



MUSCULAR DYSTROPHY QUEENSLAND

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MUSCULAR DYSTROPHY QUEENSLAND LAUNCHES NEW HELPLINE

Muscular Dystrophy Queensland has just launched a new Queensland Helpline.

The Helpline is available to anyone in the community who needs information about neuromuscular conditions. Our friendly staff will be on hand to answer questions and direct you to other accredited information sources. If we don't know the answer, we will find out and get back to you.

So you can tell your family, friends, teachers, and health professionals that they can call 1800 676 364 and ask any questions that they may have about neuromuscular conditions.



NDIS TO LAUNCH IN TOWNSVILLE, CHARTERS TOWERS & PALM ISLAND 2016

The National Disability Insurance Scheme (NDIS) will progressively rollout across Queensland over three years from 1 July 2016 to June 2019. The scheme will launch early in North Queensland ahead of the three year rollout. From April 2016 children and young people aged under 18 years in Townsville and Charters Towers, and all eligible people with disability on Palm Island will be the first Queenslanders with disability to access the NDIS.

The early launch will be available to anyone who meets eligibility requirements and is not just for people who currently receive a disability support service through the Queensland Government. You may be eligible for support through the NDIS even if you are not registered with Disability Services. Please contact your MDQ Case Worker on 07 3243 9700 if you have any questions about the NDIS.

TOWNSVILLE VISIT

In preparation for the early NDIS rollout, CEO Helene Frayne and Case Worker Maryanne Dover made the trip up to Townsville to meet with clients and to host an NDIS readiness workshop.

We are very grateful for the funding we receive from the ANZ Staff Foundation to be able to visit families in regional Queensland which is particularly important in the leadup to the introduction of the NDIS in the Townsville region.



We had great feedback from the clients who attended the workshop, everyone there said that it had increased their knowledge of the NDIS and they were keen to get started on the planning workbook which was discussed during the session.

The trip was also an important opportunity to provide face-to-face casework with many clients from the region. We were able to connect with more than half the clients from the Townsville region with some clients even travelling to Townsville from further out specifically to connect with us and learn more about the NDIS.

NDIS ADVISORY GROUP

MD Qld is committed to continuing our NDIS Advisory Group. The group consisted of clients, parents of clients, MD Qld Staff and board members who met to discuss the priorities and expectations of clients and their families as well as how MD Qld may be able to provide the services that you want and need once the NDIS begins rolling out in July 2016.

We are thankful for all the attendees' involvement and look forward to future discussions. We value all our clients input and would love to hear from you, so please contact us if you have any suggestions or concerns that you would like to share.

TAKING THE TRAIN HOME - by Doug Robins

As the recipient of the first Access Arts Achievement Award, for his powerful stage performance in 'Propelled' Doug was flown to Brisbane to collect his award. This is his story of the journey home...



A long train journey was always on my bucket list so I chose to come home to Townsville on my own dime aboard the Spirit of Queensland.

It took a couple of hours to speak to Queensland rail about the measurements of my wheelchair and confirm logistics, but after handing over \$300 for both myself and my mum (a bargain I say), there was no turning back - we were taking the sleeper carriage home to Cairns. We knew it would take 24 hours.

The maxi taxi dropped us off right at the Spirit of Queensland platform at Roma Street transit station. I hadn't done enough research obviously because there were a couple of surprises.

First, unless you have a much skinnier/collapsible wheelchair, it can't travel in the sleeper carriage with you. So after taking my seat in carriage C, mum had to drive my power wheelchair back out to the platform and up into carriage E.

My mum and the steward, the very gracious Alistair, used the Here-to-There chair to drag me downhill from my wheelchair into my seat. The reclining armchair style seat was not uncomfortable with the addition of a few cushions and bolsters. Each seat /pod also had a reading light, USB port and power socket to charge your phone or run your v-pap machine at night. My daytime ventilator circuit snapped onto the arm of the chair so I could sip breaths, given that I was not so stable in this unfamiliar seat. Much larger than an airplane seat, it also had a foldout table for meals. Before the train departed we were given a cool ginger ale as a welcome drink and a toiletry gift bag.

A nice surprise was the dickie seat that folded out of the back of the armchair in front. This meant mum could sit across the table from me and help me with meals... speaking of meals...three course meals (alternate drop) were delivered three times a day and were so filling that we didn't go to the dining car once. Behind our seats was a fully accessible toilet and shower, drinking fountain and racks for all our carry-on luggage. Having no shower chair with us, I managed with my urinal for the 24 hour journey.

