 - People from Culturally and Linguistically Diverse (CALD) backgrounds
 - People from LGBTIQ background and other minority groups within Australian society
- Take all reasonable steps to ensure continuity of services in the event of a disaster (e.g. pandemic, natural disaster)
- Involve members of our community in decision making about the future direction of our organisation
- Strive to continually improve all aspects of our organisation
- Provide timely information about any significant changes to Muscular Dystrophy Queensland's practice or support provision
- Uphold client/customer rights, both within Muscular Dystrophy Queensland and in the broader community
- Comply with the NDIS Code of Conduct
- Comply with the NDIS Practice Standards and Quality Indicators (Nov 21)
- Take all reasonable steps to ensure the safety of Muscular Dystrophy Queensland staff and volunteers

Responsibilities of Muscular Dystrophy Queensland's Clients and Community Members

- All clients and community members must treat our staff/volunteers fairly and with respect
- Respect that our staff cannot provide services beyond the scope of Muscular Dystrophy Queensland's practice and/or beyond those specified at the time
- Respect that the relationship with Muscular Dystrophy Queensland staff/volunteers is a professional one without the expectation that it will become a personal friendship
- Respect the privacy of Muscular Dystrophy Queensland staff and volunteers by not contacting them outside of business hours (Mon-Fri 9:00am-4:30pm)
- Understand that Muscular Dystrophy Queensland provides ongoing rather than emergency services. Contact emergency providers out of hours and to source alternate services if there is an emergency

- Provide a safe and healthy environment in which staff/volunteers can work, especially when they are visiting your home for work purposes
- Inform us with adequate notice about changes which may affect service provision (e.g. cancellation of appointments, changes to funding)
- Cancel face-to-face appointments if you or a household member has an infectious disease (e.g, Covid-19, influenza, conjunctivitis, gastroenteritis)
- Wear a mask during face to face visits when asked to by staff/volunteers or let them know if you are unable to wear a mask
- Notify us if your contact details change
- Meet the terms of Muscular Dystrophy Queensland's Service Agreements in terms of payments and proactively address any invoicing issues
- Let us know if you are having issues with our services or the staff providing those services so we can resolve them. You can give feedback or complaints to a staff member, the CEO or via our feedback form (see p28)
- Speak with respect within the neuromuscular community about Muscular Dystrophy Queensland as a service provider
- Direct any concerns to us via the feedback and complaints system

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 policies including incident management, feedback and complaints, privacy, informed consent and infection control. We also have policies and processes which cover all of our work with clients and families.

You can find more detailed information about our policies at www.mdqld.org.au/our-policies.

If you would like to discuss our policies and processes further, please contact us.

Incident Management

Muscular Dystrophy Queensland (MDQ) is committed to providing services in a safe and competent manner and ensuring that incidents which occur in relation to the provision of services are managed consistently and effectively, and that workers can identify, manage, report and resolve incidents.

We take a risk-based approach to our services with the goal of lessening risk. We are determined to continually improve the safety and quality of our services.

Muscular Dystrophy Queensland promotes a culture of open reporting. All workers, clients and others are encouraged to report any incident or alleged incident and there will be no negative consequences for doing so. Those involved have the right to information and input throughout the investigation and reporting process, and to a support person.

What should be reported

Any incident involving a client of MDQ that has occurred during the provision of MDQ services that has caused harm (or could have caused harm) should be reported. This includes:

- Injury (minor, major or potential)
- Death
- Abuse or neglect
- Emotional trauma
- Sexual misconduct or inappropriate behaviour
- Unauthorised restrictive practice
- Security incident
- Damage to property or the environment

Immediate action should be taken to remove or minimise danger to clients, staff and witnesses. Emergency services will be called and first administered if required. MDQ staff will report any incident to their supervisor or manager who will complete MDQ's incident investigation process. Those involved have the right to information and input throughout the investigation and reporting process, and to a support person.

