Assessing Fitness to Drive Standards

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What is MS?

Multiple Sclerosis (MS) remains one of the most common causes of neurological disability in the young adult population (aged 18–40 years) with over 2.9 million people affected worldwide. More than 37,756 Australians live with MS and over 7.6 million Australians know someone or have a loved one with this potentially debilitating disease.

Three times as many women have MS than men. Symptoms vary between people and can come and go; they can include severe pain, walking difficulties, debilitating fatigue, partial blindness and thinking and memory problems. For some, MS is characterised by periods of relapse and remission, while for others it has a progressive pattern of disability. MS robs people of quality of life, primarily driven by the impact of MS on pain, independent living, mental health and relationships.

MS Australia is Australia's national multiple sclerosis (MS) not-for-profit organisation that empowers researchers to identify ways to treat, prevent and cure MS, seeks sustained and systemic policy change via advocacy, and acts as the national champion for Australia's community of people affected by MS.

MS Australia represents and collaborates with its state and territory MS Member Organisations, people with MS, their carers, families and friends and various national and international bodies to:

- Fund, coordinate, educate and advocate for MS research as part of the worldwide effort to solve MS
- Provide the latest evidence-based information and resources
- Help meet the needs of people affected by MS

George Pampacos
President

Rohan Greenland
Chief Executive Officer

Assessing Fitness to Drive Standards

MS Australia welcomes the opportunity to provide feedback and respond to the specific questions sought on the *Assessing Fitness to Drive* Standards (the Standards) to the National Transport Commission (NTC).

This submission draws on the experiences and expertise of MS Australia's Lived Experience Expert Panel (LEEP). The LEEP is a panel of people who either live with MS or are a carer for someone living with MS, and who provide MS Australia with expert advice to inform our advocacy work. In this submission, their feedback reflects lived experience perspectives on challenges getting, keeping or renewing a driver's licence; experiences with medical reviews, requests for medical information and driving assessments; whether processes recognised the fluctuating nature of MS symptoms; and what licensing authorities, health professionals and governments need to better understand to make the process clearer, fairer and more person-centred.

MS Australia Recommendations

- **Recognise the fluctuating nature of MS symptoms:** The Standards should better reflect that MS symptoms can vary from day to day, over time, and even within the same day. Fitness to drive assessments should avoid assuming that a person's capacity is static or that a single assessment captures their usual or ongoing ability to drive safely.
- **Adopt a more person-centred approach to assessment and decision-making**: Licensing and medical review processes should recognise that people with MS often have strong insight into how their symptoms affect them and when it is or is not safe for them to drive. Assessments should consider actual functional impact, rather than assuming that diagnosis or symptoms alone affect a person's fitness to drive.
- **Improve clarity and consistency in reporting requirements:** The Standards should provide clear, nationally consistent guidance about when MS must be reported to driver licensing authorities, what information is required, and how medical review processes apply. This would reduce confusion for people with MS, carers, GPs and other health professionals.
- **Ensure driver's licence conditions are proportionate, flexible and regularly reviewed:** Driver's licence conditions should be tailored to a person's actual functional capacity and demonstrated driving-related need and should not be imposed on the basis of diagnosis or symptom disclosure alone. Conditions should support safe driving without creating unnecessary restrictions and should be reviewed when function, vehicle modifications or driving needs change.
- **Reduce unnecessary stress, cost and administrative burden:** Medical review and reassessment processes should be clear, timely, affordable and only required where there is a genuine safety-related need. This would help reduce avoidable stress, anxiety and fear of losing independence for people with MS.
- **Provide better guidance and education for health professionals and licensing authorities:** GPs, assessors and licensing authorities should have access to practical guidance about MS, including symptom variability, fatigue, mobility impacts, cognitive changes and the importance of individualised assessment. Guidance should help decision-makers understand these symptoms without treating their presence as automatic evidence of unsafe driving.
- **Strengthen follow-up and review processes:** Where licence restrictions or conditions are imposed, there should be a clear pathway for review, reassessment and adjustment over time. This is particularly important where conditions no longer reflect a person's current function, driving capacity or available supports.

Making fitness to drive assessments clearer, fairer and more person-centred

LEEP members identified several recurring issues with how driver licensing and medical review processes apply to people with MS. They described challenges arising from limited understanding of the fluctuating and highly individual nature of MS symptoms, unclear and inconsistent reporting requirements, inflexible driver's licence conditions, and processes that can create stress, cost and concern about loss of independence. Their experiences suggest that the revised Standards should better recognise symptom variability; support proportionate and person-centred decision-making; improve clarity for people with MS, carers, health professionals and licensing authorities; and ensure review processes remain fair, practical and responsive to changes in a person's circumstances.

To address these issues, MS Australia makes the following seven recommendations to support a clearer, fairer and more person-centred approach to fitness to drive assessment for people with MS:

1. Recognise the fluctuating nature of MS symptoms

LEEP members emphasised that MS symptoms can vary from day to day, over time and even within the same day. However, this variability is not always well understood in driver licensing and medical review processes. Their feedback suggests that fitness to drive assessments should avoid treating a person's capacity as static or relying on a single assessment as a complete picture of their usual or ongoing ability to drive safely.

> **LEEP Member Carol:**
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> "Listen to the advice about symptoms coming and going from the person living with MS and trust that the person will do the right thing. Everyone is so different and they can't make assumptions based one person for another."

MS Australia recommends that the revised Standards better recognise the fluctuating nature of MS symptoms and avoid assuming that a single assessment captures a person's usual or ongoing capacity to drive safely.