The second surprise was that the staff used a remote control to transform the seat into my bed. To do this, you couldn't be sitting in your seat. With Alistair and another staff member's help I was shifted across to mum's bed (already made up) where I would plug in my v-pap machine and sleep for the night covered with a soft, warm doona. Meanwhile my seat could be converted into Mum's bed. This worked fine but only because the staff didn't mind helping mum lift me despite their 20kg lifting limit. I am 60kg so the three of them managed to use the here-to-there chair to put me in the collapsible wheelchair onboard the carriage, then slid me into the bed. In the morning we did things in reverse. Mum did adjust me a couple of times, but on the whole we both got a good night's sleep.

Next time, knowing the situation with the seats/beds, we would take another person with us so that we could be totally independent with transfers, although people were happy to help. It would also mean that I would be able to try the toilet and shower, which Mum couldn't manage without both a second person or hoist.

The scenery whizzed by because the ride itself was not at all rough or noisy. The entertainment unit embedded in the seat-back in front meant that we had some quality films and TV series to watch even if not the latest releases.

The day/night went pretty fast and Alistair, the steward, was endlessly patient and friendly. It was nice to be home but I really enjoyed the experience of travelling by train, for something different, something from another era, even if it did add an extra day to our trip away. I would recommend travelling on the Spirit of Queensland but would advise in hindsight that you make it even easier by travelling with two AB carers (not just one) and a collapsible commode chair. We managed easily only because we had a urinal, a trusty here-to-there chair and friendly Queensland Rail staff who were amenable to helping transfer me to bed. I may not have thought of everything, but no one was harmed in the pursuit of this experience - especially me!



We thank Doug for sharing his experience with us and hope that it may make it a little easier for anyone else considering a long train journey to plan their trip...and a hearty congratulations from everyone at MDQ for winning the Achievement Award!

SPECIAL THANKS

We'd like to send out a big thank you to everyone at Clifford Gouldson Lawyers in Toowoomba. They had their annual Artist in Residence Program with the talented Laura Douglas. The evening was incredible and we're overwhelmed with their generosity towards our organisation. From everyone here at MDQ and on behalf of all the families we support - Thank you for selecting us as your charity this year.

CHRISTMAS GATHERINGS

Don't forget to RSVP if you are planning to come along to one of our Christmas gatherings. We hope you will come along and share some food and friendship as we celebrate the Christmas season!

BRISBANE: Come and join us for our South East Queensland Client Christmas Party which will be held at The Community Place in Stafford on Sunday 29th November.

CAIRNS: Friends, families & supporters of Muscular Dystrophy Queensland are meeting for a Community Christmas Party at the Cairns Esplanade Fun Ship Parkland on Saturday 5th December.

BUNDABERG: The Coral Coast Muscular Dystrophy Network are meeting for Christmas Lunch at the East Bundaberg Sports Club on Saturday 12th December.



WEAR RED FOR MUSCULAR DYSTROPHY

Next year, Muscular Dystrophy Queensland is aiming to inspire schools across the state to hold a free dress day and "Wear Red for Muscular Dystrophy". Our aim is to raise awareness of muscular dystrophy and other neuromuscular conditions.

If you would like a brochure to give to your local school, please contact our events team on 07 3243 9700 or email events@mdqld.org.au.

WAYS YOU CAN HELP OUR MD COMMUNITY

Have you ever wondered how you and your friends and family can get involved to raise awareness and much needed funds for Muscular Dystrophy Queensland?

WEAR RED FOR MUSCULAR DYSTROPHY: Don't let the school kids have all the fun! If you would like to host your own 'Wear Red for muscular dystrophy' day please contact our events team on 07 3243 9700.

MORNING TEA 4MD: Muscular Dystrophy Queensland will again be encouraging everyone to participate in our 'Morning Tea 4MD' campaign which coincides with our annual Red Bow Appeal in March. Get out your recipe books and plan to host your own tea party or encourage your friends and family to get involved.

ART UNION TICKETS: Great prize packages are always up for grabs in our quarterly Art Union draws. How would you like a \$20,000 shopping spree at Harvey Norman, a dream holiday, or would you just take the gold? Tickets are only \$10 each and limited to only 10,000 tickets. If you'd like an order form for you or your family and friends, or maybe a poster to put up on your work notice board, please let us know.

SHANE WARNE NECESSITOUS CIRCUMSTANCES FUND

The Shane Warne Foundation Necessitous Circumstances Fund is able to help individual families and children who need funding for specialist treatment, custom made equipment, vehicle and home modifications and various other necessities to enrich their child's life, that they may not be able to get anywhere else.

If you think that your family may be eligible, the next funding for the NCF round starts in mid November 2015 with amounts of up to \$15,000 available for successful applicants. For further information go to www.tswf.com.au/necessitous-circumstances-fund



THANKS TO PAINT YOUR LIFE

A very special thanks goes out to the Paint Your Life Foundation for facilitating free art workshops on the Gold Coast for our clients.

