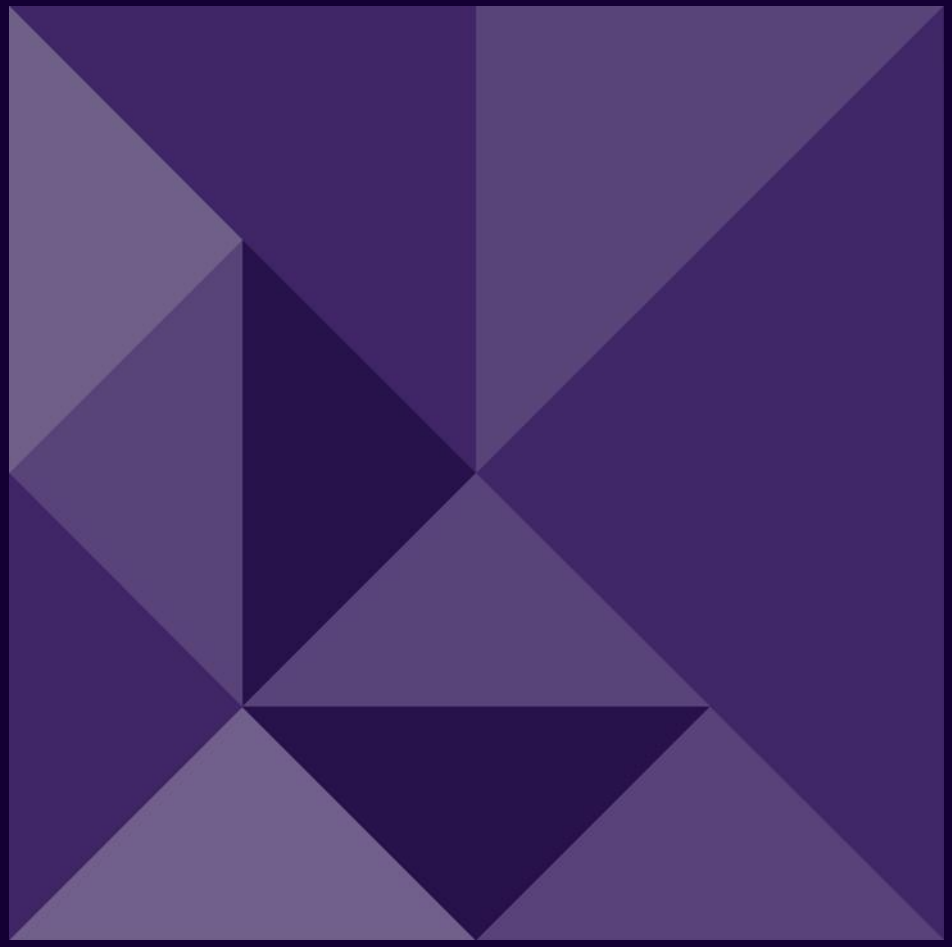
ACIL ALLEN

# MND Community Survey

## Final Report

16 May 2025



## About ACIL Allen

ACIL Allen is a leading independent economics, policy and strategy advisory firm, dedicated to helping clients solve complex issues.

Our purpose is to help clients make informed decisions about complex economic and public policy issues.

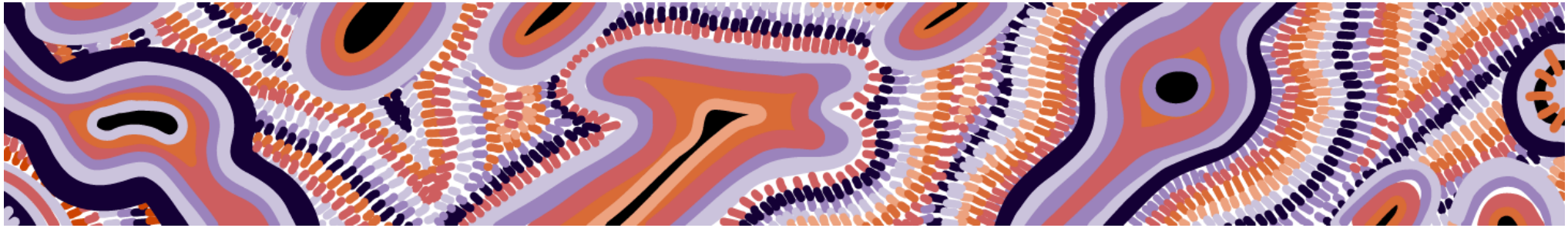
Our vision is to be Australia's most trusted economics, policy and strategy advisory firm. We are committed and passionate about providing rigorous independent advice that contributes to a better world.

## Report to:

### MND Australia and FightMND



ACIL Allen acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of the land and its waters. We pay our respects to Elders, past and present, and to the youth, for the future. We extend this to all Aboriginal and Torres Strait Islander peoples reading this report.



Goomup, by Jarni McGuire

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# Contents

# Executive Summary

MND Australia and FightMND engaged ACIL Allen to conduct the 2025 MND Community Survey. The survey gathered feedback from people living with MND, current and former carers, and asymptomatic gene carriers about their experiences of MND and priorities for future research and advocacy.

The sample was sufficient to deliver a robust national snapshot. There were 495 responses, including people living with MND (227 responses, estimated to be 8.4% of those living with MND), current and recent carers (<1 year post death) (133 responses), former carers (>1 year post death) (123 responses), and gene carriers (29 responses).

## Key findings

### People living with MND

The quality of life of people living with MND was reported to be reliant on connection and access to adequate supports. Many reported not receiving the supports they require, especially equipment, home modifications, and health professionals. Though MND Clinics were reported to improve care and access to health professionals, many could not access them due to geographical barriers.

Key challenges to accessing support included delays and wait times, cost, and understanding options and acquisition processes. Many health professionals reportedly did not have sufficient knowledge of MND, impacting quality of treatment, care and support. These issues were worse for people in regional areas, newly diagnosed, those who experienced extremely impactful symptoms, and those without support from the National Disability Insurance Scheme (NDIS).

### Carers

Carers reported a lower quality of life than others impacted by MND. This reflects the intensive demands of caring and a lack of sufficient support. Most considered their access to paid support inadequate and had limited access to respite care.

Barriers for carers aligned with those for people living with MND, including the lack of knowledge of MND among paid carers, and funding limitations to access to equipment and modifications. These outcomes were worse for people in regional areas and without government support.

### Gene carriers

Gene carriers (asymptomatic) faced different challenges to the rest of the MND community. Key issues included connecting with the dispersed community across Australia, and accessing adequate genetic counselling in a timely manner. Gene carriers reported facing stigma from medical professionals in seeking care, with low understanding of the role and benefit of genetic counselling.

### Access to information

People living with MND and their carers reported having all or most of the information required to manage the disease. Gene carriers had different needs and so struggled more to find appropriate information.

The most useful sources were the MND Australia website (MND Connect), State MND Association newsletters, and in-person sessions. Preferences differed by age, education, and gender.

## Research priorities

Overall, the top 2 research priorities were identifying the cause of MND and developing new clinical trials to slow disease progression. These were followed by research to improve quality of life, and improve the diagnosis process. Priorities differed slightly for people with more severe symptoms, and between respondent types.

Most survey respondents expressed a desire to participate in research and increased information concerning clinical trials. The reported barriers to research participation included limiting inclusion criteria, physical barriers and accessibility. Many reported not being updated on research outcomes, impacting the understanding of progress made.

## Advocacy priorities

The top advocacy priority by a considerable margin was equitable access to disability funding, regardless of age at funding commencement. There was a set of other competing priorities associated with the needs of differing cohorts, though additional funding for MND Clinics was a leader amongst these.

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# Introduction

# 1 Context

## MND Community Survey

The MND Community Survey was commissioned by FightMND and MND Australia. FightMND funds research aimed at better treatments, improved care/support, and finding a cure for motor neurone disease (MND). MND Australia is the national peak body for MND, working to improve the lives of everyone impacted by MND, by advancing high quality care, research and national advocacy. Furthering national collaborative efforts, the survey creates a snapshot of the care needs and priorities of people with lived experience of MND in Australia. The survey captured perspectives of people living with MND, current and former carers of someone living with MND, and gene carriers. The survey aimed to:

- provide an opportunity for people impacted by MND to voice their interests, needs, priorities and concerns
- ensure priorities in care, support and research are guided by the needs of people affected by MND
- better understand the supports and services needed to meet community needs
- inform the future direction of research and advocacy efforts.

The survey provides a foundation for community research that can be repeated every 3-4 years to provide updated insights and build a long-term evidence base.

This report is intended to be used by FightMND and MND Australia, as well as the broader MND community including state MND associations, researchers, healthcare professionals, and other not-for-profit organisations both in Australia and internationally, to better advocate for the needs of people impacted by MND.

## Structure

This research report is structured as follows:

- People living with MND
  a) Quality of life
  b) Equipment and home modifications
  c) Access to health professionals
  d) MND Clinics
  e) Treatment
- Carers
- Gene carriers
- Information
  f) Availability of information
  g) Research participation
- Community priorities
  h) Research
  i) Advocacy.

Each section addresses:

- Outcomes – reported outcomes from the MND community
- Drivers – potential causes or influences on these outcomes
- Differences – how the outcomes and drivers might differ between demographics.

# 2 Methods

## Survey development

The survey was designed in collaboration with:

- MND Australia and FightMND
- State MND Associations
- clinicians and care researchers
- people living with MND
- current or former carers of those living with MND
- gene carriers.

Following initial drafts, the survey instrument was validated with people living with MND, ensuring the design met accessibility needs.

## Distribution

The survey was distributed by the State MND Associations via email to people currently living with MND and current carers who were registered with their services. It was also shared on social media platforms of MND Australia, FightMND, and the State MND Associations, and emailed to subscribers of MND Australia's & FightMND's e-newsletters.

This distribution method may create a bias in responses, as distribution reached only those who were engaged with the State MND Associations, MND Australia, or FightMND. The survey bias includes low representation from cultural and linguistical diversity, remote and very remote respondents, people living with MND with more severe symptoms, and other limitations outlined further below.

## Validation

The high-level findings from the survey were validated through a series of workshops with the abovementioned stakeholders to inform interpretations and further analysis.

## Respondents – Demographics

### Experience with MND

The survey received 495 responses from the following groups (noting respondents could be part of more than one group):

- people living with MND: 227
- current or recent carers (<1 year post death): 133
- former carers (>1 year post death): 123
- gene carriers: 29.

Although this sample is not statistically representative of the population, the response rate is sufficiently robust for people living with MND. Compared to the estimated 2,688 people living with MND,[1] the sample represents 8.4% of the population.

Current carers and former carers less than one year post death were grouped together and comprise the focus of the analysis to best reflect current circumstances. The population for current or recent carers has not been estimated, and so it is not possible to determine whether the sample is statistically representative.

[1] Deloitte Access Economics report Economic analysis of MND in Australia, 2015.
MND Australia, MND background information sheet, accessed 30 April 2025 on https://www.mndaustralia.org.au/mnd-connect/information-resources/mnd-background-information-sheet

Due to the low response rate of gene carriers, their findings cannot be seen to be representative; particularly given it is unknown how large this population is.

## Geographic distribution

The geographic distribution of respondents was analysed using Remoteness Areas, as defined by the Australian Bureau of Statistics.[2] The majority of respondents lived in major cities or inner regional Australia. The number of respondents living in outer regional Australia was sufficient to make comparisons by region. Some responses provided input from people living in remote Australia, however the sample was too small for statistical comparison.

Table 2.1 Demographics – regionality

| Demographic group | Proportion (%) | Count (n) |
|---|---|---|
| Major Cities of Australia | 57% | 274 |
| Inner Regional Australia | 27% | 129 |
| Outer Regional Australia | 13% | 62 |
| Remote Australia | 3% | 13 |
| Very Remote Australia | 0% | 2 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## State

The response rates from the states largely aligns with distribution of the broader population, with the larger states having relatively equal response rates.

Table 2.2 Demographics – state

| Demographic group | Proportion (%) | Count (n) |
|---|---|---|
| NSW | 29% | 140 |
| VIC | 25% | 122 |
| QLD | 25% | 121 |
| WA | 10% | 49 |
| SA | 6% | 29 |
| TAS | 2% | 9 |
| ACT | 2% | 11 |
| NT | <1% | 1 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Age

Most respondents to the survey were above the age of 65. Carer participants were somewhat younger on average than those diagnosed. Gene carriers tended to be over 35 but were much younger on average than carers and those living with MND.

