



**NEURO  
MUSCULAR  
WA**

# **Services & Information Booklet**



# WE'RE HERE FOR YOU



Neuromuscular WA (formerly Muscular Dystrophy WA) is a community-centric organisation that supports people with neuromuscular conditions (NMCs) in WA.

We aim to improve the quality of life for people living with NMCs by providing practical help that extends beyond medical care.

Being a member of the Neuromuscular WA community means access to services and support, which we call *Support for Life*.

We work with hundreds of families and are here for you, so please join our community and become a member (membership is free) by visiting [www.neuromuscularwa.org.au](http://www.neuromuscularwa.org.au).

You can then access any of our services, which include counselling, education and information, NDIS support, social programs and advocacy.

As an organisation, we support our members throughout their life, when they need it.

Receiving a diagnosis can be overwhelming and confusing for yourself, or someone you love.

Often with rare diseases like neuromuscular conditions, it is difficult to know what steps to take and when.

We encourage you to get in touch with us at Neuromuscular WA so we can welcome you into our community.

It will allow us to guide you in the right direction for the answers you need and, when you are ready, introduce you to other people and families living with a neuromuscular condition.

We want you to know you are not alone and we are here to support you throughout your new journey. We have short-term counselling support available if you or a family member would like to access this.



## SYSTEM NAVIGATION

Our System Navigator can connect and link you with the services and supports you need, at the time you need them.

These services and supports are not limited to health and disability but encompass all areas such as mental health, advocacy, housing, Centrelink, carer support, employment, equipment, support groups, education, transport, sibling support and research.

You can self-refer to our our system navigation service by visiting our website and clicking on the referral button on the homepage.

Alternatively you can contact the System Navigator by phoning 9380 3400 or emailing [systemnav@neuromuscularwa.org.au](mailto:systemnav@neuromuscularwa.org.au). The first appointment can be conducted either face-to-face, online or over the phone.

There is no cost for the system navigation service and the System Navigator is available to support you when you need it.

For more information about system navigation visit [www.neuromuscularwa.org.au](http://www.neuromuscularwa.org.au).



## WHAT ARE NMCs?

Neuromuscular conditions (NMCs) are a group of rare, genetic (inherited or acquired) conditions that impact the muscles and the nervous system supporting them, causing muscle degeneration and weakness. They affect more than 40,000 Australians and we support around 700 people in Western Australia.

## HOW DO THEY AFFECT?

While muscles would normally rebuild and continue to grow, in neuromuscular conditions once the muscles are damaged, they have limited ability to repair, often due to the gene that would ordinarily produce protein (which protects the muscles) being defective.

## HOW MANY TYPES?

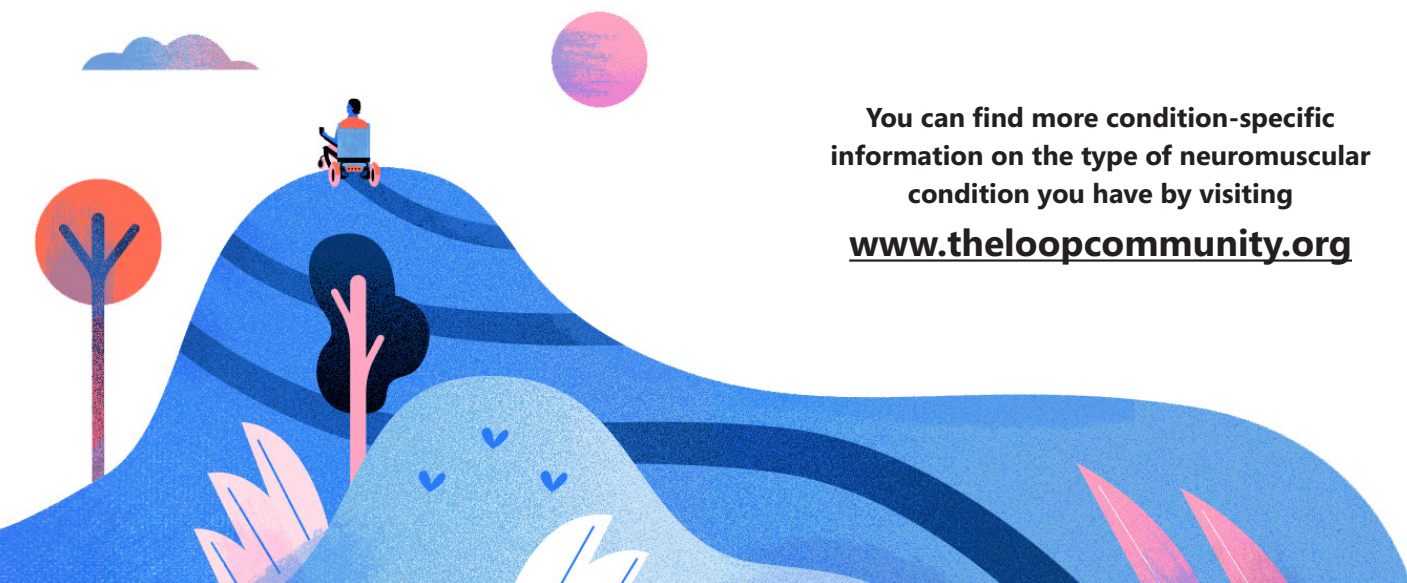
There are more than 75 conditions that are collectively known as NMCs, which include all the different types of muscular dystrophies as well as conditions such as spinal muscular atrophy and Charcot-Marie-Tooth.

