Muscular
Dystrophy
Queensland

Can you help bridge the gap for people living with progressive conditions?

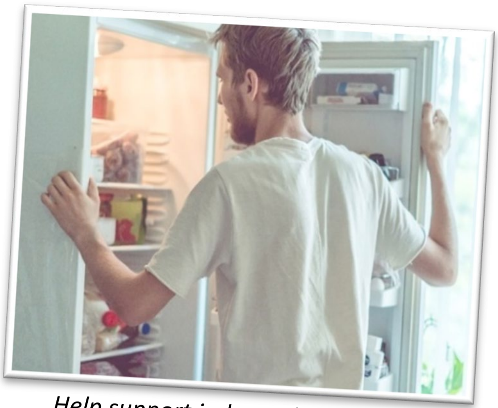
Every day we work with community members whose disability related supports are met via successful entry into the National Disability Insurance Scheme (NDIS). It is wonderful to see their lives transformed and to be part of the support network that enables people to take part in daily life, to work towards and achieve their goals. Even when those goals are as modest as cooking their own meal to keeping up with friends at school.

Of course, the NDIS doesn't offer all the answers. Entry into the scheme is a months-long process that is becoming increasingly difficult as the Federal Government works to 'reign in the scheme'. Funding plans assume people live with a stable disability, expecting people to increase their capacity over time – not well aligned to a progressive condition like muscular dystrophy and similar neuromuscular conditions. And family members, whose lives are so profoundly impacted when a loved one lives with disability, cannot access supports via the funding plan.

For all these reasons and many more, my wonderful team at MDQ works to address the gaps our community faces. Like Senior Occupational Therapist (OT), Zoe Matthews who recently shared with me her 'typical day at the office'. I was struck by how regularly Zoe calls on our free charitable programs and thought you would be interested to know the difference your kind support recently made for two of her clients.

«Salutation», let's keep working together to help people move past the hurdles they face, to strive for lives well lived. Your tax time donation to Muscular Dystrophy Queensland really can help local Queensland families managing the challenging progressions and the difficult times muscular dystrophy conditions can bring.

By the time Zoe met with Tony, he had lost all confidence in the kitchen and was feeling anxious and depressed. The sudden recent change in his condition had begun to take away his independence and he worried about what future progressions would bring.



Help support independence for people like Tony.

Muscular Dystrophy Queensland Ltd
Office: Unit 5, 2996 Logan Rd, Underwood Qld 4119
Post: Locked Bag 3020, Springwood Qld 4127
Freecall: 1800 676 364 **Phone:** 07 3243 9700
Email: info@mdqld.org.au **Web:** www.mdqld.org.au
ACN: 621 816 975 **ABN:** 14 908 553 738

Imagine for a moment being Tony. You wander into your kitchen to make a sandwich for lunch but struggle to open the fridge. Your strength and coordination have declined overnight but you struggle on. Finally, you get the door open and grab a jar of jam only to have it fall to the floor, shattering and creating a sticky mess, too hard to clean up.

At 44 years old, Tony felt too young to be losing his independence. The rare metabolic myopathy he had inherited typically creates challenges with upper limb strength and coordination, and loss of coordination that can result in increased falls. Zoe had been working with Tony to plan for the changes he might face.

Before heading to Tony's home that morning, Zoe prepared a group of aids he could trial. Working to improve his safety and maintain his independence in the kitchen, she gathered a range of equipment he could trial via our free charitable loan program, researched quotes for some bigger items like anti-slip mats and an induction cooker, and gathered a range of simple '5 ingredient or less' recipes to encourage Tony to maintain a healthy diet and weight, which would help him to maintain his functional abilities further. Eventually, this equipment would be funded under his NDIS plan, but Zoe wanted to ensure the equipment suited his needs before making her final recommendations.

Zoe pictured with items available for trial via MDQ's free equipment loan programs.

"I am trained as an OT to think holistically, to tackle a lot of different angles, goals, and needs, to support people like Tony be as independent as possible, focusing on their wellbeing, social access, engagement activities, and of course their safety in their own home," Zoe said.

As is often the case, Zoe pulled on her pseudo-counsellor hat to talk through the emotions Tony was feeling. Sometimes our team member is the only one there to listen, and so we do. As she listened, Zoe realised this recent event had really jolted Tony's mental wellbeing. Ideally, she would be able to refer Tony to a counsellor or psychologist to talk through the issues, but she knew this support was not funded in his plan and was out of reach financially on his meagre disability pension.

Thanks to our donors like you, MDQ was able to re-introduce our community connection events last year. It wasn't all that Tony needed but Zoe was grateful to have a possible solution to offer him.