Table 2.3 Demographics – Age

| Demographic group | People living with MND | | Current or recent carer | | Gene carrier | |
|---|---|---|---|---|---|---|
| | % | n | % | n | % | n |
| 25-35 | 0% | 1 | 2% | 2 | 4% | 1 |
| 35-45 | 2% | 5 | 3% | 4 | 25% | 7 |
| 45-55 | 6% | 14 | 16% | 21 | 21% | 6 |
| 55-65 | 18% | 40 | 22% | 28 | 25% | 7 |
| 65-75 | 42% | 93 | 33% | 42 | 18% | 5 |

[2] Australian Bureau of Statistics, Remoteness Areas, accessed 29 April 2025 from https://www.abs.gov.au/statistics/standards/australian-statistical-geography-standard-asgs-edition-3/jul2021-jun2026/remoteness-structure/remoteness-areas

| Demographic group | People living with MND | | Current or recent carer | | Gene carrier | |
|---|---|---|---|---|---|---|
| | % | n | % | n | % | n |
| 75-85 | 27% | 59 | 23% | 29 | 7% | 2 |
| 85-95 | 4% | 9 | 2% | 2 | 0% | 0 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Cultural and linguistic diversity

Very few respondents were from cultural or linguistically diverse backgrounds, (language backgrounds other than English, ~10%, n<15 per respondent type). Only one respondent identified as Aboriginal and Torres Strait Islander.

## Housing

Most people living with MND resided in their own home (93%, n=206), and the majority of current or recent carers were caring for someone in their own home (93%, n=99). This reflects a bias to those not in palliative or end-of-life care.

## Education

Respondents tended to be university educated (47%), followed by high school education (26%) and vocationally trained (24%).

Table 2.4 Demographics – Education

| Demographic group | Proportion (%) | Count (n) |
|---|---|---|
| University | 47% | 231 |
| TAFE / Vocational Education and Training (VET) | 24% | 120 |
| High school | 26% | 129 |
| Prefer not to say | 2% | 12 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Gender

The majority of respondents were women, though this representation was much higher for carers (72%) and gene carriers (72%) than those living with MND (46%).

Table 2.5 Demographics – Gender

| Demographic group | People living with MND | | Current or recent carer | | Gene carrier | |
|---|---|---|---|---|---|---|
| | % | n | % | n | % | n |
| Woman / female | 46% | 104 | 72% | 96 | 72% | 21 |
| Man / male | 53% | 120 | 27% | 36 | 28% | 8 |
| I use a different term (please specify if you choose) | 0.4% | 1 | 0% | 0 | 0% | 0 |
| Prefer not to say | 0.4% | 1 | 0.8% | 1 | 0.8% | 1 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Government funding and support

The majority of people living with MND were receiving support from the NDIS (51%), My Aged Care (25%), or had no government support (22%).

Table 2.6 Demographics – Living with MND government support

| Demographic group | Proportion (%) | Count (n) |
|---|---|---|
| NDIS | 51% | 115 |
| My Aged Care (Home Care Package or Commonwealth Home Support Programme) | 25% | 56 |
| None | 22% | 50 |
| Unsure | 2% | 5 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

Some states had a larger proportion of respondents without government support. These included New South Wales (32%, n=24), Western Australia (25%, n=6) and Victoria (19%, n=11).

Table 2.7 Demographics – Living with MND government support by state

| | NSW (n=75) | WA (n=24) | SA (n=16) | VIC (n=57) | QLD (n=40) |
|---|---|---|---|---|---|
| NDIS | 49% | 33% | 38% | 51% | 70% |
| My Aged Care* | 19% | 33% | 31% | 26% | 23% |
| None | 32% | 25% | 25% | 19% | 8% |
| Unsure | 0% | 8% | 6% | 4% | 0% |

Note: *(Home Care Package or Commonwealth Home Support Programme)

*Source: MND Community Survey 2025, analysis by ACIL Allen*

People not receiving government funding were more likely to be older, with the majority (63%, n=30) of them in the 75-85 age bracket. They were also more likely to be male (66%, n=33) than people receiving support from My Aged Care (55%, n=30) or the NDIS (46%, n=53).

Of current and recent carers, more than half (54%) did not receive either carer allowance or carer support payment.

Table 2.8 Demographics – Current and recent carer government support

| Demographic group | Proportion (%) | Count (n) |
|---|---|---|
| Carer allowance | 28% | 37 |
| Carer support payment | 17% | 23 |
| Neither | 54% | 72 |
| Unsure | 1% | 1 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Type of MND

Respondents living with MND reported having the following types of MND:

- Amyotrophic lateral sclerosis (ALS) – 42% (n=93)
- Progressive bulbar palsy (PBP) – 14% (n=32)
- MND with frontal temporal dementia (MND/FTD) – 1% (n=3) of the respondents (though expected to be 5-15% of the population, likely indicating difficulty of survey engagement for this group).
- Flail-arm/leg variants – 4% (n=8)
- Primary lateral sclerosis (PLS) – 12% (n=26)

The remainder included 12% (n=26) that reported that their neurologist had not explained what type of MND they had; and 11% (n=25) were unsure.

## Disease duration

Respondents living with MND were asked to report the length of time since their diagnosis of MND. Responses were categorised as between 0-1 years (24%), between 1-2 years (24%), between 2-5 years (22%), between 5-10 years (16%) and between 10-20 years (14%).

Duration is associated with type of MND. The proportion living with PBP declines rapidly after 2 years, while the proportion living with PLS increases.

# Symptoms

Symptoms of MND can differ considerably. For the purposes of this report, frequent MND-related symptoms are categorised into groups, as per Table 2.9.

Table 2.9 MND symptom categories

| Category | Symptoms |
|---|---|
| Physical | Weakness in limbs (hands, arms, or legs) |
| | Neck weakness or head drop |
| Respiratory | Shortness of breath |
| Bulbar | Slurred speech |
| | Coughing or choking on foods, drinks or saliva |
| | Runny, excessive, or thick saliva |
| Bowel and bladder dysfunction | Bowel or bladder incontinence |
| | Constipation |
| Fatigue and sleep | Insomnia (i.e., poor sleep) |
| | Fatigue |
| Mood and cognition | Depressed mood |
| | Cognitive deterioration (i.e., changes in thinking skills or personality) |
| Pain | Pain |
| | Muscle cramping or spasms |

*Source: ACIL Allen, What matters most survey*[3]

People living with MND were asked to what extent they experienced these symptoms: from 'moderate' to 'very' to 'extremely' impactful. These were weighted equally within each group, and an overall rating was taken as the highest rating in any category (i.e. if any of the symptoms were extremely impactful, the overall rating was 'extremely impactful').

About half (46%) reported experiencing at least one symptom type as extremely impactful and so received an overall rating of 'extremely impactful'. Of these, the most common symptoms were extremely impactful physical (28%) and bulbar (17%) issues.

Table 2.10 Symptom types and proportion experiencing them as "very" or "*extremely impactful*" (people living with MND, n=222)

| Demographic group | Very impactful (%) | Extremely impactful |
|---|---|---|
| Overall | 37% | 46% |
| Physical | 35% | 28% |
| Bulbar | 17% | 17% |
| Fatigue and sleep | 22% | 11% |
| Pain | 20% | 9% |
| Respiratory | 12% | 5% |
| Bowel and bladder dysfunction | 11% | 4% |
| Mood and cognition | 5% | 3% |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

[3] ALS Health Index Short Form (ALS-HI-SF) from ALS Association, 2020, ALS Focus Results from the What Matters Most Survey, accessed 30 April 2025 from https://www.als.org/research/als-focus/survey-results/survey-2-results

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# People living with MND

# 3 Quality of life

Finding 1 Quality of life

- Most people living with MND reported having a good quality of life. This relied on connections (family and friends, community participation) and sufficient supports (including equipment, home modifications, health professionals, and medical treatment).
- However, there were barriers to community participation, including a lack of understanding of MND within the community, accessibility issues and availability of transport.

## Overview

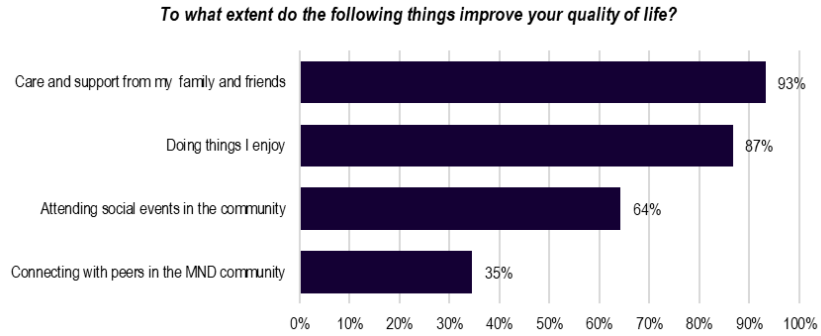
Quality of life measures people's perception of their overall wellbeing and experience. For people living with MND, quality of life may be impacted by the nature of the disease and the extent to which it impacts day-to-day life.

## Outcomes

Most people living with MND reported living with a good quality of life. A majority reported that their quality of life was either very good (17%, n=38) or good (46%, n=103), with a large minority reporting neutral (23%, n=51), poor (11%, n=25) or very poor (2%, n=5).

Quality of life was reliant on connections with family, friends, and community. The following contributors were reported to improve quality of life for people living with MND: care and support from family and friends (93%), doing things I enjoy (87%), attending social events in the community, and to a lesser extent connecting with peers in the community (35%).

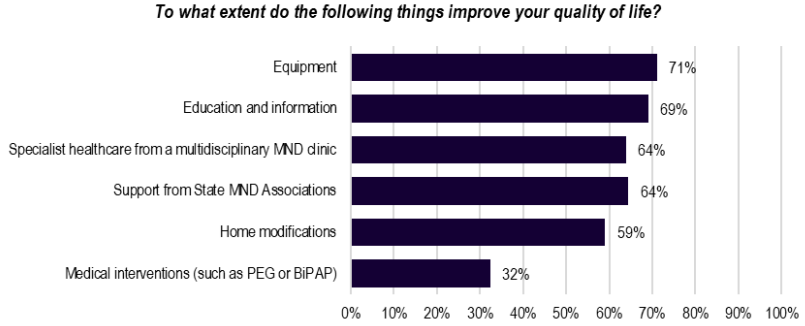
Figure 3.1 Contributors to quality of life (n=222)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

However, supports are necessary to facilitate these connections and maintain quality of life. Those living with MND reported that their quality of life is reliant on equipment (71%), education and information (69%), specialist support from MND clinics (64%), home modifications (59%), and medical interventions (32%).

Figure 3.2 Supports for quality of life with a very or somewhat strong impact (n=222)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Connections

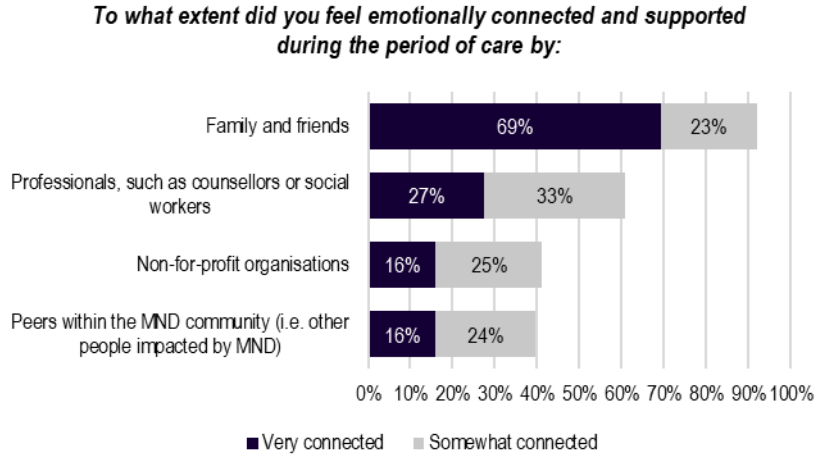
Almost all (92%) of the respondents living with MND felt 'very connected' (69%) or 'somewhat connected' (23%) to family and friends for emotional connection and support, emphasising the importance of these immediate relationships.

People also relied on other avenues, though to a lesser extent. A majority (60%) felt very (33%) or somewhat (27%) emotionally connected to and supported by professionals such as counsellors or social workers, with qualitative data indicating that people rely on these professionals for expert advice as well as emotional support.

A minority (41%) felt very (16%) or somewhat (25%) emotionally connected to and supported by not-for-profits. Qualitative data from those living with MND, State MND Association representatives, and clinicians reported that these relationships can provide key support functions for some.

People living with MND had mixed views on their connection to peers in the MND community. Some noted that they got immense satisfaction out of connecting with peers, reflecting the smaller proportion that felt very (16%) or somewhat (24%) connected. Others acknowledged that connecting with those living with the disease, particularly those who were more advanced, could be confronting, leading them to avoid such connections.

Figure 3.3 Connections for people living with MND (n=222)



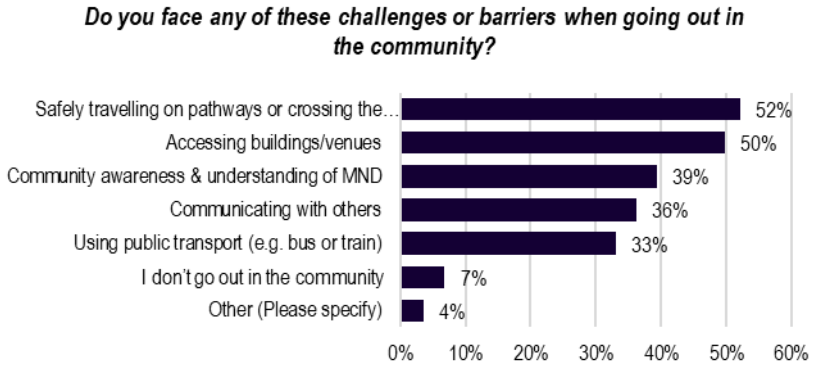

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Community barriers

People living with MND reported that community participation can improve their quality of life, however, many reported experiencing barriers to engagement. The majority noted that significant physical barriers, including safely travelling on pathways or crossing the road (52%), accessing buildings and venues (50%), and to a lesser extent using public transport (33%).

