



# Draft Updated Whole Journey Guide

---

**June 2026**



AUSTRALIA

RESEARCH  
ADVOCACY  
CURE



**RESEARCH  
ADVOCACY  
CURE**

## 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**

# Draft Updated Whole Journey Guide

## Executive Summary

MS Australia welcomes the opportunity to provide feedback and respond to the specific questions sought on the Draft updated *Whole Journey Guide* (the Guide) to the Department of Infrastructure, Transport, Regional Development, Communications and the Arts (Department).

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. Their feedback reflects lived experience perspectives on the Guide's clarity, accessibility, practicality and potential use. LEEP members also provided input in our previous submission on the Department's [Exposure Draft: Reform of the Disability Standards for Accessible Public Transport 2002 \(Transport Standards\)](#) and [Aviation Green Paper](#).

Over five and a half million Australians currently live with a disability<sup>1</sup> and they represent over 20 per cent of the Australian community. Ensuring public transport services are accessible and inclusive is essential for Australians living with disabilities to connect them to all aspects of public life. Accessing public transport services and traveling by public transport can pose formidable and ongoing obstacles for people with disability, including people living with MS.

People with MS use public transport for a range of reasons including to travel long distances for medical appointments, to get to work, participate in social events or to take a holiday. They need to be confident the public transport services will provide a service that is safe, accessible and reliable. This is especially true for people with MS living in regional, rural or remote settings where public transport services may be limited, much less frequent and/or non-existent.

For many people with MS, their symptoms are hidden, and they live with an invisible disability. MS symptoms that are hard to see include fatigue, pain, cognitive problems like memory loss or trouble solving problems, weakness, blurred vision, numbness, prickly or tingling sensations, heat sensitivity, dizziness, balance/coordination problems, and bladder or bowel issues. Sometimes these symptoms result in mobility issues and a person having to use a wheelchair, a motorised scooter or a walking aid. Sometimes they do not. It is important for all public transport service staff to understand that not all disabilities are visible and people may sometimes need additional assistance.

Overall, feedback from the LEEP suggests that the Guide is well intentioned and contains useful content, but its usefulness is constrained by its length, design and lack of practicality. Members consistently called for a shorter, more streamlined and easier-to-navigate resource, with clearer audience-specific guidance, less repetition, fewer non-essential images, and a stronger focus on practical measures that improve accessibility for people with disability, including people living with MS.

## MS Australia Recommendations

- Substantially shorten the Guide and develop a companion guide for people with disability who use public transport.
- Improve the Guide's structure, navigation and audience-specific usability, including through a glossary and expanded content on air travel.
- Strengthen the focus on practical measures such as staff training, invisible disability awareness, and direct assistance at transport hubs.
- Redesign the Guide so it can be more readily applied by organisations in policy, planning and service delivery.

## 1. Is the draft revised Whole Journey Guide clear and accessible?

Feedback from our LEEP indicates that the Guide has strong potential to be a valuable and important resource. Overall, the LEEP found the Guide generally clear, readable and well intentioned, with useful content and a number of strong examples. However, the most consistent feedback was that, in its current form, the Guide is significantly longer than necessary and therefore less practical.

Several LEEP members considered the current length of approximately 90 pages to be a substantial barrier to engagement and noted that many readers would be unlikely to read the document in full. Feedback also suggested that the Guide could be reduced considerably, potentially to less than a third of its current length, by removing repetition, reducing pages with limited content and consolidating sections where appropriate.

LEEP members also noted that the document relies heavily on visual presentation, with an excessive number of illustrations in some places and several images that do not appear essential to the content. The small font size and limited use of page space also reinforce the impression that the document could be more concise, practical and user focused. On the basis of this feedback, MS Australia considers the Guide would be more accessible and effective if it were substantially shortened, streamlined and designed primarily as a practical, user-friendly tool rather than a highly designed publication.

Our LEEP also suggested there could be value in developing a companion guide of no more than 20 pages for people who use public transport, written in plain language, co-designed with people with disability, and made available in accessible formats so that key information can be located and applied quickly.

**MS Australia recommends** substantially shortening the main Guide, including by removing repetition, consolidating sections with limited content and reducing unnecessary imagery, and developing a separate companion guide of no more than 20 pages for people who use public transport.

## 2. Are there any sections in the document where additional information is needed?

Feedback from the LEEP noted that the principal issue is not the need for substantial additional content, but rather the need for the existing content to be better organised and easier to navigate. Suggestions included adding a glossary and improving the structure so that different audiences, such as bus operators, depot managers and airport staff, can quickly identify the sections most relevant to them.

LEEP members also noted that air travel requires greater attention, as the Guide appears to focus more heavily on train and tram transport. In addition, several members identified minor wording issues that should be corrected for clarity. For instance, page 16 states that “an airport should be trained to confidently and respectfully process people with disability through airport security” and is likely missing the word “staff” after “airport”.

**MS Australia recommends** clearer structure, improved navigation and targeted revisions, such as a glossary, clearer audience-specific sections, wording corrections and expanded air travel content, rather than significant additional material.

## 3. Are the suggested solutions helpful for people with disability?

Feedback from our LEEP indicated that the proposed solutions are helpful and broadly aligned with their needs and experiences. Members of the LEEP particularly valued practical measures such as improved signage relating to invisible disability, staff training, appropriate dwell times, and the availability of direct assistance at transport hubs.

There was also support for stronger experiential training for transport staff, including opportunities to develop a better understanding of the barriers that people with disability may encounter when navigating transport systems.

**MS Australia recommends** retaining the proposed solutions, with a stronger emphasis on staff training, invisible disability awareness, practical assistance at transport hubs and experiential learning informed by people with disability. Their impact would be strengthened if they were presented in a shorter, more direct and more practical format.

#### 4. Would your organisation use this guidance?

Feedback from our LEEP on this question was mixed. However, it indicates that the Guide has potential value if it is substantially revised. Some LEEP members considered that a central guide of this kind could usefully inform organisational policy and practice. Others indicated that, in its current form, it is too long and insufficiently practical to be used as an effective working resource.

**MS Australia recommends** redesigning the Guide as a shorter, more practical resource that can be readily used by policy makers, planners, service providers and operators to inform policy, planning and service delivery.

In conclusion, feedback from people living with MS indicates that the Guide has strong potential to be a valuable resource, but that its effectiveness is currently limited by its length, layout and overall presentation. MS Australia supports the intent of the Guide and considers that its usefulness for both people with disability and organisations would be significantly enhanced if it were shorter, more practical and easier to navigate. In particular, the Guide would benefit from a clearer structure, more targeted content, less repetition, fewer non-essential images, and a stronger focus on accessibility and practical application.

## Reference

<sup>1</sup> Australian Bureau of Statistics (2022), [Disability, Ageing and Carers, Australia: Summary of Findings](#), ABS Website, accessed 10 June 2026.

