

Talking Point

**MUSCULAR
DYSTROPHY**
NSW BUILDING STRENGTH
REACHING POTENTIAL

MUSCULAR DYSTROPHY NSW NEWSLETTER JULY 2020

AN UPDATE FROM OUR CEO

WELCOME TO THE JULY EDITION OF TALKING POINT. I HOPE THAT YOU ARE ALL STAYING SAFE AND LOOKING AFTER YOURSELF DURING THIS TIME.



We understand that this is a time of uncertainty and worry for everyone and that is why we want you to know that we are here to support you and keep you informed and updated with any relevant information. Talking Point will continue to be full of helpful information regarding COVID-19, NDIS, news and stories from MDNSW.

We are relieved to see that restrictions are easing in NSW.

We remind everyone to please continue to stay safe and follow government instructions.

As you know, all our face-to-face appointments, programs and services are now being moved online in order to ensure the health and safety of our members. This edition includes information on many virtual events we have coming up that you can participate in from the comfort of your home.

We encourage you to stay connected and help each other during this time.

We are also excited to announce The Loop is now live! The Loop is an online resource and forum built for the neuromuscular community by people living with neuromuscular conditions themselves. The details about how to access The Loop are in the newsletter.

We will continue to provide you with opportunities to connect with MDNSW and with members which enable our community to build strength and reach potential!

Please get in contact with one of our team members if you have any concerns or questions on **1800 635 109** (choose option 1 for Client Services).

Kind regards,

CHARLOTTE SANGSTER

Chief Executive Officer, Muscular Dystrophy NSW

CLIENT SERVICES

**MUSCULAR
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COVID-19
Communication
to Members

We have put together some useful information and resources on our website, which include health, mental health, NDIS information, resources for people living with neuromuscular conditions and more.

We will be updating our website regularly to keep you up to date.

If you have any concerns regarding COVID-19, please feel free to contact our Client Services Team on **1800 635 109** (choose option 1 for Client Services).

Visit our website for more information:

www.mdnsw.org.au/the-peer-collective/coronavirus-information

NDIS UPDATE

We 
ndis

NDIS has developed a range of new resources including animations and 'how to' articles to assist you with navigating the new plan changes and changes due to COVID-19.

Find further information and resources on their website www.ndis.gov.au/coronavirus

You can also find resources to assist you with your NDIS plan at www.mdnsw.org.au/the-peer-collective/ndis-toolkit

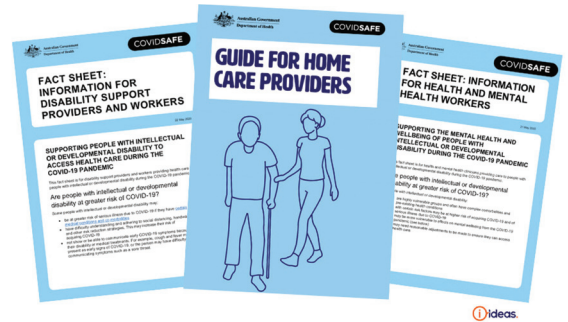
If you have any questions about your plan, please contact our Client Services team for assistance on **1800 635 109** (choose option 1 for Client Services) or email info@mdnsw.org.au

COVID SAFE FACT SHEETS

The Australian Government have put together a range of resources to assist people with disabilities during COVID-19.

There is a wide variety of information to support different groups of people, including individuals with a disability, home carers, support workers, health care providers and families.

Access these resources and more on the **IDEAS** website:
www.ideas.org.au/factsheets/covid-19-factsheets



The Disability Information Helpline is now available



Providing information and referrals for people with disability who need help because of Coronavirus (COVID-19).

The Helpline can help families, carers, support workers and services, too.

Contact the Disability Information Helpline on **1800 643 787**.

The Helpline is available Monday to Friday 8am to 8pm (AEST) and Saturday and Sunday 9am to 7pm (AEST). It's not available on national public holidays.

Visit www.dss.gov.au/disabilityhelp for more information, including Auslan and Easy Read materials.

The Loop

IS OFFICIALLY HERE!



The Loop
Your Neuromuscular Resource Hub

The Loop is a secure and informative website built by, and for, the neuromuscular community.

At The Loop you'll find a wealth of expert information about neuromuscular conditions, allowing you to understand and manage your condition at your own pace.

Customisable condition guides can help you process a new diagnosis or find more information. They are easy to tailor, download and share, so you can let the people in your life understand your condition.