Other barriers include community awareness and understanding (39%) and ability to communicate with others (36%). A small proportion reported never going out into the community (7%).

Figure 3.4 Community barriers for those living with MND (n=221)



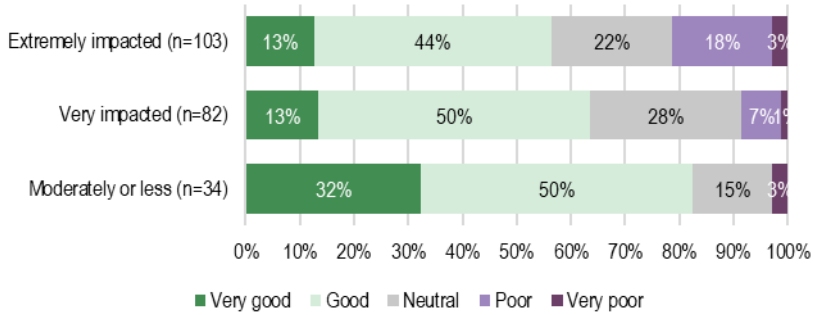

*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Differences

## Severity of symptoms

Those with extremely impactful symptoms were able to maintain a good quality of life with sufficient supports. The majority of those living with extreme symptoms report either very good or good quality of life. Though, as symptom severity increases, the proportion that report their quality of life as very good decreases.

Figure 3.5 People living with MND quality of life and symptom severity




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# 4 Equipment and home modifications

Finding 2 Equipment and home modifications

- Approximately half of those living with MND did not have the equipment nor home modifications required for mobility, personal care, or communication.
- Drivers are complex, including delays (due to government processes), cost (requiring people to leverage their own funds as well as government), difficulty understanding the options and acquisition (due to complex processes), and finding tradespeople (worsened by pressures on housing).
- Issues were worse for those in outer regional and remote areas and those newly diagnosed.

## Overview

People living with MND require equipment ('assistive technology') and home modifications to maximise independence, comfort and safety in the home. Equipment can be broken into broad categories:

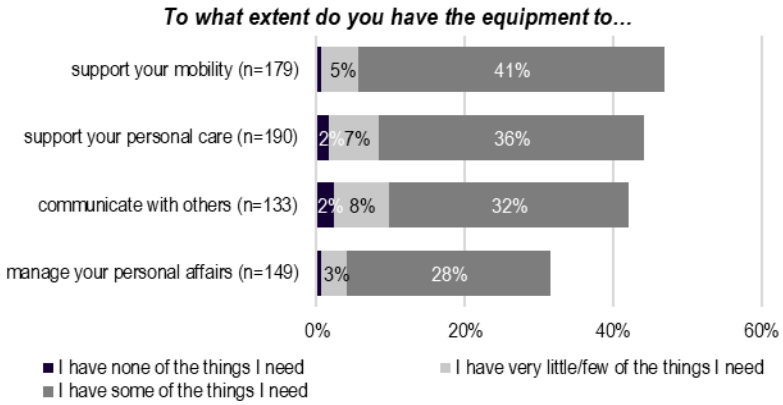
- aids to support mobility within and beyond the home (e.g. walkers and wheelchairs)
- aids to support personal care, such as feeding, showering and toileting (e.g. adaptive cutlery, commode, or shower chair)
- communication aids (e.g. iPad or eye-gaze technology)
- technology to maintain personal affairs (e.g. speech to text technology).

## Outcomes

Almost half of those living with MND reported that they did not have a suitable residence nor all the equipment and home modifications to maximise their quality of life.

Of people with MND that required equipment, almost half did not have all that they required to support their mobility (47%), personal care (44%), and communication (42%). A third did not have all they needed to manage their personal affairs (32%). Some who needed equipment (5-10%) had very little, or no access to it.

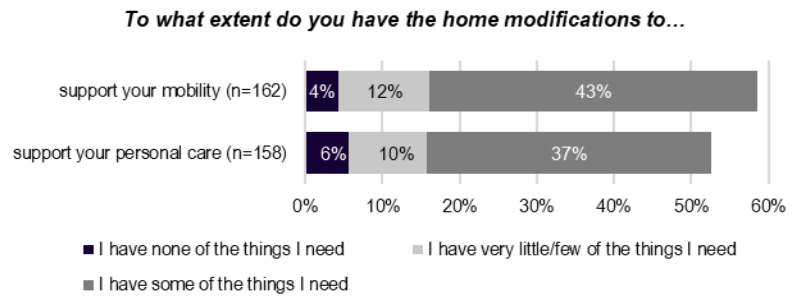
Figure 4.1 Equipment access for those living with MND




*Source: MND Community Survey 2025, analysis by ACIL Allen*

Access to home modifications was reported to be more challenging than access to equipment. The majority did not have the home modifications required to support mobility (59%) or personal care (53%). A reasonable minority (larger than that of equipment, 16%) had very little, or no access, to home modifications.

Figure 4.2 Home modification access for those living with MND



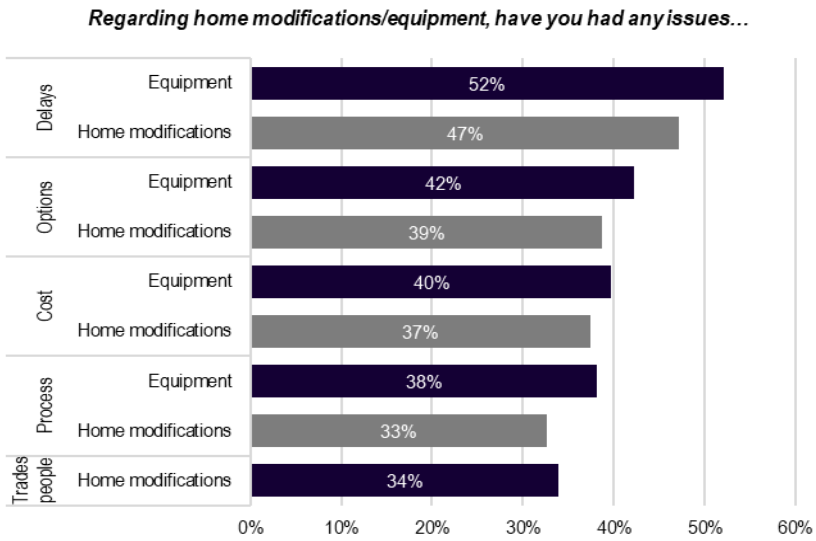

*Source: MND Community Survey 2025, analysis by ACIL Allen*

Only a minority of those living with MND considered their residence to be adequately equipped to support them (27%). Almost half considered theirs somewhat equipped (44%), with the remainder split between neither equipped nor unequipped (13%), somewhat unequipped (9%) and very unequipped (7%).

# Drivers

The issues that people with MND face in getting equipment and home modifications were delays (~50%), followed by understanding the options, cost, understanding the process of acquisition (all ~40%), and finding suitable tradespeople (34%).

Figure 4.3 Home modifications and equipment issues (n=220)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Delays

Delays impact quality of life and the utility of supports. Those living with MND noted that the delays in NDIS and My Aged Care approvals can be significant and exacerbated by overly restrictive requirements. The acquisition process can also take time. This can result in equipment arriving, or modifications being installed, after the disease has progressed further, making it useless for their needs.

Those living with MND emphasised the importance of government staff having adequate knowledge and understanding of MND. The new NDIS 'Priority Eligibility Decision pathway' for those living with MND under 65 years of age was intended to assist with this by fast tracking the commencement of NDIS support.[4] However, of the 10 respondents that were diagnosed since implementation of this pathway, 3 reported some issues with delays and one reported significant issues with equipment delays. This may indicate that the new NDIS pathway's focus on commencement does not address equipment and home modification delays on an ongoing basis.

## Tradespeople

Access to tradespeople impacts timelines for home modifications. Those living with MND reported that it can be difficult to find a suitable tradesperson in the local area that can do the work, and even when found, there can be further delays given workforce shortages. Issues worsened in regional and rural areas.

## Understanding options and acquisition

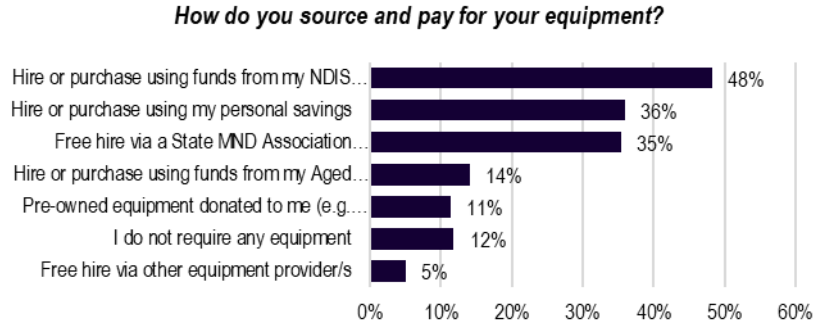
Processes for exploring options and accessing equipment and home modifications are complicated. People living with MND and their carers reported that understanding the funding process, their options, and the process of acquisition was a steep learning curve. The time commitment required can be burdensome and overwhelming for people, particularly as the disease progresses and care needs increase.

## Cost

Financial pressure can be a significant barrier for both equipment and home modifications. People with MND reported that the cost for equipment and modifications were both high, with some citing that equipment was often more expensive as a result of being associated with MND or the NDIS. Some felt there was an unnecessary price premium being placed on equipment, given suppliers awareness that it was often paid for using government funding.

This cost pressure was reflected in how those living with MND pay for their equipment. Most funded equipment and modifications through the NDIS (48%) and My Aged Care support (35%). Many also paid using their personal savings (36%), made use of free hire services (35%), or used pre-owned equipment (11%).

Figure 4.4 How those living with MND source equipment (n=220)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

[4] NDIS, When do we make priority eligibility decisions?, accessed 14 May 2025, https://ourguidelines.ndis.gov.au/home/becoming-participant/applying-ndis/when-do-we-make-priority-eligibility-decisions

# Differences

## Funding source

Access is impacted by nature of government assistance. A larger proportion of those on My Aged Care reported more significant issues with cost (26%, n=13) than those on NDIS (15%, n=16). Though it was reported that the new Aged Care arrangements have improved, people living with MND reported that it was still insufficient for many people's needs.

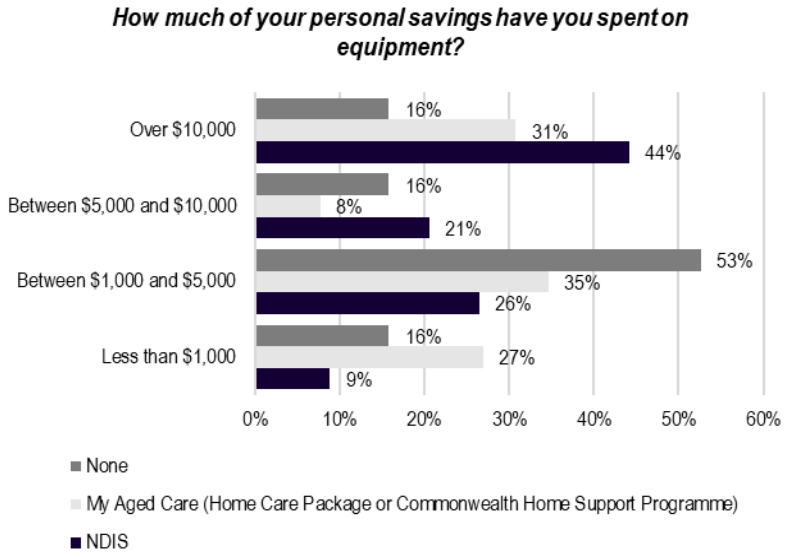
Reflecting the lower level of support:

— a larger proportion of people receiving support from My Aged Care utilised State MND Association hire more than those receiving NDIS support (63% n=34 compared to 25% n=27)

— a larger proportion of people receiving support from My Aged Care utilised their personal savings (48% n=26) than those on NDIS (31% n=34), though those on My Aged Care did so for smaller purchases, where NDIS recipients did so for larger ones.

Of people living with MND that didn't receive government support, a large minority (41%, n=20) did not require any equipment. Those that did require equipment utilised free hire via state associations (29%, n=14) or purchased via personal savings (39%, n=19). When utilising personal savings, it was largely for smaller purchases like those on My Aged Care.

