Australian MND Community Survey 2025 – Infographic report

ACIL ALLEN

Survey responses



TOTAL respondents across Australia



people living with MND



current or recent carers (<1 year post death)



former carers (>1 year post death)



gene carriers

People living with MND: Treatment, MND clinics, and health professionals

Access to drugs and medical interventions





Riluzole



NIV / BiPAP



Gastronomy tube



Cough-assist device



Toferson / Qalsody



Tracheostomy

MND Clinics improve outcomes





have received healthcare or support from an MND clinic



somewhat or extremely satisfied with the quality of care



rated clinic allied health profesionals as highly knowledgeable with MND



reported MND clinic care improved quality of life Improves access to health professionals by



Issues accessing health professionals



47%

struggle to find health professionals with MND experience



38%

experience lengthy wait times





report physical barriers



have accessed a psychology or counselling professional

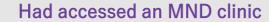


report high costs

27%

have accessed a social work professional

Healthcare inequities for people living in outer regional areas





89%

Major cities



Outer regional

Faced significant issues with travel distance



distances

Major cities



Outer regional

Faced issues finding allied health professionals who have experience with MND



Major cities



Outer regional

People living with MND: Issues accessing equipment and home modifications



49%

of people with MND do not have all the equipment and home modifications they need to meet their mobility, personal care, or communication needs



experience delays



experience cost barriers



struggle to understand what options are available



cannot find qualified tradespeople



struggle to understand process of acquisition



Carers need more support





consider their quality of life to be good

spend all their

time caring

at all



consider their access to paid care/support insufficient



consider their funding less than what they need



do not access respite care



do not have all the equipment and home modifications they need



consider paid carers not knowledgeable



do not get moderate or significant family and friend support with care



do not have a very well-equipped residence





increased govt funding for their loved one, to access more paid carers & suitable equipment/home mods



more financial support from the government



paid carers to be better trained in MND



encouragement to link in with peer support programs

Improving research communications



want more communication about and access to current research opportunities





of research participants do not hear about outcomes

Priorities

Research Priorities



identifying the cause of MND



new therapies or technology to improve quality of life



new clinical trials to slow progression



making the process of diagnosis quicker and easier



Advocacy Priorities



equitable access to disability funding regardless of age at funding commencement



increasing funding for multidisciplinary MND clinics