



MUSCULAR DYSTROPHY QUEENSLAND

1149 SANDGATE RD, NUNDAH
(07) 3243 9700 • 1800 676 364



MUSCULAR DYSTROPHY QUEENSLAND NDIS READINESS WORKSHOPS

MDQ is continuing to host NDIS Readiness Workshops and will endeavour to get the word out to each region as the NDIS rollout starts across Queensland. Our next stop will be Toowoomba on the 18th June. With the NDIS coming to Toowoomba and west to the border as of 1st January 2017 this will be an important opportunity to find out how the NDIS will affect you. Topics discussed in the workshops are constantly being updated so that they are relevant.



People are telling us that they have learned useful information from the workshops and feel more knowledgeable and less stressed about the NDIS. Our workshops are tailored for people with neuromuscular conditions and are not limited to clients of Muscular Dystrophy Queensland. There will also be time available for individual meetings with our Case Management Officers around the time of the workshop. Be sure to book in a time for this valuable service.

Call Muscular Dystrophy Queensland to book into the NDIS Information workshop; to arrange an individual meeting with your Case Management Officer; or to have help with preparing for your NDIS Plan. We love to help!

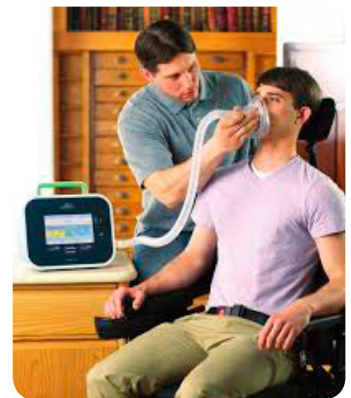
We are also in the process of organising trips to Mackay and Townsville in June/July 2016. We will let you know when dates are confirmed.

COUGH ASSIST PROGRAM

Winter is coming... though you may not have noticed yet with the warm weather remaining with us throughout Queensland! It is however, the season for colds and flu - a time that can be particularly dangerous for anyone who lives with reduced respiratory function.

The CoughAssist machine works by simulating a cough which can help clear secretions from the lungs without the need for suctioning. It can be used in your own home and has been proven to reduce the risk of hospitalisation due to infections or pneumonia.

Muscular Dystrophy Queensland has negotiated with Philips Respironics to make CoughAssist machines available to our clients for a reasonable cost through a rental agreement. We are also aware renting equipment (even at a reduced rate) may be out of reach for some of our families and we do not want anyone who needs this equipment to miss out. For this reason, MDQ has established a fund to cover the rental cost for families who are unable to do so.



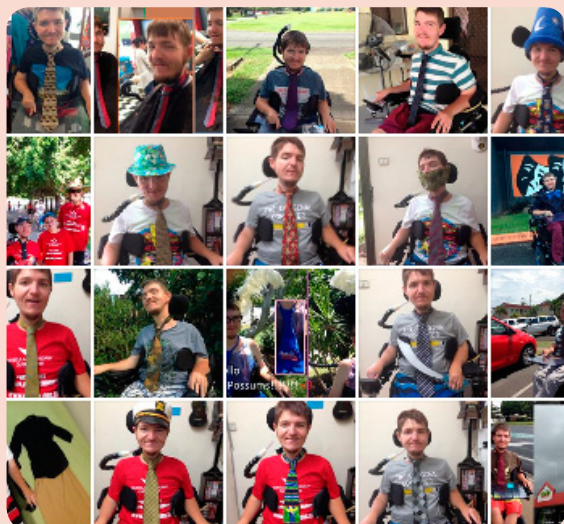
Please contact us on 07 3243 9700 if you would like more information or need to rent a CoughAssist machine.

THANKS DOUG!

Our ambassador in Cairns, Doug Robins, has been raising awareness as well as funds for the MDQ CoughAssist Program by wearing a tie a day in the lead up to his new stage play opening in 2017. He's already 6 months in - that's over 150 ties and still many more to come!

Doug has advanced Duchenne muscular dystrophy and believes the ties are symbolic of his journey with Duchenne; the tie representing the 'ever-tightening noose' of throat and chest weakness that can cause problems with breathing, swallowing, coughing or choking. Doug uses a CoughAssist machine and knows just how beneficial they are. He wants to make sure that everyone who needs a CoughAssist machine will have access to one.