In the Living Life section you'll hear from voices like your own. It's a place where members of our community can share experiences, hacks and advice from their experience of living with a neuromuscular condition.

The conversation is now open to join.

Check out some of The Loop's features;

- Create a personalised condition guide to communicate your needs
- Download and share your condition guide with your support network
- Share and get advice on everyday life stuff from your community
- Tell your story, share your experiences, create groups and connect with people on our forums

You can sign up today by visiting:
www.theloopcommunity.org

Concessions

Depending on the nature of your disability, you may be eligible for concessions or payments to help you with household and other expenses.

To find out more, visit 'The Peer Collective':

www.mdns.org.au/the-peer-collective/entitlements-and-concessions

Meet Chris, MDNSW staff member living with Ullrich congenital muscular dystrophy. Chris has had many outstanding achievements through his university experience.

Find out more about Chris' story at 'The Peer Collective'.

If you have a story you would like to share at 'The Peer Collective' send it to carolyn.cm@mdns.org.au and receive a \$50 gift voucher.



the peer collective

Peer Support

SAT
25 JULY
2PM

Virtual Meetup

SMARTIES

MDNSW is hosting a peer group event for people with Spinal Muscular Atrophy and their families.

Many people are facing the same challenges during this time, these groups are a great way to problem solve and share ideas.

Join us to meet new people, connect with peers and share information.

Contact Carolyn on **0408 472 510** or email carolyn.cm@mdnsw.org.au

WED
15 JULY
6PM

The Power Hour

via Zoom

If you are aged 18-30 and are a power chair user, we would love you to join us!

Contact Mitch on **0417 062 212** or email mitch.taylor@mdnsw.org.au

FRI
17 JULY
7.30PM

Mums Wine & Chat

via Zoom

This group is a chance for Mums to come together to share stories & experiences with each other.

Contact Joan on **0448 098 744** or email jenny.smith@mdnsw.org.au

FRI
10 JULY
11AM

Adults with MD

via Zoom

This group is for adults with MD, their partners, carers & friends.

This is a chance to hear about 10 ways to use your NDIS funding.

Contact Carolyn on **0408 472 510** or email carolyn.cm@mdnsw.org.au

COMING
SOON

Calling all Dads

We are hoping to create a
Dads Peer Support group

The aim of the group is to share challenges & experiences with other Dads in similar situations.

These groups will be online for now, but we hope to hold BBQ catch ups when it is safe to do so.

Contact Mitch on 0417 062 212 or email mitch.taylor@mdnsw.org.au

Contact and Feedback

We value your feedback!

If you have any feedback on what we are doing well or how we can do things better, please contact us.

Feedback, including complaints is an essential part of our improvement process.

You can provide your feedback through the following channels:

by post Muscular Dystrophy Association of NSW; 80 Betty Cuthbert Drive, Lidcombe NSW 2141

email info@mdnsw.org.au

phone 02 9888 5711 or

free call 1800 635 109

website mdnsw.org.au/contact-us

ARE YOU ELIGIBLE FOR A TRAVEL CARD?

In January 2020, a trial began for a new \$250 Regional Senior Travel Card. The prepaid card will let seniors in regional and remote areas buy fuel, use taxi services or book a NSW Trainlink fare, so as to ease the cost of travel.

To find out if you are eligible, visit Service NSW website: www.service.nsw.gov.au/regional-senior-travel

The website has a 'apply online' point to enable a person to receive an email or SMS text to see when they can apply for the trial. The Card will be preloaded with \$250 to pay for travel-related expenses over the phone, online and at retail outlets.

We have lots of stories on travel in 'The Peer Collective' on the MDNSW website:



www.mdnsw.org.au/the-peer-collective



Mobility Parking Scheme

Now Online

Customers seeking to renew or replace a Mobility Parking Scheme permit can now submit their application online via the Service NSW website.

This eliminates the need for customers to visit a Service NSW Service Centre to complete their transaction.

The transaction is quick and simple and just requires the customer to fill out and upload the application form and medical certificate completed by their doctor. Clear photos from a mobile device will suffice for the upload.

If a customer does not have a valid stored image in Service NSW's, but otherwise meets all the requirements for a permit, they may still be able to obtain a temporary six month permit. Applicants who are not yet established in the system will still need to attend a Service NSW centre.

For further information visit: www.service.nsw.gov.au or call 13 77 88.

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