Supporting clients

Throughout the incident management process, from initial response through to review, clients will be supported by the organisation through means of:

- Reassurance if a client or family member was involved in or reported the incident
- Where required, trauma and counselling services
- If necessary, changes to regular supports
- Clear, ongoing communication regarding the progress and outcomes of the investigation.

Clients will be involved in the management and resolution of the incident where appropriate including ongoing information as incidents are being investigated, copies of reports and notification of any changes as a result of the investigation

Assessment and investigation

Following a report from a worker, client or member of the public, the relevant supervisor or manager is responsible for creating an initial assessment of any incident. They will determine the severity of an incident and establish the need for, and scope of, an investigation. The matter may be referred to the manager or CEO, based on the type and seriousness of the incident. Minor incidents can be managed internally.

If the incident happened in connection to an NDIS service and is classified as a Reportable Incident, Muscular Dystrophy Queensland will also report the incident to the NDIS Commission. NDIS reportable incidents include:

- The death of a person with disability
- Serious injury of a person with disability
- Abuse or neglect of a person with disability
- Unlawful sexual or physical contact with, or assault of, a person with disability
- Sexual misconduct, committed against, or in the presence of, a person with disability, including grooming of the person with disability for sexual activity
- Unauthorised use of restrictive practices in relation to a person with disability.

The NDIS Quality and Safeguards Commission also has a Participant Fact Sheet about this.

Incidents involving criminal allegations will be reported to law enforcement, who will receive full support of the organisation in their investigations.

Whenever an investigation into an incident is conducted, it should establish:

- Participants in the incident
- The cause of an incident
- The effect of an incident
- Any organisational processes that contributed to or did not function in preventing an incident
- Changes the organisation can make in order to prevent further incidents from occurring

Information related to incident investigations, including records of phone conversations and face to face interviews, emails and documents will be recorded and kept in strict confidence. The organisation keeps an accurate register of all incidents that occur in relation to the provision of Muscular Dystrophy Queensland's services. Records will be kept for a minimum of seven years for an adult and for seven years post a child achieving adulthood.

Incident resolution

Based on MDQ's assessment, the organisation may undertake remedial action proportionate to the severity of the incident, including but not limited to:

- Providing an apology
- Disciplinary action
- Offer of psychological and emotional support
- Financial compensation

The organisation collects and reviews data on incidents to inform improvement activities. The Chief Executive officer regularly reports incidents to the Directors and also provides an annual report addressing incidents – how they have been managed and actions which have been taken to continually improve practice as a result of the learning from incidents.

You also have the right to report incidents to appropriate external agencies and we will ensure that you are treated with respect and without retribution.

Muscular Dystrophy Queensland's full Incident Management policy is available on request.

Feedback, Complaints and Resolution

Muscular Dystrophy Queensland 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.

We are 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.

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?

- Have a conversation with a Muscular Dystrophy Queensland 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 Feedback form is available on our website: www.mdqld.org.au/feedback-and-complaints
- You can email the CEO at info@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 and suggestions for future programs
- 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 the complaint handling process so where you have a need, we will assist you in making a complaint. Muscular Dystrophy Queensland 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 does not argue the case on behalf of the person making the complaint.

Once my feedback is received, what happens?

Muscular Dystrophy Queensland 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 can happen and if we are in the wrong, we will apologise for them and take steps to prevent them in the future
- Clarification through information provided to the person complaining
- Changes in the processes which Muscular Dystrophy Queensland follows
- Staff training

- Reallocation of a client to another team member for service provision (if possible)

We will also communicate our actions in writing to the complainant and ask if they are satisfied to consider the complaint resolved.

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 Muscular Dystrophy Queensland 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 (Muscular Dystrophy Queensland 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 www.acnc.gov.au/contact-us
- Queensland legal system
- As a whistleblower for matters of public interest or misconduct. (Muscular Dystrophy Queensland also has an [information sheet](#) about making a complaint as a whistleblower)

How does Muscular Dystrophy Queensland 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. We are committed to continually improving all aspects of our service.

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.