You can check out Doug's 'tie of the day' by following his facebook page www.facebook.com/Atieperdayuntiltheplay



WINTER WARMERS

We are incredibly fortunate to have a group of wonderful and generous ladies who have spent countless hours sewing quilts for our families. Bette was inspired one cold night at the footy to make quilts for wheelchair users and very generously offered to make some for our clients. Her idea has snow-balled and now several groups are supplying beautiful quilts. Some are specifically designed for use while in a wheelchair whilst others are a traditional square or rectangular shape. They have also started to make fleecy ponchos which are warm and easy to use and cut short in the back for wheelchair users.

Please let us know if you'd like any of these items and we'll try to get one out to you.



CARING FOR CARERS

Carer Gateway is a national online and phone service that provides practical information and resources to support carers. Caring for someone can be rewarding, but it can also be hard work. The good news is that there are people and organisations who can support you. The Carer Gateway helps carers connect to local support services. Visit www.carergateway.gov.au for lots of helpful information or free call 1800 422 737 for support and advice Monday to Friday 8am to 6pm.

The Carer Gateway is the first stage of the Australian Government's New Integrated Plan for Carer Support Services. The next step is to develop the new Carer Support Service System that aims to deliver provisions that reduce carer strain, increase carer well-being and assists carers to continue in their carer role. A draft Service Concept has been developed through research, workshops with carers and input from the Carer Gateway Advisory Group. The draft Service Concept sets out the types of services that could be delivered under a future Service Delivery Model. The Government is asking for YOUR thoughts and ideas on the proposed draft by Thursday 2nd June, 2016. So why not have your say via www.engage.dss.gov.au

We care too! If you need help please call us - our Case Management Officers will do their best to help you find a solution.

ATM SAFETY ALERT



We were recently contacted by one of our clients, a wheelchair user in her 60's, who had her card and cash stolen when using an ATM. It was a public location in the middle of the day. Many people may be seen as a "soft target"... are you alone, in a wheelchair, elderly, a mum with a pram...many of us will fit into one or more of these categories.

Police advice is to only use an ATM within a bank vestibule or alternatively get cash out through the supermarket and be aware of your surroundings - some good advice for us all!

WHAT YOU CAN DO TO PREPARE FOR THE NDIS

When the NDIS comes to your area, an NDIS planner will discuss your goals; what you think your reasonable and necessary supports should be; and what outcomes you wish to achieve with the funds allocated to you in your NDIS package. If you are not currently receiving a support package from Disability Services you may need to contact the NDIA to make sure they are aware that you need support. A little preparation now will help the whole process run more smoothly for you and you will be less likely to miss something important.

- Ask the question, am I eligible for an Individual Funding Package (plan) under the NDIS? You can call your Case Management Officer at Muscular Dystrophy Queensland and go through the eligibility criteria if you are unsure.
- If you believe you are eligible, it would be a good idea to check whether you are registered with Disability Services. This helps them to know how many people will be entering the NDIS. Again your Case Management Officer can help.
- It is not too early (or too late) to start preparing for your planning meeting with the following steps:
 - Buy a notebook or make a spreadsheet and list ALL your funded supports and the sources of that funding e.g. for support workers, household assistance etc. You also should list other supports you might be receiving which are related to your disability e.g. taxi concessions, travel allowances.
 - Then list all of your free supports and services - these might be performed by family and friends and don't forget to consider supports provided by not-for-profit organisations such as Muscular Dystrophy Queensland. You may have a hi-lo bed through MDQ's free rental scheme and the hours that an MDQ Case Management Officer spends with you will also need to be included in your package when you have your plan.
 - Think about the gaps in your life now. We know that some of you have significant reasonable and necessary needs now, just to live a basic life and yet receive absolutely no funding. Some of you may think that your funding package is inadequate and there are gaps in it which the NDIS may fill.
 - Make some goals - you can start by asking yourself where you want to be in one year; in three years. The NDIS plan is structured to provide reasonable and necessary supports for outcomes that you wish to achieve. This can be a bit complex so call the MDQ Case Management Officers to ask lots of questions.

NDIS AND MUSCULAR DYSTROPHY QUEENSLAND'S SERVICES

The NDIS has come to Queensland. This is so exciting and a little bit scary too. Everyone is preparing for it – our clients and also our organisation. As the NDIS is rolled out, funding will be allocated directly to our clients and they will then buy services from providers (including Muscular Dystrophy Queensland) with that funding. Your level of funding is determined by what you include in your NDIS Individual Funding Package – your NDIS Plan!

Muscular Dystrophy Qld is preparing for the NDIS by re-shaping our current case management services so our clients can include them in their NDIS Plans. We are also adjusting to the situation where we will be directly charging our clients for services rather than receiving government funding to provide those services.