Figure 4.5 Personal savings spent by type of government support (NDIS n=34, My Aged Care n=26, None n=19)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Symptoms

Access was not correlated with severity of symptoms. Taking mobility equipment as an example, the proportion that had all the equipment they needed increased with muscular symptom severity: from 46% (n=22) for those with moderate, to 51% (n=37) very impactful, to 56% (n=31) extremely impactful. This pattern was consistent across equipment and mobility categories. This indicates that those with sufficient support to access equipment can get what they need even with severe symptoms.

There is a small minority that were experiencing very or extremely impactful symptoms that did not have the equipment and modifications they needed.

- Of those with very or extreme muscular issues:
  - 10% (n=15) do not have the home mobility modifications they need, and 5% (n=7) do not have the mobility equipment they need.
- Of those with very significant or extreme bulbar issues:
  - 12% (n=9) do not have the communication equipment they need.

## Newly diagnosed

Those early in their MND journey had greater challenges. Taking mobility equipment as an example: only 35% (n=13) of those within one year of their diagnosis had the equipment they needed, which increased to more than 50% for those 1-2 (n=22) and 2-5 years (n=20), and up to more than 60% (n=40) for those with 5+ years. This pattern was consistent across equipment and mobility categories.

## Renters

Some of those living with MND reported that many rentals are not appropriate for larger equipment items, such as electric wheelchairs, hoists, or hospital beds; and that home modifications are often impossible to install, due to landlord restrictions.

## Regionality

Equipment access was worse for those in outer regional and remote Australia. In the case of mobility equipment, a small majority of those in major cities (57%, n=54) and inner regional areas (59%, n=32) had the equipment they needed compared to a third (33%, n=8) of those in outer regional Australia. Though there were few remote respondents (n=5), none of them reported having the equipment they needed for mobility. This pattern was consistent across other equipment and home modification categories.

Reflecting the lower level of support, a larger proportion of those on My Aged Care had utilised State MND Association hire more than those receiving NDIS support (63%, n=34 compared to 25%, n=27). Though access to this support is more difficult for those in outer regional areas (14%, n=4) than major cities (40%, n=45) or inner regional areas (42%, n=28).

# 5 Access to health professionals

Finding 3 Access to health professionals

- Nearly all of those living with MND received care from a range of health professionals, such as neurologists, occupational therapists, and physiotherapists.
- Barriers to access were significant and included limited knowledge of MND within the health sector, workforce shortages, wait times and the requirement to travel (particularly for regional and rural communities).
- There were specific barriers for psychology, counselling, social work and genetic counselling, with funding availability a key contributor.

## Overview

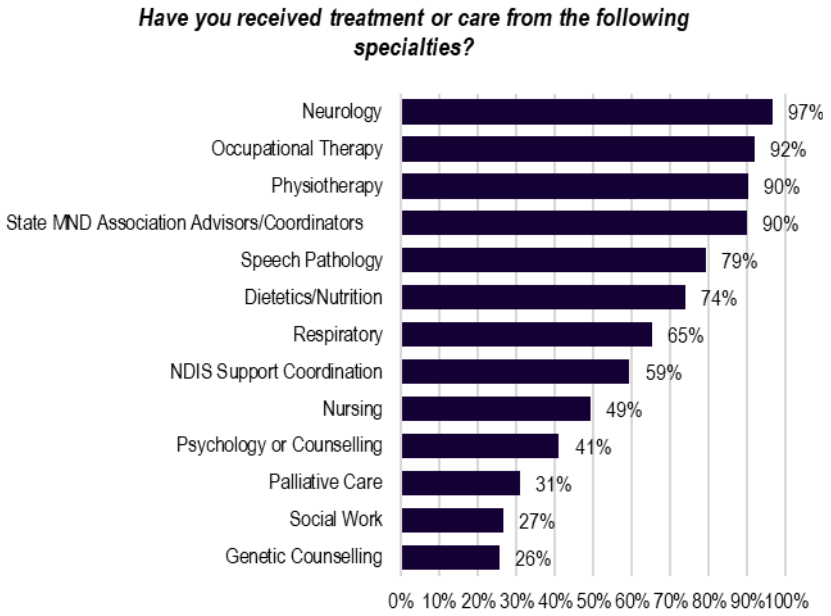
People living with MND require support from a range of specialists to receive direct treatment and care, as well as referrals, reports and scripts for their other supports. These can be understood in 2 main groups: the first is general and should be accessed by almost all of those living with MND, the second is specific and dependent on symptoms and needs.

## Outcomes

Nearly all those living with MND had received treatment and care from neurologists (97%), occupational therapists (92%), physiotherapists (92%) and State MND Association advisors or coordinators (90%). Access to other specialisations, such as speech pathology, dietetics, respiratory, NDIS Support Coordination and nursing, ranged between 49% to 80%.

Being diagnosed with a progressive, terminal illness can contribute to significant emotional and psychological distress. However, only a minority accessed psychology / counselling (41%), and social work (27%). Access to genetic counselling was also low (26%).

Figure 5.1 Access to specialists (n=220)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

The need to access health professionals is dependent on the symptoms that the person living with MND is experiencing, and the severity of these. When results are disaggregated by symptom type and severity, access to professionals increase for those with physical, respiratory, and bulbar issues, but not for the others (with the exception of palliative care for fatigue and sleep).

Only 31% of respondents had accessed palliative care. Those with extremely impactful symptoms in general were more likely to access palliative care (40%, n=40) than those with very (26%, n=21) or moderately (6%, n=2) impactful symptoms.

Table 5.1 Access to health professionals by symptom

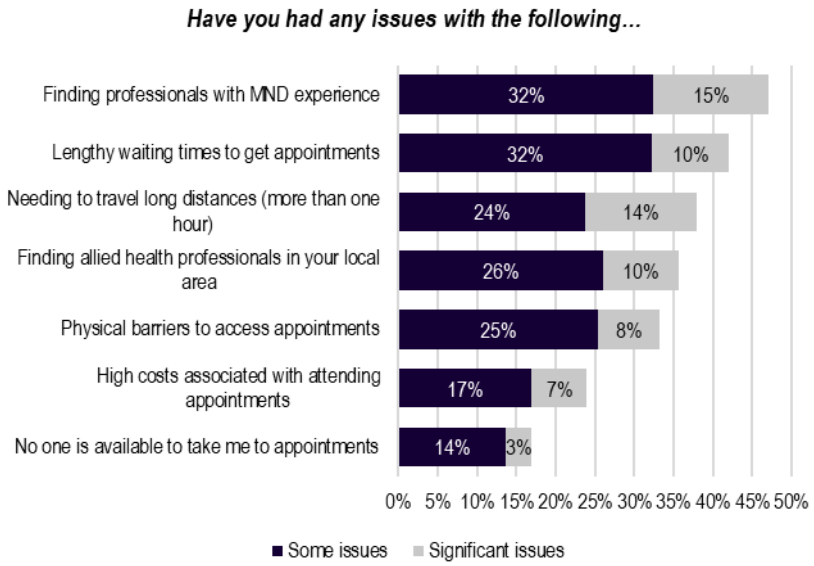
| Professional type | Moderate | Extremely | Difference |
|---|---|---|---|
| Physical | | | |
| *Respondents* | *n=64* | *n=60* | |
| Physiotherapist | 80% | 93% | +14% |
| Occupational therapist | 84% | 97% | +12% |
| Respiratory | | | |
| *Respondents* | *n=71* | *n=11* | |
| Palliative care | 37% | 73% | +36% |
| Respiratory | 73% | 91% | +18% |
| Bulbar | | | |
| *Respondents* | *n=68* | *n=36* | |
| Speech pathologist | 75% | 100% | +25% |
| Dietetics/Nutrition | 71% | 92% | +21% |
| Bowel and bladder dysfunction | | | |
| *Respondents* | *n=92* | *n=8* | |
| Nursing | 52% | 50% | -2% |
| Dietetics/Nutrition | 77% | 63% | -15% |
| Palliative care | 34% | 13% | -21% |
| Fatigue and sleep | | | |
| *Respondents* | *n=105* | *n=25* | |
| Respiratory | 67% | 60% | -7% |
| Palliative care | 25% | 36% | +11% |
| Mood and cognition | | | |
| *Respondents* | *n=107* | *n=7* | |
| Psychology/counselling | 49% | 43% | -6% |
| Pain | | | |
| *Respondents* | *n=108* | *n=19* | |
| Palliative care | 24% | 21% | -3% |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

Knowledge of MND and delays were the most prevalent issues impacting access to health professionals. This was followed by needing to travel long distances, local availability, physical barriers and support to attend appointments. Cost was also a barrier for some.

Figure 5.2 Issues accessing allied health professionals (n=220)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

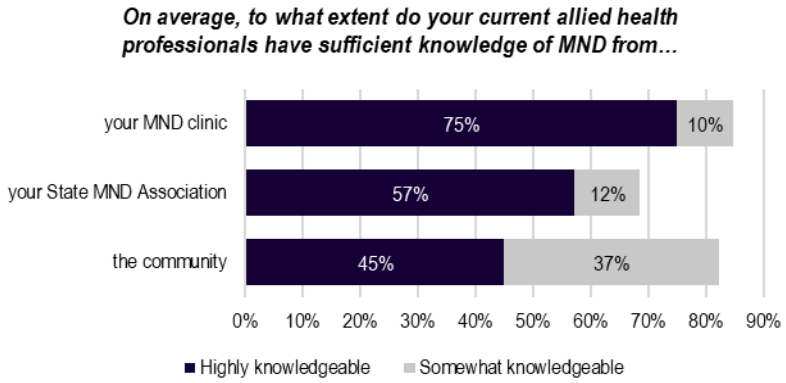
## Knowledge of MND

People living with MND reported that few professionals had adequate experience with the disease. This was particularly relevant for General Practitioners, which all those with MND need to access. Only 19% (n=42) of those with MND reported their GP to be highly knowledgeable regarding MND. Those living with MND also noted in consultation a low level of knowledge in public hospitals, such as emergency departments.

Those that do have relevant expertise are often more expensive, increasing the cost burden for those living with MND in accessing treatment and care.

Allied health professionals accessed through MND Clinics and State MND Associations were seen to be more knowledge of MND than those in the community. A large majority (75%) of allied health from MND clinics were considered highly knowledgeable, followed by a small majority of those from a State MND Association (57%), compared to a large minority (45%) of those in the community.

Figure 5.3 Knowledgeability of allied health professionals by method of access (n=217)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

### Service system capacity

People living with MND reported in consultations that finding health professionals in their local area can be difficult. This difficulty was due in part to shortages in many roles across the health sector, including allied health, GPs and palliative care. Barriers to access, or delays due to shortages, can have significant ramifications for care and support.

### Ambiguity on the role of palliative care

There is confusion on the role of palliative care in MND management. People living with MND and health professionals noted in consultations that many assume palliative care is only for end-of-life care, with limited understanding that it can be accessed earlier to manage symptoms, facilitate advance care planning discussions and improve quality of life. MND clinics that integrate palliative care were reported in consultations to improve quality of life.

### Funding

Access to psychology, counselling, and social work is impacted by funding. Clinicians and State MND Associations noted in consultations that it can be difficult to gain approvals to use government support to fund these services, or often there is no funding left for these services after more pressing physical health or personal care needs are paid for.

### Genetic counselling

Availability, willingness, and cost impact access to genetic counselling. Most MND clinics do not have a genetic counsellor attached to the clinic, which requires a separate referral. Clinicians noted that genetic counselling and testing can be distressing, so many decide not to pursue this care. Genetic counselling costs are also often not covered by government funding.

## Differences

### Regionality

Some issues were exacerbated by regionality. Travel times were reported as a significant issue for a sizeable minority (34%, n=10) of those in outer regional areas, more so than in major cities (4%, n=4) and inner regional areas (18%, n=12). A majority in outer regional areas reported issues finding allied health professionals with experience in MND (62%, n=18), compared to major cities (46%, n=51) and inner regional areas (37%, n=24).

Fewer of those in regional areas rated their professionals as highly knowledgeable (38%, n=10) than in major cities (44%, n=43) or inner regional areas (52%, n=33). This issue extended to GPs, with the fewer reported to be highly knowledgeable with MND (7%, n=2) compared to major cities (15%, n=17), and inner regional areas (30%, n=20). This indicates that even when professionals are accessed, it is less specialised and effective.

### State

Three State MND Associations provide allied health services for their members (MND QLD, MND WA and MND SA). This aligns with their higher reported levels of access and knowledgeability. Though there is a smaller number of respondents from WA (n=23) it is notable that it was the only state with higher levels of allied health professional access via a State MND Association than an MND clinic (39%, n=9 compared to 35%, n=8). The allied health provided through these State Associations was reported to be highly knowledgeable in QLD (88%, n=21), SA (83%, n=10), and WA (82%, n=14).

## Government support

Care settings differ between types of government support. Those receiving support from the NDIS access allied health professionals from private practice (n=108) more often than those on My Aged Care (n=56) (61% to 24%). Conversely, those on My Aged Care utilise public hospitals more often than those on NDIS (30% compared to 16%).

## Education

University educated respondents also reported higher levels of access to private practitioners (53%, n=58) when compared to those who went to TAFE (34%, n=18) or high school (27%, n=14).

