



**NEURO
MUSCULAR
WA**

**Advocacy,
Counselling
& Support Groups**



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.

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.

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.

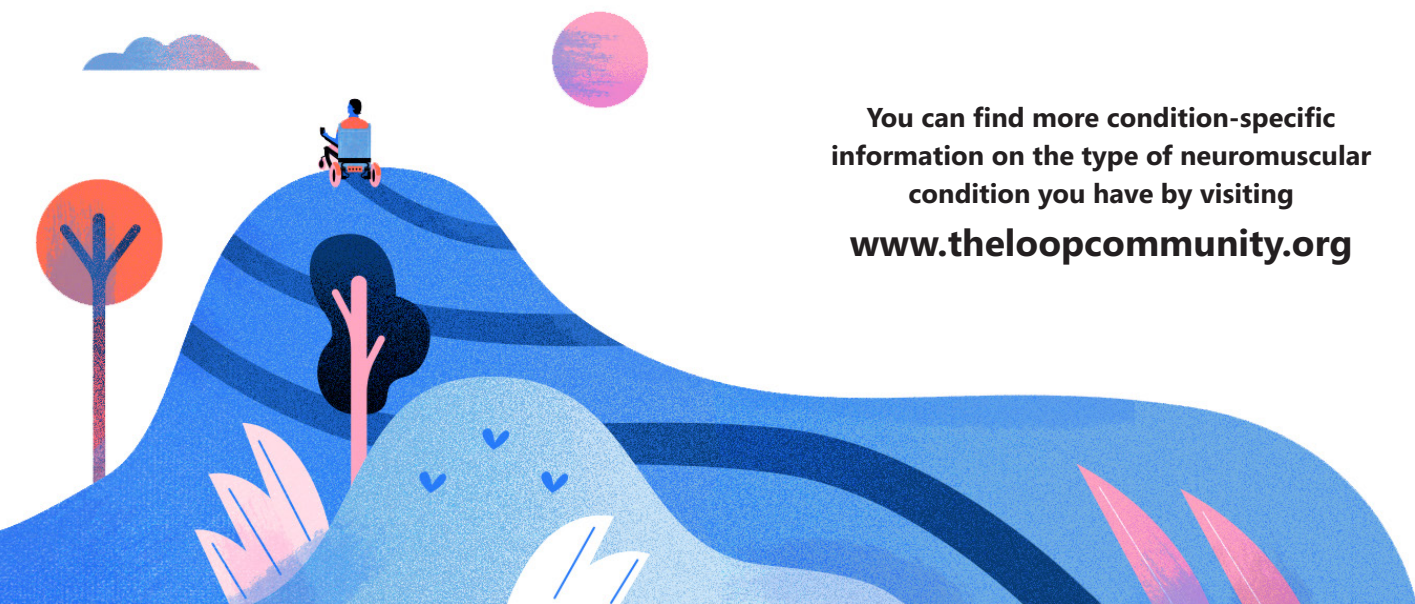
HOW MANY TYPES?

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 SMA, FSHD, IBM and CMT.

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



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.



COUNSELLING SERVICES

Neuromuscular WA

Neuromuscular WA provides access to a free counselling service for its members. Counselling is provided by us through a third-party organisation and aims to support people living with a neuromuscular condition and/or their families with 6-8 sessions available during transition phases of their journey.

Ph: Sarah on 9380 3400

info@neuromuscularwa.org.au

www.neuromuscularwa.org.au

Mental Health Treatment Plan

A Mental Health Treatment Plan is available from your GP and can help you access subsidised treatment provided by mental health professionals for anxiety, depression and other mental health concerns. You do not have to be diagnosed with a mental health condition to talk to your GP about making a mental health care plan.

Having the plan means you are entitled to a Medicare rebate on up to 10 individual sessions or group appointments with a psychologist or counsellor per calendar year.



Peer Pathways

Consumers of Mental Health WA run a Peer Pathways helpline that helps Western Australians navigate supports and services needed to promote mental and physical wellbeing. This state-wide helpline is free and confidential.

Ph: 9477 2809

www.peerpathways.org.au

9am to 5pm, Monday-Friday

Think Mental Health

This is a helpful government website that offers advice and numerous tips on how to look after your own and someone else's mental health.

Think Mental Health offers self-assessment check-up tools and can direct you to other services in the mental health space.

<https://www.thinkmentalhealthwa.com.au/>

Support Lines

Emergency Respite – Carers Gateway
1800 422 737 (24hrs)

Lifeline 13 11 14 (24hrs)

Mental Health Emergency Response
1300 555 788 (24 hrs)

SUPPORT GROUPS

Neuromuscular WA

We offer our community an extensive program of events and activities consisting mostly of social get-togethers for different age groups and carers.