Currently, our Case Management Officers (CMOs), Nic Velez and Maryanne Dover provide your services. Nic and Maryanne respond to your urgent needs and support you when a situation arises, such as a progression in your condition. They stand up for you and link you into funded services in Health, Disability and Education. They also try to contact you to check on how you are going and whether you have needs which they can assist you with, which will improve your access to services or to your quality of life.

Our Case Management Officers at Muscular Dystrophy Queensland are here to help you to prepare for your NDIS plan and to receive reasonable and necessary supports under the NDIS.

Just call us on **1800 676 364** or **3243 9700** or email **info@mdqld.org.au**

We are all getting used to the new language of the NDIS.....

In the NDIS, Muscular Dystrophy Queensland will provide

- Support Connection
- Coordination of Supports
- Life Transition Planning
- Plan Management Provider
- Equipment

Support Connection: Strengthens your ability to connect with information, mainstream and funded supports, and assists you to participate in the NDIS as independently as possible.

Support Coordination: This is the core of Muscular Dystrophy Queensland's current work and includes assistance for you to coordinate supports in a complex service delivery environment with supports from a range of sources. It includes support in times of crisis and once we help you to overcome the crisis, to safeguard your future.

Life transition planning: This includes mentoring and peer support to plan for your future needs.

Plan Management Provider: Muscular Dystrophy Qld can act as a financial and services support to help you to develop your skills in managing your plan. If you want Muscular Dystrophy Queensland to help you by being a Plan Management Provider, you will need to include that in your Plan. There is a separate article in the Client Update about what this service looks like.

Equipment: MDQ will continue its hi-lo bed program. Those people who already have a hi-lo bed on long term loan from Muscular Dystrophy Qld can continue to use the current bed, even if you have access to an NDIS Plan, you do need to call us when you are preparing for your meeting with your planner, because we will be asking you to include repair costs in your Plan.

If you are eligible to have an NDIS Plan and you wish Muscular Dystrophy Qld to continue to provide your case management services for you, we need to have a conversation with you as you are preparing for your planning meeting. You will need to include in your plan, some hours for the programs we are going to provide under the NDIS. We can help you with this.

Muscular Dystrophy Queensland will continue to provide some charitable services.

NDIS is just a part of our work. Our focus is on you as our valued client, not just the business of the NDIS!

Our charitable services will include:

- Information and support through our website and Helpline
- Case management services (similar to the NDIS services we talked about) and hi-lo bed program for people who are not eligible for an NDIS Plan e.g. over 65 years, immigrants, people with milder disabilities.
- Linking people who can support each other through friendships.

YOU HAVE YOUR NDIS PLAN...WHAT NEXT?

Now you have your NDIS Plan and access to some money to employ your supports. What next?

As an NDIS participant, you can choose how to manage the funding for the supports in your plan. When you meet with your NDIS planner to develop your plan, you will need to decide which plan management option is right for you.

You can choose one or more of the options below, from totally managing your Plan to employing a Plan Management Provider to assist you.

Self-managed: You (or your nominee) will be responsible for finding and organising your supports, making payments to your chosen providers, managing your budget, and keeping all records of your plan purchases.

Plan Management Provider: You can employ a registered plan management provider such as Muscular Dystrophy Queensland who will assist you in increasing your skills in self-managing your NDIS Plan; paying providers and processing expense claims; coordinating the provision of support; sourcing providers; developing monthly statements and claiming from the NDIA. You can employ your Plan Management Provider as purely a financial support or as a financial and service support. If you need further information about this, call MDQ on 07 3243 9700.

National Disability Insurance Agency (NDIA): You can choose the NDIA to pay registered providers on your behalf.

Combination: You can choose a combination of the above options.

This is complicated but we can help you to understand the options. Just call us on 07 3243 9700 or email info@mdqld.org.au

WHEN WILL I GET THE NDIS

The NDIS is being introduced in stages, because it's a big change and it is important to get it right and make it sustainable. Existing service users and new participants will enter the NDIS progressively. In Queensland, the NDIS will be rolled out geographically. People will move to the NDIS at different times depending on where they live.

Existing Commonwealth and state-based services and supports will continue until eligible people start their plans with the NDIS.

NOW

- Palm Island
- Under 18's in Townsville & Charters Towers

1st July 2016

- Remainder of Townsville & Charters Towers
- Hinchinbrook, Burdekin, west to Mount Isa, and up to the gulf

1st November 2016

- Mackay, Isaac and Whitsundays

1st January 2017

- Toowoomba and west to the borders

1st July 2017

- Ipswich, Lockyer, Scenic Rim and Somerset

1st October 2017

- Bundaberg

1st January 2018

- Rockhampton, Gladstone and west to the borders

1st July 2018

- Brisbane
- Cairns, Cassowary Coast, Tablelands, Croydon, Etheridge, Cape York and Torres Strait
- Gold Coast and Hinterland
- Logan and Redlands
- Fraser Coast, North Burnett, South Burnett and Cherbourg

1st January 2019

- Moreton Bay including Strathpine and Caboolture
- Sunshine Coast, Noosa and Gympie

If you are unsure about when the NDIS will come to your region, you can enter your postcode or suburb on the Department of Communities website www.communities.qld.gov.au or call our office on 07 3243 9700 and we should be able to assist you.