## Survey bias

People living with MND with more severe symptoms were less likely to respond to the survey, creating a bias that underrepresents those with extremely impactful symptoms and access to professionals such as palliative care.

Those engaged with the State MND Associations were more likely to respond to the survey, meaning the proportion receiving support from State MND Associations (i.e. advisors / coordinators or allied health), is likely overrepresented.

# 6 MND Clinics

Finding 4 MND Clinics

- Most of those living with MND reported accessing a specialist MND clinic.
- Most of those that had attended an MND clinic were satisfied with their care.
- Almost half of respondents living with MND had accessed their health professionals through an MND clinic, and those that do report increased access to health professionals.

## Overview

MND Clinics deliver coordinated multidisciplinary care for those living with MND. Clinics are available in all states and territories except for NT. Each clinic operates differently, with varying numbers of disciplines involved, services provided and funding models. Some may only have 3 or 4 disciplines servicing the clinic, whereas others have all required medical, allied health, nursing and support disciplines involved.

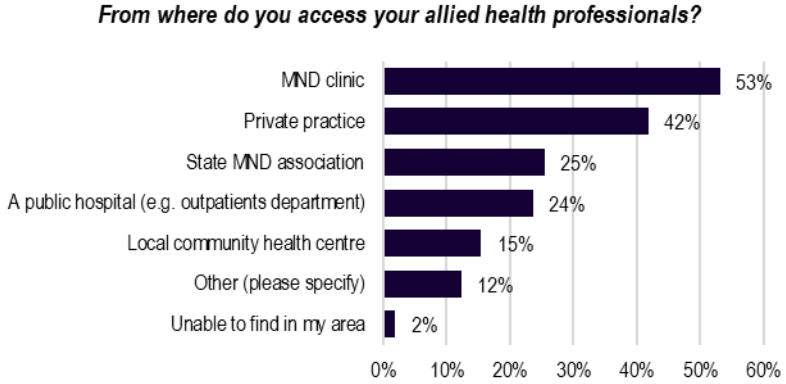
Those linked to an MND clinic may be reviewed every 3 to 6 months, depending on their rate of progression. Between clinic reviews, people living with MND may access support from clinic staff as needed, or from other health professionals (such as community allied health or private practitioners). This means they may often have a large number of healthcare professionals involved in their care, from a variety of settings.

## Outcomes

Most respondents (84%, n=185) had accessed an MND clinic. A large majority of whom were either extremely satisfied (68%, n=124) or somewhat satisfied (28%, n=52). Only a small minority (4%, n=7) were not at all satisfied.

People access allied health professionals from a variety of settings, but primarily through MND clinics (53%) and private practice (42%). A quarter accessed them through state MND associations (25%) and departments within a public hospital (24%).

Figure 6.1 How allied health professionals are accessed (n=220)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

Access to MND Clinics improves access to professionals. Comparing those who don't access clinics (47%, n=105) to those who do access (53%, n=115), access to specialist professionals decreased by 10% on average. This difference was greater for genetic counselling, State MND Association support, nursing, physiotherapy, psychology, and social work. Note that access to State MND Association Advisors and/or Support Coordinators and NDIS Support Coordinators may instead lead to increased access to MND Clinics, as they are unlikely to be referred from the clinic.

Table 6.1 Improvement in access through MND clinics

| Specialty | With MND Clinic (n=117) | Without MND Clinic (n=110) | Difference |
|---|---|---|---|
| Genetic Counselling | 26% | 0% | +26% |
| State MND Association Advisors and/or Support Coordinators | 91% | 77% | +14% |
| Nursing | 51% | 41% | +10% |
| Physiotherapy | 90% | 80% | +10% |
| Psychology or Counselling | 43% | 33% | +10% |
| Social Work | 30% | 20% | +10% |
| Dietetics/Nutrition | 74% | 65% | +9% |
| Speech Pathology | 78% | 70% | +8% |
| Neurology | 95% | 87% | +8% |
| Respiratory | 64% | 58% | +6% |
| Occupational Therapy | 89% | 84% | +5% |
| Palliative Care | 30% | 28% | +3% |
| NDIS Support Coordination | 57% | 55% | +1% |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Multidisciplinary care

People living with MND noted that the 'one stop shop' approach made access to informed professionals easy, who were then better able to coordinate care, treatment and support. This holistic care, they reported, underpinned the effectiveness of the other professionals they access and their outcomes in general.

## Continuity of care

Those living with MND often have to connect their MND Clinic health professionals to their health professionals based in the community, or from other services. In consultation, some reported frustration in having to detail records at their MND Clinic sessions, which they then communicated to professionals in the community to improve continuity of care. Those that received their care in more connected and localised communities reported that their health professionals often initiate and maintained communication with each-other, filling this gap.

# Differences

## Survey bias

Results are likely impacted by survey bias, in that those responding to the survey are more likely to be engaged with the State MND Associations and other supports. This explains the very high proportion that received support from a State MND Association, as well as the high proportion that had accessed an MND Clinic.

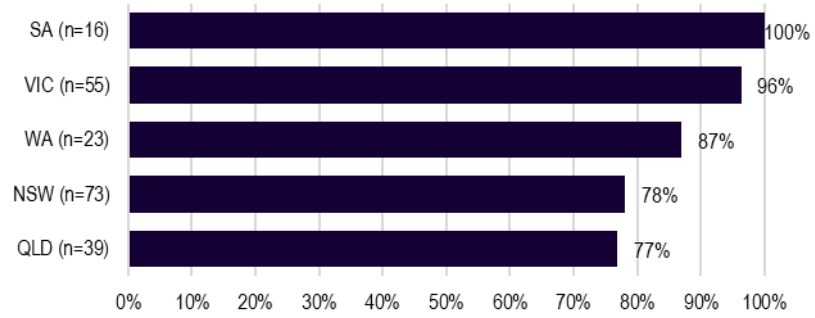
## Regionality

Results differed for those in outer regional areas, where reduced access to professionals through MND clinics was observed 31% (n=9), compared to for major cities 58% (n=65) and inner regional 56% (n=37). They were more dependent on private practice (62% compared to 38% for major cities and inner regional) and public hospitals (38% compared to 16% for major cities and 30% for inner regional).

## State

Access to MND Clinics differed by state. The sample size for some states was too small for comparison: TAS (n=4), ACT (n=3), and NT (n=1). Access was high (>75%) across all compared states, with the highest rates in SA and VIC followed by WA and NSW, and QLD the lowest.

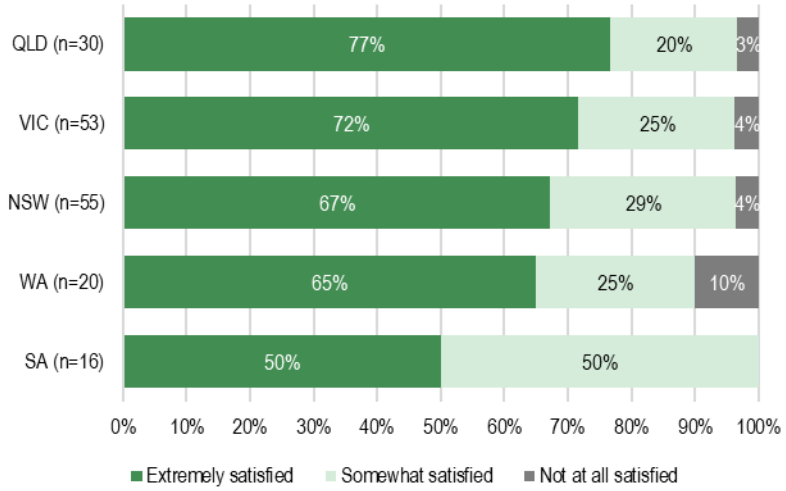
Figure 6.2 Access to MND clinics by state for people living with MND




*Source: MND Community Survey 2025, analysis by ACIL Allen*

Satisfaction with quality of care also differed by state. The proportion that was extremely or somewhat satisfied was high (>75%) for all compared states, though the QLD had the largest majority that was extremely satisfied, followed by VIC, NSW, and WA close together, and SA the lowest.

Figure 6.3 Satisfaction with MND clinic quality of care by state for people living with MND




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# 7 Treatment

Finding 5 Treatment

- Access to treatments was highly dependent on the needs of the person living with MND.
- Barriers to access included wait times / delays, cost, and understanding the options available.

## Overview

People living with MND can access treatments and medical interventions that may help to either manage symptoms or improve quality of life. Prescription and use were dependent on the needs and preferences of the person living with MND.

## Outcomes

Access to drugs depended on the type of MND and severity of symptoms. Most people living with MND accessed the drug Riluzole (76%, n=161) which can be prescribed to those with ALS and its variants. Tofersen / Qalsody had much lower access (3%, n=6), which is to be expected, given it is only for those with the SOD1+ mutation.

Access to medical interventions also depended on symptoms. A minority of people living with MND accessed an NIV/BiPAP (30%, n=56), gastronomy tube for feeding (25%, n=51), a cough-assist device (13%, n=24), or a tracheostomy (2%, n=4). Access to some medical interventions increased sharply for those extremely impacted by the relevant symptoms, such as NIV/BiPAP for respiratory issues (+58%) and gastrostomy tube for bulbar issues (+32%). Some decreased, such as cough-assist device (-11%) and tracheostomy (-5%).

Table 7.1 Medical interventions access by symptom type and impact

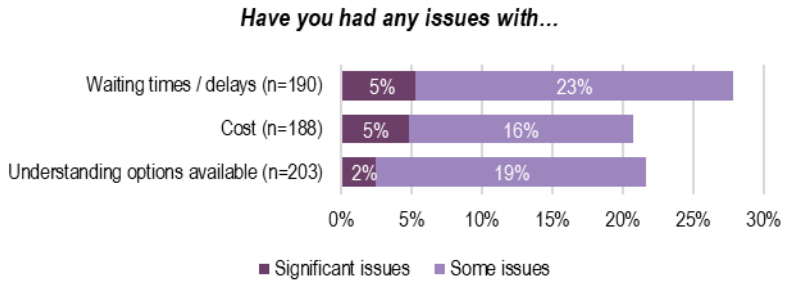
| Medical intervention | Moderate | Extremely | Difference |
|---|---|---|---|
| Respiratory | | | |
| *Respondents* | *n=67* | *n=9* | |
| NIV / BiPAP | 32% | 90% | +58% |
| Cough-assist device | 22% | 11% | -11% |
| Tracheostomy | 5% | 0% | -5% |
| Bulbar | | | |
| *Respondents* | *n=63* | *n=36* | |
| Gastrostomy tube for feeding (i.e. PEG or RIG) | 24% | 56% | +32% |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Drivers

Barriers to access were aligned with those of equipment, modifications, and professionals, including waiting times (27%), cost (21%), and understanding what options are available (21%).

Figure 7.1 Treatment barriers




*Source: MND Community Survey 2025, analysis by ACIL Allen*

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# Carers

# 8 Carer experiences

Finding 6 Carer

- Carers rated their quality of life as lower than other respondent groups. This is driven by the significant time spent caring due to limited access to paid support. In turn, this reduces opportunities for self-care, employment and community participation.
- Half of carers reported not having a well-equipped residence, nor having all the equipment or home modifications required to meet the needs of the person they care for. This was largely driven by lack of funding, with almost half considering their funding insufficient.
- Outcomes and barriers are worse for carers in regional areas, or those without government financial support.

## Overview

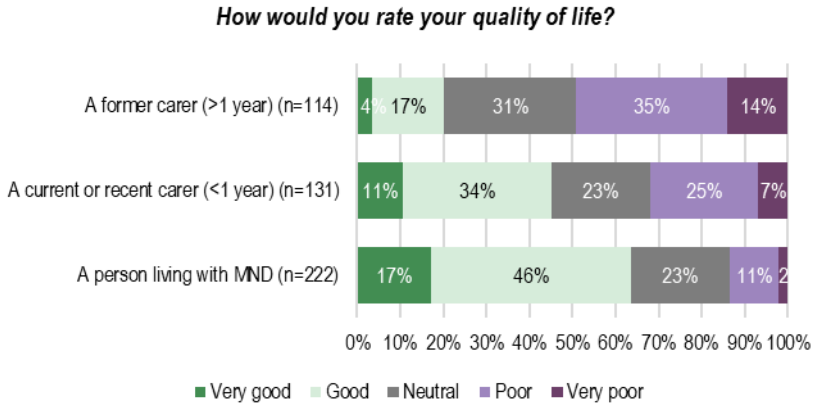
Those living with MND require dedicated support, with a single person usually taking on the role as the primary carer. This role is often undertaken by partners, but can also be a child, sibling, or friend.

Being a carer involves taking responsibility for the wellbeing of the person living with MND by actively caring for them day-to-day and acting as their advocate within the various support systems.

## Outcomes

Carers rated their quality of life poorer than both those living with MND and gene carriers. Less than half of current or recent carers reported their quality of life as good (34%) or very good (11%). The proportion was even lower for former carers, whereby only a small minority (21%) rated their quality of life as very good (17%) or good (4%), during the period of care.