They are all about nurturing connections with people in our community and include adults and school aged programs.

Ph: 9380 3400

info@neuromuscularwa.org.au

www.neuromuscularwa.org.au

Kiind

Kiind (formerly Kalparrin) has several groups that parents can join to share knowledge and experiences, ask questions, seek advice and build resilience as a parent of a child with additional needs.

Ph: 6164 9806

support@kiind.com.au

www.kiind.com.au

Siblings Australia

Siblings Australia is a national organisation that offers numerous resources and services to parents and siblings.

Please contact them to find out what support they can offer you and your family.

info@siblingsaustralia.org.au

www.siblingsaustralia.org.au



SUPPORT GROUPS continued

Carers WA

Having a supportive social network helps carers to provide the best care they can.

Carers WA provide Linking Together Social Support groups for its members to take a short break from their caring role and to meet others in their local community. Linking Together Social Support group attendance is free, however you must be registered with Carers WA.

To find out if there is a group in your area, contact the Carers WA Social Support team.

Ph: 1300 227 377
socialsupport@carerswa.asn.au

Neurological Council of WA

The Neurological Council of WA (NCWA) run monthly support groups that are open to people of all ages who may be affected by any neurological condition, disease or symptoms, and their loved ones and carers.

The support groups are held at The Niche in Nedlands. Bookings are essential.

Ph: 6457 7533
events@ncwa.com.au

CONDITION SPECIFIC GROUPS

There are several condition specific organisations such as SMA Australia, CMT WA, Myositis WA, Duchenne Australia, Save Our Sons Duchenne Foundation and FSHD Global.

To find out more about these organisations please contact Neuromuscular WA.

Ph: 9380 3400
info@neuromuscularwa.org.au

ADVOCACY

Advocacy is about supporting another person to protect their rights, needs and interests.

People can be their own advocate, or you can enlist the help of a trained advocate.

Listed below are advocacy organisations who can help.

Neuromuscular WA

Neuromuscular WA's community services team advocates, protects and advances the legal, human and service rights of our community of people living with neuromuscular conditions in WA.

Please note you do not have to be eligible for NDIS funding to receive our help.

Ph: 9380 3400
info@neuromuscularwa.org.au

People with Disability WA

People with Disability WA assist any people living with disability throughout WA (even those not on NDIS).

The advocacy service they provide is free of charge and they assist people with any non-legal advocacy issues including Centrelink and NDIS.

23/2 Dehli Street, West Perth
Ph: 9420 7279 or Country Callers 1800 193 331
dutyadvocate@pwdwa.org
www.pwdwa.org



ADVOCACY continued

Explorability

Explorability offers advocacy to people living with a disability, their families and carers throughout WA. Explorability WA is unable to offer advocacy for federal-related issues such as Centrelink or NDIS.

Some examples of areas of advocacy that they can offer is discrimination, abuse or neglect issues, navigating health matters, using feedback and complaints processes, accessing mental health or non-NDIS services, navigating the education system, transport and community.

Ph: 1800 290 690
admin@explorability.org.au
www.explorability.org.au/advocacy

Uniting WA

Uniting WA assist any people living with disability in the Perth metro area.

Ph: 1300 663 298
yoursay@unitingwa.org.au
www.unitingwa.org.au

Advocacy WA

Advocacy WA assists people living in the Southwest region only. They support clients with a range of issues eg. NDIS, Centrelink, education, child protection matters, issues with service providers, legal matters and other issues.

Ph: 9721 6444
admin@advocacywa.org.au
www.advocacywa.org.au

Midlas

Midlas is a not-for-profit community legal centre based in Midland that provides financial counselling, tenancy advocacy, disability advocacy and legal services.

Please note Midlas only supports NDIS clients from the North East metro region of Perth.

Ph: 9250 2123
admin@midlas.org.au
www.midlas.org.au

Sussex St Community Law Service Inc

Sussex St Community Law Service Inc provides advocacy services to people with disabilities, their family members and carers.

It is an independent, free and confidential service to people in Perth and the regional areas of the Mid-West, Goldfields/Esperance and the Great Southern areas of Western Australia.

Ph: 1300 648 655
www.sscls.asn.au





**YOU MATTER,
YOU BELONG**



9380 3400

info@neuromuscularwa.org.au

www.neuromuscularwa.org.au

The Niche,
11 Aberdare Road, Nedlands