Muscular Dystrophy Queensland's full Feedback, Complaints and Resolution policy is available on request.

Privacy

Muscular Dystrophy Queensland 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 visiting www.oaic.gov.au

To provide programs and services, Muscular Dystrophy Queensland 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 with the consent of the individual
- protect sensitive information
- ensure that people know what sort of personal information is held, what purposes it is held 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, Muscular Dystrophy Queensland 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. Muscular Dystrophy Queensland 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. Where parents share custody of a child, we will undertake to source consent from each parent.

How Muscular Dystrophy Queensland collects personal information

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

- Through a call to Muscular Dystrophy Queensland'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 Muscular Dystrophy Queensland's fundraising campaigns

What information is stored?

Only personal information that is needed is stored. Muscular Dystrophy Queensland requires personal information to:

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

Muscular Dystrophy Queensland 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 us. 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.

Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland'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
- Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland 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 our records. We may ask questions to verify identity in this process.

Access may be denied if we 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 Muscular Dystrophy Queensland anonymously or use a pseudonym instead of your personal details when engaging with us, 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, however, this will impact the services that we will be able to provide to you. Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland.

What happens when you share personal information online?

The Muscular Dystrophy Queensland website may use cookies to track site visits, navigate within Muscular Dystrophy Queensland 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 our website, Facebook or other social media sites, you are providing implied consent.

Cyber security

Muscular Dystrophy Queensland treats the security of our data and that of our stakeholders as a high priority and has cyber security policy and procedures in place and a data breach response plan. Please contact us if you would like any further information about cyber security.

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 Muscular Dystrophy Queensland's Privacy Officer (details below).

Muscular Dystrophy Queensland 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).

Muscular Dystrophy Queensland's full Privacy Policy is available on request.

Contact Details

Privacy Officer
Locked Bag 3000 Eagle Farm BC 4009
Telephone: 07 3243 9700 or 1800 676 364
Email: privacy@mdqld.org.au

Informed Consent

Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland services and is obtained through the completion of our Consent Form.

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

Who can give consent?

- An adult client of Muscular Dystrophy Queensland. 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, Muscular Dystrophy Queensland 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. Muscular Dystrophy Queensland 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. Where parents share custody of a child, we will undertake to source consent from each parent.

What does Muscular Dystrophy Queensland need consent for?

Consent to provide services: Muscular Dystrophy Queensland 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, Muscular Dystrophy Queensland 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) Muscular Dystrophy Queensland 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 written consent via our consent form which allows 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 of you and digital media can be used. Muscular Dystrophy Queensland may wish to use photos, video and media for:

- assessment, treatment or your NDIS goals
- educational purposes
- Muscular Dystrophy Queensland 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 Muscular Dystrophy Queensland.

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 consent at any time.

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

Infection Control

Muscular Dystrophy Queensland is committed to the health of our clients, staff/ volunteers and other stakeholders. We recognise that many of our clients are particularly vulnerable to respiratory and other infections.

Muscular Dystrophy has an Infection Control Committee that closely follows advice issued by Queensland Health and sets on appropriate measures that use this advice as a minimum standard. We may at times adopt measures above and beyond those recommended by Queensland Health if we believe it is in the best interest of our clients. Measures may include:

- Enhanced cleaning
- Mandatory handwashing/sanitisation
- Social Distancing
- Limiting physical contact
- Use of protective personal equipment (PPE) such as masks, face shields, gowns and gloves as appropriate to the service being provided
- Pre-visit wellness questionnaires

We recognise that many of our clients are particularly vulnerable to respiratory and other infections. Our staff will be happy to wear a face mask if you ask them to, even at times that this is not a requirement..

How you can help

- Answer pre-visit questionnaire truthfully and let us know if your situation changes.
- Cancel face-to-face appointments if you or a household member has an infectious disease (e.g, Covid-19, influenza, conjunctivitis, gastroenteritis).
- Wear a mask during face to face visits when asked to by staff/volunteers or let them know if you are unable to wear a mask

We're stronger **together**



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