

# Neuromuscular Support tip sheet

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

As your condition progresses, you may need more practical support at home, work, university or school. This is your roadmap to funding, services and people who can help you navigate these changes.

## Your Support journey: The NDIS



The National Disability Insurance Scheme (NDIS) provides funding and support to help eligible people aged 7-64 with disability to live independently, access services and participate in their community.

When applying, it's important to clearly explain how your neuromuscular condition affects your daily life and how it's likely to continue having an impact.

### What you'll need

- A functional capacity assessment, usually from an occupational therapist.
- Proof of diagnosis from your healthcare provider, e.g. neurologist.
- Supporting information from doctors, therapists or other professionals.

The more detail you provide, the easier it is to show your needs.

### Need help?

- [Learn more about applying for the NDIS here](#)
- [Contact MDNSW for personalised support here](#)



## My Aged Care

If you're 65 or over (or 50 and over for Aboriginal and Torres Strait Islander people), My Aged Care is the main entry point for government-funded aged care services.

If you develop a disability after turning 65, My Aged Care is the system that provides ongoing support rather than the NDIS. If you already had NDIS support before turning 65, you may continue your plan until your care needs change, you start receiving regular home care, or you move into aged care. At this point, you will need to transition to My Aged Care.



[Learn more here](#)

## Advice from the MDNSW Community



*Keep a diary or notebook handy, for notes, names of doctors, medications, questions and ideas. This can be a useful way to keep things in order, without feeling overwhelmed. Just find a system that helps you keep things in order and feel less overwhelmed.*



*Connect with others in similar situations. Sometimes the best information is user tested and from lived experience.*

# Building your Support Team and Finding Services



Once you know which funding or services you can access, you may choose to start building your support team. It could include occupational therapists, physiotherapists, support workers and other professionals.

## Tips for choosing the right people

- Ask others living with neuromuscular conditions for recommendations as personal experience is often the best guide.
- Don't hesitate to try different options until you find the right fit for you.
- Look for therapists or support workers who have experience with neuromuscular conditions or are open to learning about them.

## Finding support services

**Clickability:** an online directory where people with disability rate and review services – like a TripAdvisor for disability supports.

**HireUp** and **Mable:** online platforms where you can find and directly engage independent support workers.



## Support at Work

If you need workplace adjustments, advice or funding, JobAccess is the government's national hub for disability employment. It provides free guidance and resources for both employees and employers.



[Learn more here](#)

## Looking for information or connection?

As your neuromuscular support community, our role is to connect you with the right information, resources and people to help you feel informed, supported and in control. Whether you're looking for specialised clinics, NDIS guidance or community connection – our team is here for you.

# Entitlements and Concessions



You may be eligible for a range of payments, subsidies and concessions to help with daily living costs and community access.

## Financial supports

**Disability Support Pension:** Financial help if you have a condition that is likely to persist for more than two years and prevents you from working.

**Department of Human Services:** Allowances and assistance programs for people living with disability and their carers.

**Chronic Disease Management Plans (via your GP):**

Access to Medicare rebates for allied health services.

## Travel and transport

### Isolated Patients Travel and Accommodation

**Assistance Scheme:** Helps cover travel and accommodation costs for travelling long distances for specialist medical treatment.

**The Transport Taxi Subsidy Scheme:** Provides fare subsidies if you cannot use public transport due to a severe and permanent disability.

**Mobility Parking Scheme:** Allows you to park in disability spaces and sometimes park for free or longer in certain areas.

**Assisted School Travel Program:** Helps students with disability get to school when parents or carers cannot provide transport.

## Access and participation

**Companion Card:** Allows you to take a support person to participating events and venues without paying for an extra ticket.