Figure 8.1 Quality of life




Note: For former carers the question had the addition 'during the period of care'

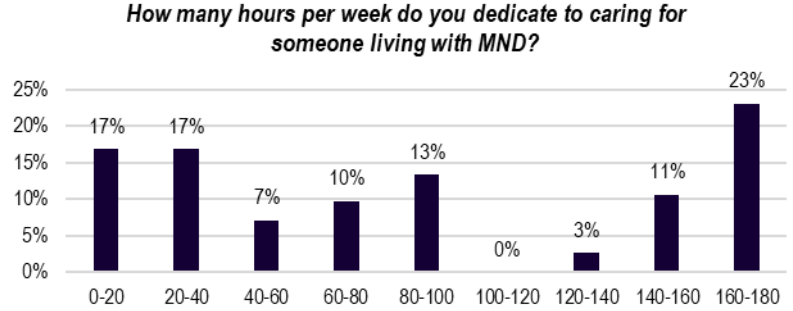
*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Time commitment

There are high demands of carers. Of current and recent carers (n=114), almost a quarter (23%) reported spending all their time caring (+160 hours per week), and the majority (66%) spent more than a full-time job (+40 hours per week). Demands often increased as the disease progressed and needs became more severe, requiring additional support.

Figure 8.2 Time commitment for current and recent carers (n=114)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Respite care

Only a minority of carers reported accessing respite care (15%, n=16), either in the home, in an aged care facility, or within a palliative care unit. Reasons for not accessing respite included feeling they don't need it (54%, n=58), choosing not to access it (12%, n=13). Some carers reportedly wanted to access respite care but couldn't, because the person they care for refused (7%, n=7), or they were unable to find suitable options (11%, n=12).

## Paid support

Support from paid / formal carers was insufficient for most carers. While a sizeable minority (43%, n=39) consider paid support to be sufficient, the remainder report that they only receive some (31%, n=28), little (12%, n=11), or insufficient support (14%, n=13).

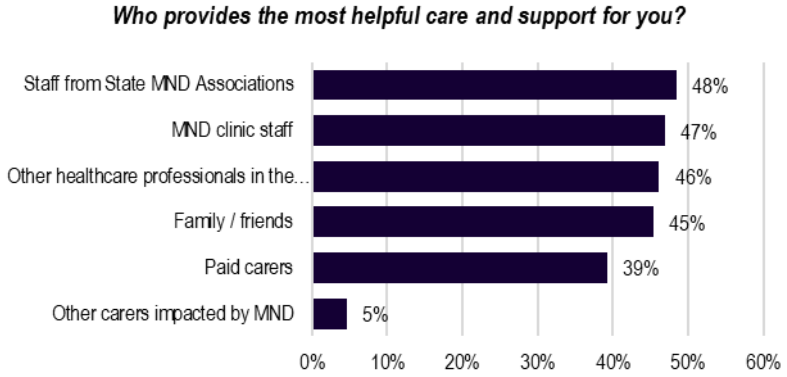
Of those that access paid support, the number of hours provided was limited. The large minority (39%, n=45) reported accessing 10 hours or less, with most of the remaining minority (12%, n=14) accessing 10-20 hours, and very few accessing 20-30 (8%, n=9) or 30-40 (6%, n=7) hours of care. There was a minority that accessed a very high level of paid care, more than 40 hours per week (14%, n=16).

The quality of paid support is impacted by the limited knowledge of MND. Only a small minority (7%, n=6) considered paid carers to be highly knowledgeable, half (57%, n=52) considered them somewhat knowledgeable, and a sizeable minority (29%, n=26) considered them to be not knowledgeable at all. Carers reported in consultations that this was driven in part by inconsistency of staffing, which requires ongoing upskilling of paid support to understand MND and its impacts.

## Care and support for carers

Carers considered support from paid carers to be the least helpful type of care and support for them. Other options rated more highly, notably staff from state MND associations, MND clinic staff, other healthcare professionals in the community, and family/ friends; noting not all carers get access to all these supports.

Figure 8.3 Most helpful care and support for current and recent carers (n=130)



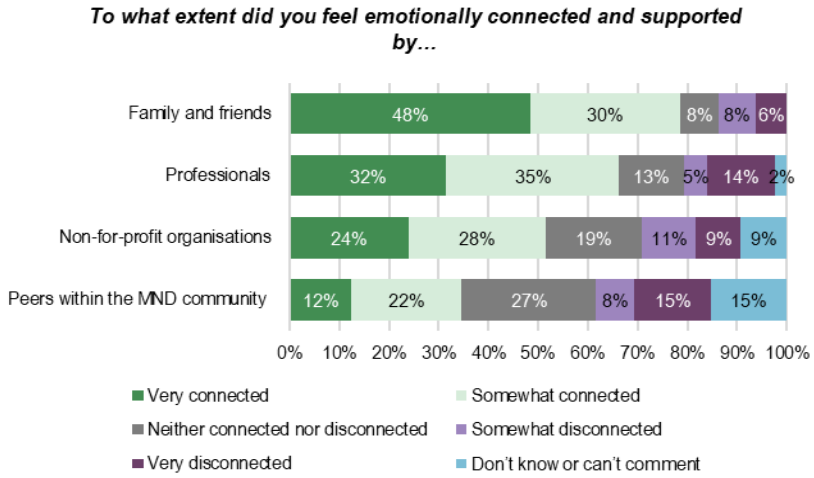

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Emotional connection and support

Carers draw on multiple sources of emotional connection and support. A majority of carers (78%) reported feeling very (48%) or somewhat (30%) emotionally connected and supported by family and friends, as well as professionals (very 32% and somewhat 35%). Some carers reported no emotional connections or support from family / friends (22%), or peers within the MND community (23%).

Carers may be at additional risk of isolation or burnout, reinforcing the importance of emotional support from professionals or not-for-profit organisations.

Figure 8.4 Emotional connection and support for current and recent carers (n=130)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

Carers who did access peer support reported it was essential for them, providing both emotional connection and support, as well as practical information. There may be a number of carers who would like to access peer support, but struggle to do so due to limited time and prioritising the needs of the person living with MND. However, few (5%) reported these were most helpful when compared to family / friends, staff from state MND associations, MND clinic staff, and other healthcare professionals in the community.

## Family support

While most reported strong emotional connection and support from family and friends, for many this support does not extend to assisting with care. Only a minority reported receiving significant (16%) or moderate (17%) support from family, with the majority reported getting help sometimes (38%) or not at all (30%).

## Equipment

Carers also identified difficulties in accessing equipment, reporting that access was worse for home modifications.

- Regarding their residence, a sizeable minority (38%) considered it very equipped to support a person living with MND, the rest considered it somewhat (35%), neither equipped nor unequipped (11%), somewhat unequipped (9%), or very unequipped (6%).
- Regarding equipment, and consistent with the reports of those living with MND, half (46%) reported they had everything they needed, while the other half reported they had some (44%) or none (9%) of what they needed.
- Regarding home modifications, only a minority (35%) reported having everything they needed, and the majority reported they had only some (40%) or none (20%) of what they needed.

These issues result in additional effort, work, and risk for carers as they compensate through taking on demands, such as lifting, in the absence of required equipment and modifications. This can translate into income impacts due to the reduced ability to take on paid employment.

## Carer income and funding

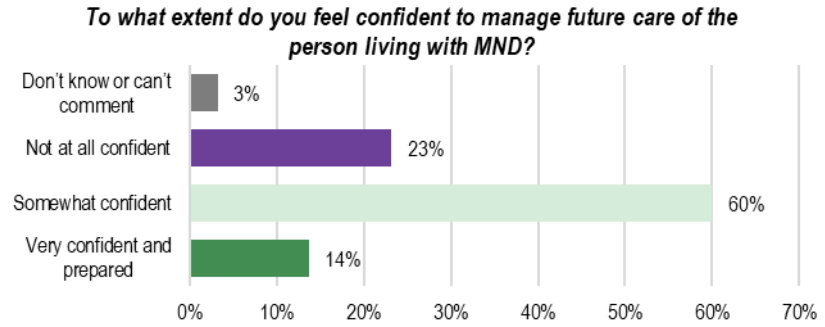
The acquisition of equipment, home modifications, and other support is contingent on the funds to purchase them. Though many of those living with MND receive government funding, as noted above there can be significant delays or additional costs.

This issue is compounded by the impact of the disease on the carer's income: the majority reported that their income has been significantly (43%) or moderately (14%) reduced. Additionally, a significant minority reported that their funding was somewhat (21%) or significantly (21%) less than what they needed.

## Future care needs

Given the uncertainty of the disease, carers live with a high level of ambiguity about the future. Only a small minority (14%) reported that they felt very confident and prepared, with a larger minority reporting they were not at all confident (23%) to manage future care needs.

Figure 8.5 Confidence managing future care for current and recent carers (n=95)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Differences

## Regionality

Those in outer regional areas reported similar levels of time commitment as well as reliance on and relationship with family and friends. However, they reported lower levels of support.

Access to paid and respite care was lower and less knowledgeable. More of those in outer regional areas (39%, n=7) reported having insufficient access to paid carers compared to major cities (18%, n=17); more of them were reported to be not knowledgeable concerning MND (61%, n=11) compared to major cities (35%, n=34). The same was true for respite care, with fewer (16%, n=5) getting access compared to major cities (23%, n=33).

Carers in regional areas also reported having additional needs, fewer supports, and lower confidence. More reported that they did not have the equipment they needed (16%, n=5) compared to major cities (8%, n=11). Fewer reported helpful support from MND clinics (16%, n=5) compared to major cities (49%, n=70). More reported that their income had been significantly impacted (53%, n=17) compared to major cities (41%, n=59). Fewer reported feeling very confident and prepared to manage future care (0%) compared to major cities (15%, n=8).

Table 8.1 Carer measures by regionality

| Measure | Major cities | Outer regional |
|---|---|---|
| Insufficient access to paid care | 18% | 39% |
| | (n=17) | (n=7) |
| Paid care not knowledgeable concerning MND | 35% | 61% |
| | (n=34) | (n=11) |
| Accessed respite care | 23% | 16% |
| | (n=33) | (n=5) |
| Had equipment needed | 8% | 16% |
| | (n=11) | (n=5) |
| Reported helpful support from MND Clinics | 49% | 16% |
| | (n=70) | (n=5) |
| Income significantly impacted | 41% | 53% |
| | (n=59) | (n=17) |
| Confident managing future care | 15% | 0% |
| | 8 | 0 |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Government support

Almost half of those without government support payment reported they had somewhat (23%) or significantly less (25%) financial support than they needed, compared to those with carer allowance (17% and 9%respectively) and carer support payment (10% and 16% respectively). This has ramifications for their support, equipment, and residence.

Table 8.2 Funding sufficiency for current or recent carers by government support type

| Funding needed | Somewhat less than enough | Significantly less than enough |
|---|---|---|
| No government support (n=136) | 23% | 25% |
| Carer support payment (n=31) | 10% | 16% |
| Carer allowance (n=53) | 17% | 9% |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

People living with MND without government support were less likely to report they had sufficient paid support (31%) compared to those on carer allowance (43%) and carer support payment (52%).

They were also less likely to report that they had all the equipment (30%) or home modifications (21%) they needed compared to those on carer allowance (50% and 39% respectively) and carer support payment (67% and 39% respectively).

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# Gene carriers

# 9 Gene carrier experience

Finding 7 Gene carriers

- Most gene carriers struggled to connect with the MND gene carrier community. This is likely driven by how disparate and small the community is.
- Only half of respondents reported timely and adequate access to genetic counselling. This is driven by access barriers , the knowledge and supportiveness of GPs, and cost.
- Nearly all desired:
  - improved access to trials
  - more regular screening with neurologists
  - improvements to peer support platforms.

## Introduction

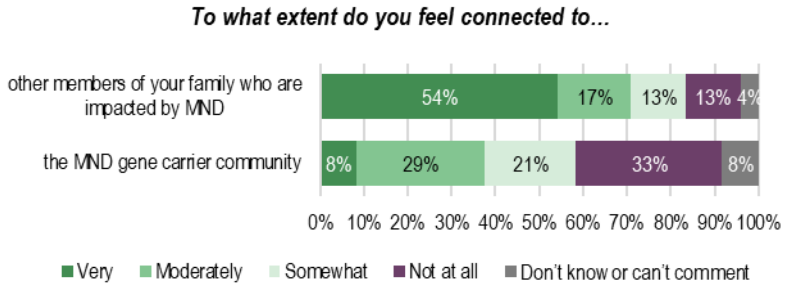
An MND gene carrier is an individual who carries a positive MND-related gene fault but is asymptomatic. These mutations are inherited, meaning they are passed down from parent to child.

While a carrier has a higher chance of developing MND, not everyone with a genetic mutation will develop the disease. Gene carriers can usually identify one or more family members who are either currently living with the disease, or have died from MND. They may have acted in the role as primary carer.

## Outcomes

The majority (54%) of gene carriers were not at all, or only somewhat, connected to the MND gene carrier community, compared to a small minority (30%) stating the same for other members of their family who are impacted by MND.