Zoe encouraged Tony to give the next community connection event a try, not only to get out and about, but also to make some new friends who might be experiencing similar journeys, to talk through what they're facing, and not feel so alone.

She farewelled Tony and as she drove away, Zoe reset her focus for her next appointment of the day – Edward, a little 9-year-old boy who had been diagnosed with Duchenne MD.

For the last few months, Edward had been having trouble with long distances. They'd trialled a manual wheelchair, often a good first mobility device to ensure kids conserve their energy for their busy days at school and at home. Edward had found he still wasn't able to keep up, so they had also trialled a small mobility scooter for a few months. Edward is a bright young boy, who enjoyed school. Zoe felt he'd be better supported to keep up if he progressed to a power wheelchair.

Understandably, it's often hard for mums to accept the changes they see in their boys. Edward's mum, Robyn, had already expressed her fears to Zoe about him maintaining a 'normal childhood'. Rotating through mobility aides was a confronting sign that her little boy's condition was progressing, and she had heard horror stories from other mums about the months-long wait for such equipment to be approved for funding under the NDIS.

Working with our physiotherapists, Zoe arranged for Edward to trial a small power wheelchair available through our equipment loan program. With a few tweaks to the seating system, the chair was adjusted to suit Edward's posture and small body. A free loan for a few weeks would enable Edward to get the hang of these new wheels, before his mum, Robyn committed to purchasing the item from his limited support funding.

A free loan for a few weeks would enable Edward to get the hang of these new wheels.

These free charitable services available for kids like Edward, are entirely funded by the support of generous people like you.

Edward was excited to go for a spin. But the sight of her boy in his first powered wheelchair was too much for Robyn to bear. She tried hard to hide her tears from him.

Supporting mums through these emotional times is vital. Knowing Edward would be occupied and under the care of our physiotherapist, while he worked out the buttons and controls in his new chair, Zoe took the opportunity to whisk Robyn away for a chat. Robyn explained that she blamed herself for passing on the affected gene to Edward, which had caused his Duchenne. How she felt she couldn't put aside that nagging guilt nor her sadness for the loss for the things Edward would never get to do.

Family members, especially mums, often need a little extra support.

It can be isolating to experience such strong emotions and feel that you cannot confide in anyone. Unanswered questions creep into your thoughts. Kids with muscular dystrophy come with parents and siblings, grandparents, aunts, and uncles. They're all affected when a genetic diagnosis emerges in a family. Of course, these family members need our support too.

It's because we have the help of generous supporters like you that we can assist mums like Robyn when they needed it most. Your donation of $«Last donation amount» can make this difference for others.

That's why we've recently launched a new program, offering time with a social worker to help work people through all the challenging feelings and changing family dynamics experienced, from diagnosis, to progression, and at end of life.

Zoe recognised Robyn would be an ideal early participant for this program and talked about it as an option when the time was right. Through 1:1 counselling, Robyn will have the opportunity to talk through all the fears and worries that she has recently been experiencing with Edward's diagnosis and recent transitions. She will then have some time to reflect on what they discuss, before checking in again for some follow-up conversations.

It made all the difference for Tony, Edward, and Robyn, that Zoe was able to offer the support as soon as she recognised the need.

With help from generous Queenslanders like you, we're also expanding more community connection programs. This year, mums like Robyn will have the opportunity to attend a weekend getaway. Just two nights away from their caring routine, with some pampering activities thrown in, these retreats are designed to introduce mums with similarly aged children, with similar rare conditions. To build friendships and connect with a person who truly understands what they're going through. Facilitation by a social worker will ensure conversations occur in a safe, protective space.

We're also working to build programs for dads to connect. And of course, our school holiday day programs provide a great opportunity for kids with muscular dystrophy and siblings to meet other kids.

Your support this tax time makes a difference. Your gift, large or small, will enable us to continue to grow services to meet the ever-increasing demand for some of our most vulnerable community members.

Your support enables Muscular Dystrophy Queensland to be there for so many vulnerable people living with neuromuscular conditions and their families, when it is needed most.

Thank you for your wonderful generosity. Please know that you make a real, lasting difference for local Queenslanders living with neuromuscular conditions. We're stronger together.

Warm regards,

Penny Deavin
CEO

P.S. If an end of financial year donation is important for you, please pop your envelope in the post as soon as possible. Any mail received that is post marked on **30 June** or before will be receipted in the current financial year.

P.P.S. To protect the privacy of our community members, names and some identifying features have been changed including the use of stock photography.