

# New Diagnosis tip sheet

**MUSCULAR  
DYSTROPHY NSW**  
YOUR NEUROMUSCULAR SUPPORT COMMUNITY

Information and tips to **empower your journey** living with a neuromuscular condition.

Being newly diagnosed with a neuromuscular condition can feel like navigating unknown territory. You don't have to do it alone. These tips and resources can help you begin your journey.

## Learn about your condition



Understanding your condition is the first step in managing it.

### Questions

It's natural to have many questions. Treating medical professionals – including neurologists, GPs and allied health professionals – can answer many. If you need information, resources or a referral, our team is here to help. Call or email us using the contact information on this flyer.

### Factsheets

We developed plain language factsheets about a wide range of neuromuscular conditions. They can help you, your family, carers, service providers, educators or work colleagues. They may also be useful in the NDIS planning process.



[Access them here](#)

### Neuromuscular clinics

These clinics bring together a multidisciplinary team of health professionals. Ensure you're connected to one for regular check-ins and ongoing support.



[Find contact details here](#)

## Look after your emotional wellbeing



A new diagnosis can stir up many feelings – relief, confusion, anxiety, loneliness, helplessness, overwhelm. Some people even experience grief. They're all normal. Every person's experience is different.

### Family and friends

- Reaching out to family and friends can help you process your diagnosis and adjust.
- You could share resources such as factsheets to help them better understand and support you.

### Professional support

- Speaking to a professional, such as a counsellor, social worker or psychologist can help you process the initial shock of a diagnosis.



## Find your community at MDNSW



Connecting with people who truly 'get it' can make all the difference. Our Peer Connect program brings people together online and in person to share experiences and learn from each other.

### What you'll find through Peer Connect:

- Online and face to face events
- Condition-specific groups
- Specific groups for parents, students and genders
- Information-sharing groups on specific topics
- Social events to share a meal and connect in a relaxed setting, or celebrate together
- Camps and retreats for all ages and stages

All events are facilitated by MDNSW staff who understand the challenges and joys of living with a neuromuscular condition.



[Explore Peer Connect](#)



## Ready to connect?



### Subscribe to Talking Point

This is our monthly community newsletter, keeping you up to date on the latest events, information and research.



[Sign up here](#)

## Information and referral service



As your neuromuscular support community, our role is to connect you with the right information, resources and services to help you feel informed, supported and in control. Whether you're looking for specialised clinics, want to understand different conditions, or are curious about the latest research, we'll guide you through it.

## Advice from the MDNSW Community



*These no urgency in planning the months and years ahead. Still make time to go have a coffee, socialise with friends or go on holidays, take care of yourself.*



*It's very helpful learning about other's challenges and the experiences we share... So important for peers to share things going on as they grow – issues, ideas and a few laughs.*



*You are not alone. There are people in same boat, who are going through the same problems and share how they are getting through.*

### Contact Us

Whether it's joining an event, attending a retreat or simply having a chat, we'd love to hear from you. Wherever you're at, you don't have to do it alone – our team is here for you.