2. Adopt a more person-centred approach to assessment and decision-making

A clear theme from LEEP feedback was that people with MS want licensing and medical review processes to recognise their knowledge of their own condition, symptoms and driving capacity. LEEP members stressed that MS affects each person differently and that decisions should be based on individual circumstances and actual functional impact, rather than assumptions about diagnosis or symptoms alone.

MS Australia recommends that licensing and medical review processes adopt a more person-centred approach to assessment and decision-making, recognising the individual's own understanding of their condition alongside clinical and functional information.

3. Improve clarity and consistency in reporting requirements

LEEP responses also pointed to uncertainty for people with MS and their health professionals about when MS needs to be reported, what information is required, and how medical review processes should be applied.

> **LEEP Member Rachel:**
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> "Like most people with MS, I have good days and bad days, even good hours and bad hours. My GP refused to complete the forms because when they saw me, I was well, and I couldn't find a firm answer on whether it was a requirement for MS, or only if symptoms meant my driving was impacted."

One LEEP member described being required to complete a driving test that the tester reportedly considered unnecessary, suggesting that processes may not always be clearly targeted or consistently applied. LEEP feedback also highlighted the importance of national consistency, rather than different requirements across state jurisdictions.

MS Australia recommends that the revised Standards provide clear, nationally consistent guidance about when MS must be reported to driver licensing authorities, what information is required, and how medical review processes apply. This would reduce confusion for people with MS, carers, GPs and other health professionals.

4. Ensure driver's licence conditions are proportionate, flexible and regularly reviewed

LEEP members described licence conditions that can be too rigid or remain in place even when they no longer reflect a person's current functional capacity, driving needs or available supports. They also raised concerns about conditions that do not account for symptom variability or changes over time, highlighting the importance of basing restrictions on demonstrated driving-related need rather than diagnosis or symptom disclosure alone.

LEEP feedback suggests that licence conditions should support safe driving without creating unnecessary or disproportionate barriers to independence and participation. This includes ensuring that requirements are tailored to current function and reviewed when a person's circumstances, vehicle modifications or driving needs change.

MS Australia recommends that driver's licence conditions be tailored to a person's actual functional capacity and demonstrated driving-related need, and not imposed on the basis of diagnosis or symptom disclosure alone. Conditions should support safe driving without creating unnecessary restrictions and should be reviewed when function, vehicle modifications or driving needs change.

5. Reduce unnecessary stress, cost and administrative burden

LEEP members described licensing and medical review processes as creating unnecessary stress, cost and administrative burden, particularly where requirements are unclear, assessments feel unnecessary, or health professionals are unsure how to apply the process. They also reported concerns about the cost of medical appointments, assessments and reports. This feedback highlights the importance of ensuring that medical review processes are clear, proportionate and required only where there is a genuine safety-related need.

> **LEEP Member Anne:**
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> "The process caused stress, anxiety or concern about losing independence."

MS Australia recommends that medical review and reassessment processes be clear, timely, affordable and required only where there is a genuine safety-related need. This would help reduce avoidable stress, anxiety and fear of losing independence for people with MS.

6. Provide better guidance and education for health professionals and licensing authorities

LEEP feedback highlighted the need for better guidance and education for health professionals, driving assessors and licensing authorities about MS and the different ways it can affect driving. LEEP members described situations where professionals appeared uncertain about reporting requirements or did not fully understand symptom variability. Feedback also emphasised that MS can affect fatigue, mobility, cognition and day-to-day function differently for each person, and that assessments should focus on actual functional impact rather than assumptions about diagnosis or symptoms alone.

MS symptoms are often hidden and may not be immediately visible. These can include fatigue, pain, cognitive changes, weakness, vision changes, numbness or tingling, heat sensitivity, dizziness, balance or coordination difficulties, and bladder or bowel issues. Some symptoms may affect mobility and require support such as a wheelchair, motorised scooter or walking aid, while others may not be visible at all. Stakeholders involved in driver licensing and fitness to drive

assessment should understand that non-visible MS symptoms may be relevant to an individualised assessment but should not be assumed to affect a person's fitness to drive or justify licence restrictions without evidence of functional impact.

MS Australia recommends that GPs, assessors and licensing authorities have access to practical guidance about MS, including symptom variability, fatigue, mobility impacts, cognitive changes and the importance of individualised assessment. Guidance should support consistent, informed and fair decision-making without treating the presence of non-visible symptoms as automatic evidence of unsafe driving.

7. Strengthen follow-up and review processes

LEEP feedback underscored the need for stronger follow-up and review processes where licence restrictions or conditions are imposed. Without a clear pathway for reassessment or adjustment, conditions may become outdated and no longer reflect a person's current function, driving capacity or available supports.

MS Australia recommends that, where licence restrictions or conditions are imposed, there should be a clear pathway for review, reassessment and adjustment over time. This is particularly important where conditions no longer reflect a person's current function, driving capacity or available supports.

In conclusion, the LEEP feedback emphasises that the current approach to fitness to drive assessment does not always reflect the lived reality of MS, particularly the variability of symptoms, the importance of individual judgement, and the significant consequences that licensing decisions can have for independence, participation and wellbeing. MS Australia supports the ongoing role of the Standards in promoting road safety, but considers that this must be balanced with clear, consistent and proportionate processes that recognise MS as a highly individual and fluctuating condition. Incorporating these recommendations into the revised Standards would help ensure that people with MS are assessed fairly, that unnecessary barriers and stress are reduced, and that licensing decisions are based on current function, relevant evidence and demonstrated impact on driving, rather than assumptions about diagnosis or non-visible symptoms.