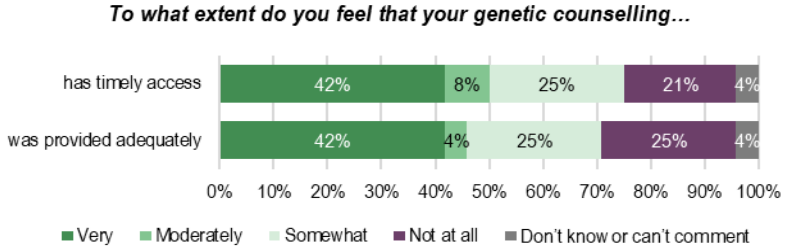
Figure 9.1 Gene carrier connection to family and community (n=24)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

In seeking genetic counselling, only approximately half believed that they got very or moderately timely access (50%) and that it was provided adequately (46% very or moderately).

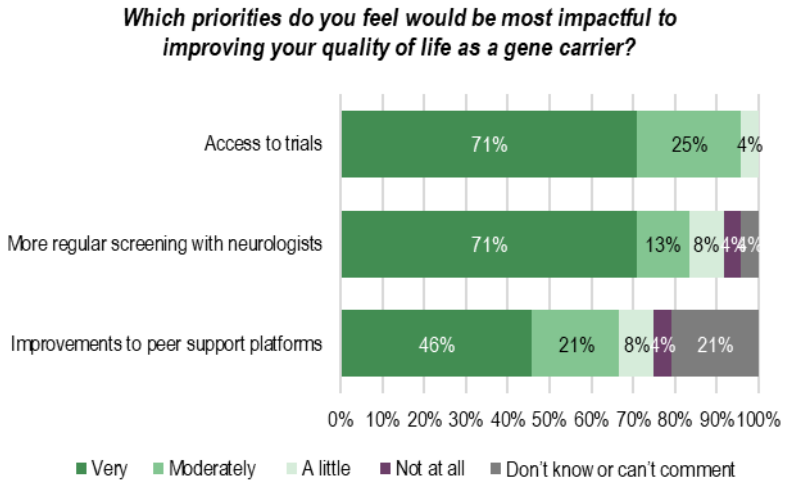
Figure 9.2 Gene carrier genetic counselling (n=24)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

When asked what would improve their quality of life, nearly all gene carriers reported that access to trials (96%, n=23), more regular screening with neurologists (84%, n=20), and improvements to peer support platforms (67%, n=16) would very or moderately improve their quality of life.

Figure 9.3 Gene carrier priorities




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Community connection

The lack of connection to the MND gene carrier community may be due to fewer known numbers of people in the community, and dispersed geographical location.

Information concerning MND gene carrier communities can be difficult to find. One respondent reported that they discovered an Australian gene carrier peer group via an international contact and only did so years into their journey.

The challenges surrounding community connection were reflected in the desire for improvements to peer support programs, with a majority (67%) noting these would very or moderately improve their quality of life.

## Genetic counselling access

Access to genetic counselling varies across Australia; and may be particularly difficult for families who are not linked to an MND clinic, or if the clinic does not have genetic counselling embedded into the service. Genetic counselling is generally not covered through government funding, often creating a financial burden.

## Knowledge of MND

Knowledge of GPs regarding MND and their support of genetic testing can prove a significant barrier to support. Gene carriers reported experiencing resistance from some GPs in providing referrals, which creates both delays and stigma for the person seeking genetic testing. As noted earlier, the knowledgeability of GPs concerning MND is reported to be low, and even lower in outer regional and remote areas.

## Neurologist access

Many gene carriers seek referrals to neurologists for screening and additional information. Access is impacted by the same wait lists that face those living with MND. The abovementioned cost barriers to genetic counselling may be even higher for these specialists, when factoring in ongoing review costs.

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# Common experiences – Information and research

# 10 Information

Finding 8 Availability of information

- The majority of those living with MND and current or recent carers reported having most of the information they need.
- The most useful information sources were MND Australia website (MND Connect), State MND Association newsletters, and in-person sessions.
- Preferences differed among cohorts:
  - Older community members preferred the state MND newsletter while younger members preferred podcasts and Facebook groups.
  - University educated community members found medical journals and international websites more useful, while those TAFE and high school educated preferred community Facebook groups.
  - Women were more likely to engage in community Facebook groups than men.

## Overview

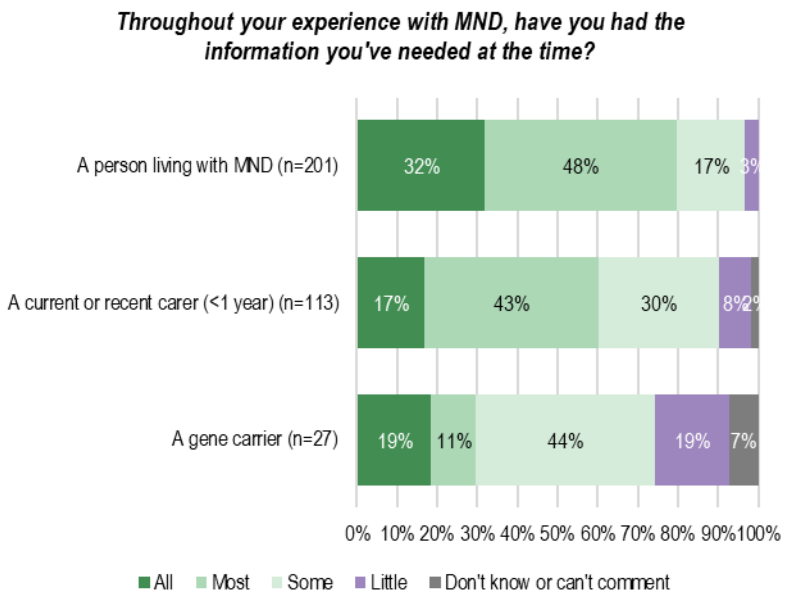
Effective management of MND requires navigating a plethora of information. The breadth of information reflects the diversity of experiences with MND, and the range of supports required. Accessing the right information at the right time is essential to self-advocate and make informed decisions.

Information can come from a variety of sources. This includes centralised and managed sources such as MND Connect, a national website of consolidated information, State MND Associations, and international MND/ALS websites. Additionally, the community has private peer Facebook groups and online platforms for information sharing.

## Outcomes

A majority of those living with MND have had all (32%) or most (48%) of the information they've needed. A smaller majority of current or recent carers reported the same (17% and 43% respectively). Conversely, only a minority of gene carriers had sufficient information (19% and 11% respectively).

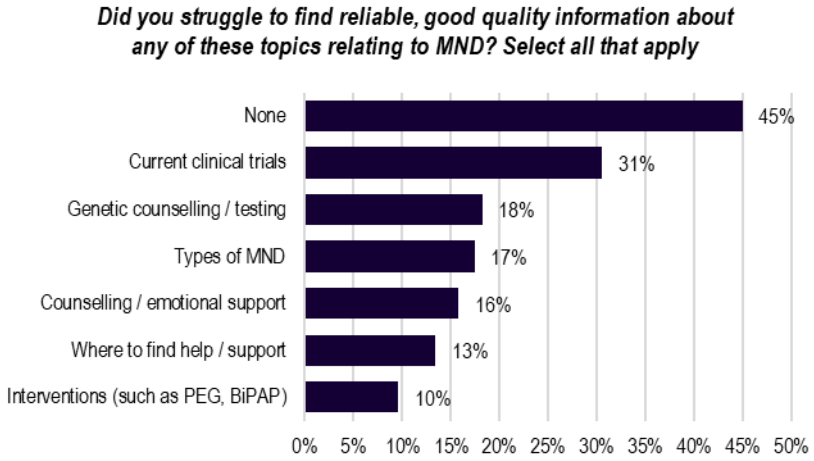
Figure 10.1 Information needed




*Source: MND Community Survey 2025, analysis by ACIL Allen*

People living with MND and their carers struggled most to find information on current clinical trials (31%).

Figure 10.2 Information topics for people living with MND and current and recent carers (<1 year) (n=305)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

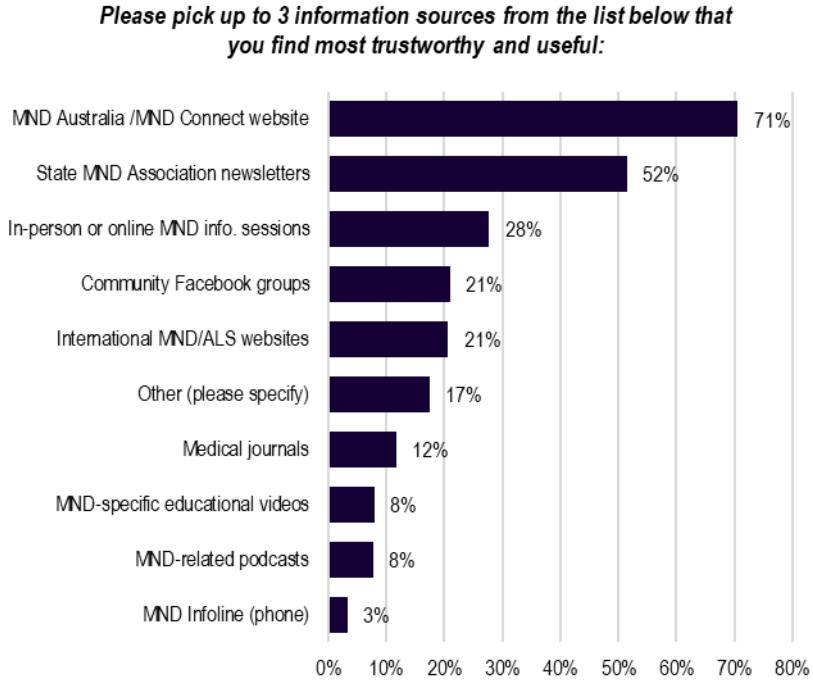
A small number of gene carriers (n=9) also responded to this question, with almost half stating they struggled with genetic counselling / testing and interventions, and a third stating they struggled with the other topics.

# Drivers

## Information sources

The most useful sources of information were MND Australia website (MND Connect) (71%), followed by State MND Association newsletters (52%). This likely reflects a bias in the survey distribution method via MND Australia and the State MND Associations.

Figure 10.3 Information sources (n=425)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

It is worth noting that respondents may have conflated the MND Australia website (MND Connect) with the MND Infoline. The MND Infoline number which people call for support and referral to State MND Associations can be accessed via the MND Australia (MND Connect) website. This means the high response (71%) may indicate that respondents are referring to both the Infoline and the website, rather than the website specifically. This could also explain why the MND Infoline (phone) is rated lowest (6%) in the survey, when further consultation with those living with MND and their carers revealed that both MND Connect and state MND Association phoneline support were an essential first step in their MND journey.

# Differences

## Gene carrier needs

While gene carriers share a connection with those living with MND and their carers, they have different information needs. Most resources are oriented to those living with, or experiencing the symptoms, of the disease. Additionally, gene carriers reported interest in accessing information on the most uncertain part of MND – its cause and genetic testing – which remains an area of ongoing research.

## Type of MND

The struggle to find information on types of MND was common across types of MND. Respondents with primary lateral sclerosis (PLS) had the highest proportion (41%) of issues, noting their low number of respondents (n=22). It was also slightly higher for those unsure about their type of MND (25%); again, noting a small number of respondents (n=20).

# 11 Research participation

Finding 9 Research participation

- Most respondents wanted to participate in research.
- A majority of those living with MND had received an offer to participate in research, while only a minority of carers had received the same.
- Most that received an offer accept, those that declined cited physical barriers (time and distance) as their primary barriers.
- When asked concerning improvements, the biggest priority was to improve the access and regular communication of research opportunities and outcomes.

## Overview

The cause of MND is not known and remains an active area of research. Research into causes, treatments, and quality of life improvements involves research participation from those in the MND community.

## Outcome

Most people living with MND and current or recent carers wanted to be involved in research. While the majority of those living with MND had received an offer to do so, only a minority of current or recent carers had the same.

For those who were invited, the majority accepted the offer and had a good experience, but few heard about the outcomes. To improve their experience and engagement with research, a large minority (40%, n=159) wanted to be kept updated on the progress of research. Some noted that getting updated about research was a “constant battle”.

Table 11.1 Research participation

| Measure | Living with MND % Yes (n) | Current or recent carers % Yes (n) |
|---|---|---|
| Desire to participate | 80% (177) | 72% (79) |
| Receive offer to participate | 64% (130) | 25% (27) |
| Accept offer to participate (of those that received an offer) | 85% (109) | 78% (21) |
| Had good experience (of those that accepted an offer) | 80% (87) | 90% (19) |
| Heard about any outcomes (of those that accepted an offer) | 31% (34) | 33% (7) |

*Source: MND Community Survey 2025, analysis by ACIL Allen*

## Drivers

### Survey bias

Those responding to the survey are likely to be engaged with the State MND Associations, and therefore also more likely to be engaged with the MND community and research opportunities. Therefore, the proportion of those living with MND participating in research is likely overinflated.