The program ran from May through to November and was a real highlight for everyone who attended. It was a wonderful opportunity for clients and family alike to bring out their creative sides while enjoying the company of those around them. Particular thanks goes also to the volunteers who attended every session to help our budding artists.

ACCESSIBLE HOUSE FOR SALE - IDALIA

One of our families is selling an accessible home in Townsville, located at 10 Springbrook Pde, Idalia.

1070m2 flat block. Single level house (240m2) with ramped front entrance. 4 bedrooms/2 bathrooms/double car garage. Large open doorways and hallways. Large open bathrooms. Close to Oonoonba State School (a P.I. school zoned for children with physical disabilities).



If you would like any further information, please contact Tanya Stack from McGrath Estate Agents: 07 4781 0541/ 0437 434 056

MY PORT DOUGLAS STORY - By Lynda Brook

In 2011 I moved from Brisbane back to Townsville to be more involved with my daughters and grandson. I lived in a Housing Department unit for 18 months but over time the location became unsafe with many break-ins, assaults and abuse becoming daily occurrences within the complex. I felt especially vulnerable whilst recovering from an operation to remove a cancerous tumour in my leg which left me bedridden for a month and my body took several months to heal. I believed God, family, friends and faith got me through this frightening ordeal and I promised myself I that my life was going to change, living in fulfilment, harmony and finding my inner peace.

I had an opportunity to travel the following year in May with my Carer to Port Douglas for the town's Annual Carnivale, and then a couple more holiday breaks over a period of 12 months where I stayed in a wheelchair accessible apartment at the Ramada Resort.

I desperately researched and planned my move, I was determined to be in Port Douglas by Christmas 2013. I found it extremely difficult to find wheelchair accessible long term accommodation, (flat or unit) in a convenient location close to town centre and facilities so I returned to the Ramada for approximately 8 weeks while I continued my search.

Finally in January 2014, I moved into my own private rental unit which has 2 bedrooms and 2 bathrooms and is in a central location allowing me to make my own way into town and to other amenities. I subsequently had ramps made for the doors so I was able to have easy access. I have my lovable pet staffy terrier named Ellie who is my companion dog.

The next step was to find suitable new support workers and I presently have 3-4 local women helping me with my daily needs. I am able to employ these staff members through my self-directed funding which gives me freedom and choice.

To meet new friends with similar interests I did weekly art classes in Mossman which is approximately 14 kilometres from Port Douglas. I also got involved with the local Neighbourhood Centre which brought me in contact with local women of all ages and backgrounds. Since completing my art classes I have taken up private singing tuition with Alteouise who is a trained Opera singer originally from USA and been involved in events with the choir at various venues around Port Douglas, Mossman and Cairns.

In 2014, I petitioned the local Council and the Manager of the Clink Theatre to install a Ramp to allow accessibility for people with disability. This Ramp was completed in May 2015 and I was able to be involved in the production of the musical "Carmen" in September 2015. Currently I am in discussion with the Douglas Shire Council to install an accessible toilet at the Clink Theatre and also accessibility for people with disabilities and the elderly to Four Mile Beach.

Port Douglas is a picturesque village with majestic beaches and surrounding rain forests. I feel it has a spiritual and tranquil atmosphere which helps me to relax and be happy. It is a very special place, where I feel safe and secure, and enjoy a small friendly community environment which offers me a pleasant, laid-back lifestyle.

It is common to feel trapped in unsuitable living arrangements but Linda's story shows that it can be possible to make a change. We applaud Linda for being pro-active in petitioning for changes to make public places more accessible, opening up more opportunities for everyone in the community.

Having self-directed funding also opens up greater opportunities. Self direction of your individualised funding is available now through Your Life Your Choice throughout Queensland and the introduction of the NDIS as it rolls out over the next few years will hopefully create even greater opportunities for all people with disability.

If you need help to change your situation or would like to talk to someone about self direction, YLYC or the NDIS, please call our office on 3243 9700 and speak to one of our Case Workers



MDQ Case Worker Maryanne caught up with Linda in Port Douglas earlier this year.



SEASONS GREETINGS

It's been a busy year at Muscular Dystrophy Queensland. Our Client Services Team has been able to visit many of our regional clients with trips to Cairns, Townsville and Hervey Bay. We have also had the opportunity to meet even more clients at the Lady Cilento Children's Hospital whilst they are in Brisbane for specialist appointments at the Childrens Neuromuscular Clinic.

The introduction of the NDIS is bound to bring in some big changes as it starts up in the Townsville Region next year. Our goal is to ensure that all of our clients get access to the supports that they need. Remember we are here to help.

We wish all our families a happy and safe Christmas season and hope many of you will be able to join the Christmas gatherings in Cairns and Brisbane and Bundaberg.