## WHO DO THEY IMPACT?

Although often thought of as childhood diseases, these conditions affect people of all ages, race and gender, which makes finding a cure difficult, and supporting a diverse community challenging.

**You can find more condition-specific information on the type of neuromuscular condition you have by visiting**

**[www.theloopcommunity.org](http://www.theloopcommunity.org)**





# COMMUNITY SERVICES

**Neuromuscular WA provides a range of services for people living with a neuromuscular condition and those that support them.**

## Advocacy

Advocacy can be provided on an individual, group or systemic basis with the overall aim of achieving equal access and rights. Advocacy can be used to provide support to help you to self-advocate or for us to advocate on your behalf, dependent upon your needs and issue. If a different advocacy organisation can better assist you, we will refer you on to them.



## Social Support Programs

We provide a range of social support programs free of charge that help our community connect and support each other while having some fun, including:

**Conversations and Connections** brings together members of our community to learn new information, be educated on relevant topics and connect with other community members.

Our annual **Community Day** sees our whole community get together once a year to reflect on challenges, celebrate wins and share experiences while enjoying delicious food in some of WA's most beautiful settings.

School-aged children with NMCs, and a school-aged sibling, can participate in fully accessible events each school holidays. We hold a **Fun Day** in January, a **Family Day** in April, the **School Holiday Program** during July and a two-night **Camp** in October. Children can attend one, or all.

The **Young Adults Social Group** sees those in our community with an NMC who are over 17 years connect with others while enjoying a meal and activity such as watching comedy acts, visiting exhibitions, or going to the Fringe Festival.

Our **Adults with an NMC** program provides an opportunity for our adult members to connect with each other, while attending accessible events.

**SUPPORT  
FOR LIFE** 

The **Carers** social group provides a much-needed break and the chance to take some time out for our family carers. This program connects parents, partners and other family carers together to spend time with those who understand.

In conjunction with Hale School, **Hale Mates** is a peer mentoring program for youth in our community aged between 11 and 17 years old. Hale School host the program after school every fortnight during the school term.

The **Ignite Award** is a self-development program for young people aged 10 to 18 years old that provides a framework to learn valuable skills, be physically active, assist others in the community and experience adventures.

Short-term **Counselling** is provided by us through a third-party organisation and aims to support people living with an NMC and/or their families with 6-8 sessions during transition phases of their journey, or during times of bereavement.

We have a range of **Education and Information** options and resources for our members, their families or other people in their lives who support them, including schools and workplaces.

Our **Empower Fund** grants provide financial support to members to help them live life to its fullest, or if they are experiencing hardship, we also have some funds to help out with that too.

We also provide **CoughAssist™** machines to our community who are not eligible to obtain a machine through the NDIS. These machines assist by inducing both a slow inhale and a rapid exhale, encouraging natural coughing.

And we continue to provide funding to support vital **Research** into innovative therapies for neuromuscular conditions.

Further information about our services can be accessed through [www.neuromuscularwa.org.au](http://www.neuromuscularwa.org.au) or by contacting the Community Services Team on 9380 3400.

WE  
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FUN





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[info@neuromuscularwa.org.au](mailto:info@neuromuscularwa.org.au)

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