### Information

When asked about how their engagement with research could be improved, responses indicated that there was a lack of information. The biggest priority (70%, n=281) was to have information about current research opportunities that was easily accessible or regularly communicated. Other priorities included being able to more readily talk to researchers about their research topics (23%, n=90) and education on how to analyse and participate in research (21%, n=82).

### Physical barriers

Some faced physical barriers. Of the proportion that declined to participate (n=30), they noted the following barriers time commitment (13%), location of the research (10%) and being unsure of what is involved with research (7%).

### Research focus

The larger proportion of those living with MND involved in research compared to carers reflects the current primary focus on discovery / scientific research, i.e. cause and treatments, rather than care and quality of life. Though this priority order aligns with the priorities of the MND community surveyed (see following section), it has been identified that care research needs additional focus.

### Gene specificity and inclusion criteria

It is important to note that while access and information to research can be improved, those living with MND also commented on the often-strict inclusion criteria for research participation. For example, some studies may be phenotype specific (e.g. only for those with ALS), or gene specific (e.g. only for SOD1+), so are not available for all to participate in. On this note, gene carriers also desired an expansion of inclusion criteria (48%, n=13) more than the average across the respondent types (20%), likely indicating a desire to be included in more research.

## Differences

The proportion of those offered the opportunity to participate in research was consistent across demographics, likely reflecting the abovementioned survey bias.

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# Community priorities

# 12 Research priorities

Finding 10 Respondent research priorities

- The biggest priorities for research were identifying the cause of MND and new clinical trials to slow progression.
- Other important priorities include improving quality of life and improving diagnosis.
- Though evidence for policy change and advocacy was considered the least important, this should not be undervalued.
- Those with more impactful symptoms have more focus on the cause and slowing progression.
- Carers put more focus on evidence for policy change than those living with MND.

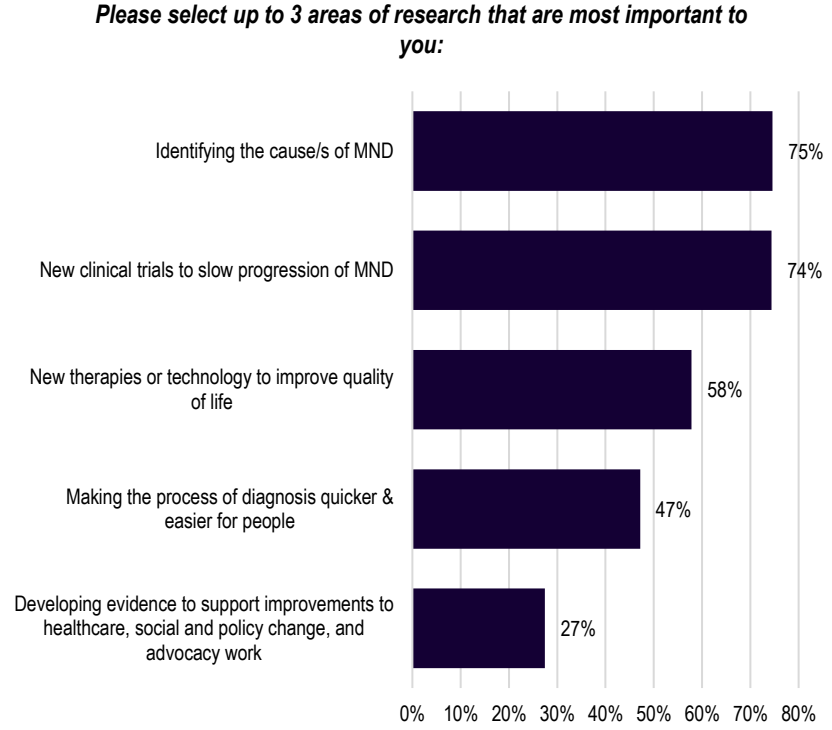
## Introduction

A core function of both MND Australia and FightMND is to fund grants for MND research, hence it is important these organisations are funding research that is meaningful and important for the MND community.

## Outcome

Across all respondents, the highest priorities for research were identifying the cause and slowing progression of MND (both ~75%). This was followed by improving quality of life (58%), improving diagnosis (47%), and evidence to support improvements to healthcare, social, and policy change (27%).

Figure 12.1 Research priorities




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Understanding with the disease

These priorities were consistent with the expectations of those living with MND and their carers, in that understanding the disease itself is a significant priority, while quality of life and diagnosis are also important.

## Evidence for policy change

When discussing developing evidence to support policy change in consultation, the MND community noted that it was unclear how this translates into quality-of-life outcomes for people living with MND and carers.

Clinicians noted that care research has historically had less focus than discovery / scientific research, and so fewer people will have been involved with this kind of research nor seen the outcomes.

Additionally, the priority of research for policy change should be viewed in the context of the advocacy priorities in the following section, and the quality-of-life issues outlined in previous sections. The importance of advocacy to improve funding, systems, and access was emphasised by those living with MND and their carers in consultations. Therefore, the importance of this kind of research should not be understated.

# Differences

## Respondent type

Priorities differed slightly between the respondent types. Those living with MND (n=204) placed a higher priority on clinical trials (83%) and less on evidence to support improvements in healthcare, social, and policy change (21%). Current and recent carers (n=92) placed additional emphasis on evidence (72% and 34%) respectively. This difference reflects the immediate focus of those living with the disease of getting help with their symptoms, while carers were able to have a more long-term view of the importance of evidence and policy.

The above pattern was also true for former carers (n=111), with the only difference with current and recent carers being an additional focus on improved diagnosis (59%). This could indicate that diagnosis was worse in the past, but it could also indicate that this is more important in hindsight.

Gene carriers (n=27) were between supported both clinical trials (85%) and evidence to support improvements in healthcare, social, and policy change (41%), but comparatively prioritised identifying causes lower (48%).

## Stage of MND journey

Answers to these questions depended on the stage of the MND journey, with those at later stages more focused on the disease itself. For those with extremely impactful MND symptoms (n=95), more of their priority is on slowing progression and improving quality of life (87% and 68%) more than identifying the cause (71%). Comparatively, those with moderate symptoms agree that all 3 of these areas are important, but the emphasis shifts to finding a cause (74%, 52%, and 77% respectively). This reflects that as the disease progresses the focus for those living with MND naturally narrows to grappling with the disease itself.

# 13 Advocacy

Finding 11 Advocacy priorities

- The top advocacy priority was equitable access to disability funding regardless of age at time of funding commencement.
- The remainder of the priorities were relatively equal and differ based on demographics, though funding for MND clinics is a leader.

## Overview

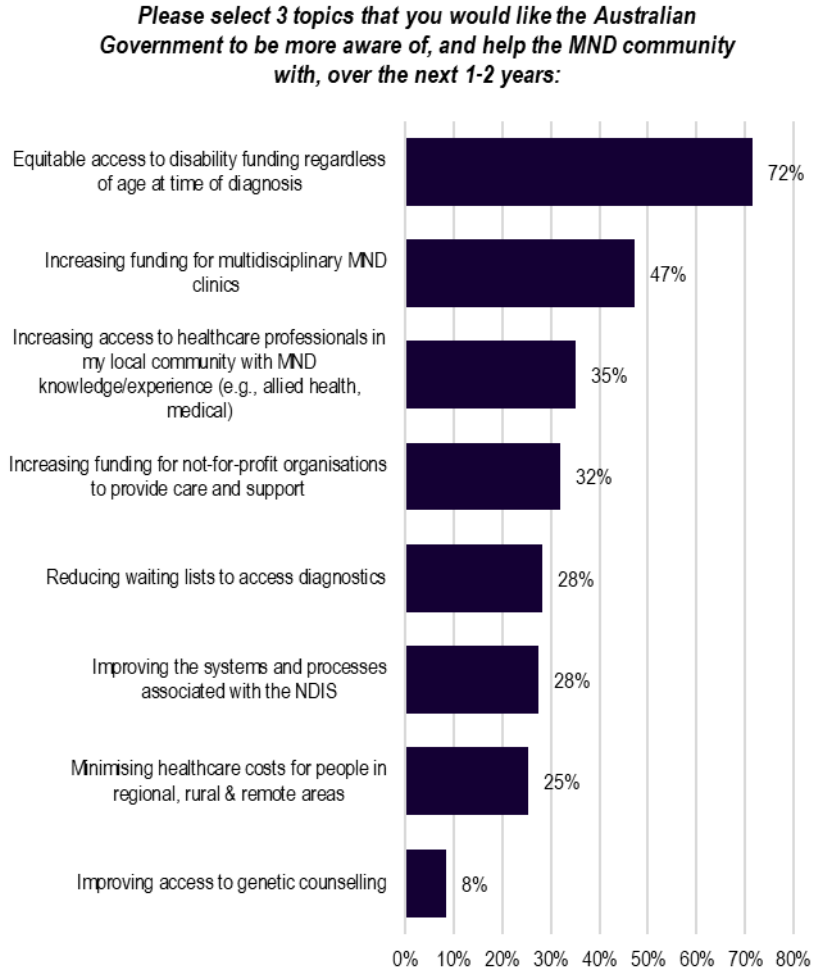
As the national peak body for people impacted by MND in Australia, MND Australia plays a large role in advocating for funding and policy improvements at a federal government level.

## Outcome

Across all respondents, the highest priorities for government advocacy was equitable access to disability funding regardless of age at time of funding commencement (72%).

A distant second was increasing funding for multidisciplinary MND clinics (47%), followed by increasing funding for healthcare professionals in the local community with expertise in MND (35%), increasing funding for not-for-profits (32%), reducing waiting lists (28%), improving systems associated with the NDIS (28%), and minimising healthcare costs for people in regional, rural, and remote areas (25%). Only a small minority (8%) considered genetic counselling a priority, which likely reflects the small proportion of responses from gene carriers.

Figure 13.1 Advocacy priorities




*Source: MND Community Survey 2025, analysis by ACIL Allen*

# Drivers

## Funding

Those living with MND reported that the prioritisation of funding was consistent with their experience. Funding is critical to getting the support that facilitates quality of life. The spread amongst the other priorities reflects the diversity of settings, locations, and supports in the MND community and differs between these groups.

# Differences

## Respondent type

Carers prioritised funding for clinics and healthcare professionals more than those living with MND (+12% for both), though they were consistent in other priorities. This difference may indicate the additional burden that carers take on in advocating for care and these professionals.

Gene carriers differed significantly from the other respondents, potentially reflecting the much lower number of respondents (n=29). Compared to all respondent types, they placed additional priority on genetic counselling (27%) and reducing waiting lists (35%) and less priority on funding for not-for-profits (26%) and equitable access to disability funding regardless of age at diagnosis (54%). Though the additional emphasis on genetic counselling reflects their needs, it should be noted that those listed as highest priority were services they were not currently accessing: equitable funding and MND clinic funding (both 54%).

## Regionality

Those in regional areas had additional emphasis on improving their access to services, and less priority on funding services they do not have. Comparing outer regional areas (n=54) to major cities (n=232) they placed:

- additional priority on:
  - waiting lists to access diagnostics (41%, n=22, compared to 28%, n=64)
  - minimising healthcare costs for people in regional, rural, and remote areas (43%, n=23, compared to 18%, n=42)
  - increasing access to healthcare professionals in my local community with MND knowledge/experience (54%, n=29, compared to 31%, n=71)
- reduced priority on:
  - funding for MND clinics (35%, n=19, compared to 49%, n=114)
  - funding for not-for-profits (11%, n=6, compared to 38%, n=89).

This reflects that in regional areas assistance with their costs and access are more important. Funding MND clinics and not-for-profits is likely lower due to limited access in these areas.

## Government support

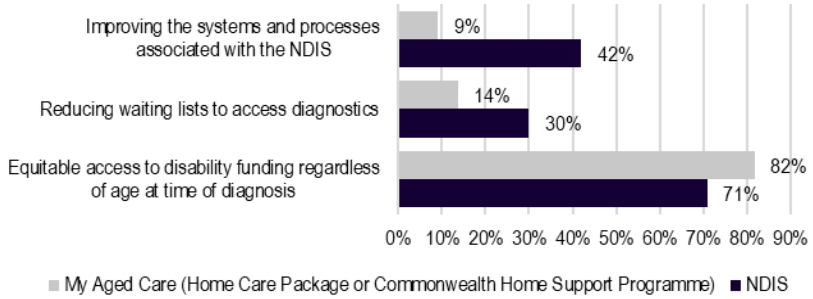
Those living with MND differed priorities based on their type of government support. Compared to those receiving support from the NDIS (n=100), those receiving support from My Aged Care (n=44) placed:

— additional priority on equitable access regardless of age at time of funding commencement (82% compared to 71%)

— reduced emphasis on improving systems and processes associated with the NDIS (9% compared to 42%) and on waiting lists to get diagnostics (14% compared to 30%).

Though these priorities reflect the source of government funding, the increased emphasis on wait lists for those on the NDIS may indicate they experience this issue more intensely.

Figure 13.2 Differences between type of government support for those living with MND (n=144)




*Source: MND Community Survey 2025, analysis by ACIL Allen*

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