ACCESSIBLE VAN FOR SALE

One of our families has a second-hand accessible van for sale. The vehicle is a 1994 Toyota Hiace (long wheelbase) Commuter bus. 175,500km (Aprox), Petrol, Manual. 5 seats (3 in front and 2 on side) and two wheelchair positions with tie downs and a rear loader. **\$5,000 ono.**

Contact Peter on 07 3353 3521 or 0429 069 737 if you are interested.

Please note: Items advertised are for private sale and MDQ cannot guarantee the quality of items or the accuracy of descriptions.



Did you know that we post regular updates on the NDIS, community events and news stories that may be relevant to our clients. It is also a great opportunity to have your say and share information with others. If you haven't already done so, just search for Muscular Dystrophy Queensland from your facebook profile and "like" our page to receive all the latest from MD Qld in your news feed.

DISABILITY LOOP

Disability Loop is a website that has been launched in an attempt to give people with disability and their families information about the National Disability Insurance Scheme (NDIS) that is up to date, easy to find and easy to use.

Disability Loop differs from the NDIS website as it is run by people with disabilities and was created for people with disabilities and their families. It also integrates information from a range of other disability-related websites, rather than solely focusing on the NDIA's webpage.

Disability Loop features stories told by people living with disability about their experiences with the NDIS. Have a look for yourselves, go to www.disabilityloop.org.au

HI-LO BED PROGRAM

Our Hi-lo bed loan program continues to be one of our most requested services and Muscular Dystrophy Queensland is committed to providing beds for clients who need them.

MDQ provides a Hi-Lo Adjustable bed for clients based on an assessment by an Occupational Therapist. These beds remain with the client for as long as they are required on a long-term loan basis. When no longer required, the beds are refurbished and returned to the loan pool.

Demand is high for this equipment and funding changes over the past years have sometimes restricted our ability to fill all requests for beds. Beds will always be allocated according to priority of need. Please know that we are constantly looking for extra funding sources and will never keep you waiting longer than necessary.

With the introduction of the NDIS to Queensland, it is probable that there will be changes to our Hi-Lo bed loan program. If you have a bed from MDQ it is necessary that you contact us before you go into your NDIS planning session.



NO INTEREST LOAN SCHEME

Did you know that Muscular Dystrophy Queensland offers a No Interest Loan Scheme (NILS)?

Loans may be used to purchase essential items such as medical equipment, educational needs or household items such as a refrigerator, washing machine or air conditioner, vehicle repairs etc. but cannot be provided for ongoing living expenses such as rent, groceries, payment of bills or debt consolidation.

You can apply for \$200 to \$2000 and loans are available for a term of 2-24 months.

Contact Marianne Hall for an application form if you are interested in applying for a NILS loan.

RED BOW MONTH CELEBRATIONS



Muscular Dystrophy Queensland holds its biggest fundraising and awareness campaign in March each year, sending out collection boxes to businesses all around Queensland and taking to the streets of Brisbane on Red Bow Day. This year we once again promoted the Morning Tea for Muscular Dystrophy so that everyone could get involved in the Red Bow celebrations.

RED BOW DAY

Once again the Year 11 Girls from All Hallows School hit the streets in the Brisbane CBD to collect donations and sell our Red Bow merchandise. This is our biggest fundraising event of the year bringing in over \$17,000! An enormous effort and we are very grateful for the girls' enthusiasm which helps to make it such a successful day.

MORNING TEA FOR MUSCULAR DYSTROPHY

During March we put out the call for people to host a Morning Tea for Muscular Dystrophy. People from around the State met together to eat cake and raise money and awareness. MDQ hosted our own morning tea in Nundah and had a lovely morning catching up with local families. Thanks to all the families and businesses that hosted a Morning Tea for Muscular Dystrophy during March. Thanks to your wonderful support we have raised over \$2500 that will help us to provide services for clients from around Queensland.



Just because March is now over doesn't mean that the fun should stop. If you would like to host a Morning Tea or have an awareness event at any time of the year just contact us at events@mdqld.org.au to see how you can get involved.