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RE: Aviation Disability Standards

Thank you for the invitation to make a submission to the consultation on creating aviation disability standards. Motor Neurone Disease (MND) Australia welcomes the opportunity to provide this submission on behalf of our [Lived Experience Network](#). We organised a workshop to hear directly from people living with MND or providing care. This submission consolidates what they told us.

What is MND?

MND Australia is the national peak body for state organisations that support those living with, and impacted by, motor neurone disease (MND). Since 1993, we have been the voice for the MND community. Our national and international networks help increase understanding of the disease and advocate for the needs of those affected.

Motor neurone disease (MND) is the name given to a group of neurological diseases in which motor neurons – the nerve cells that control the movement of voluntary muscles – progressively weaken and die. With no nerves to activate the voluntary muscles, they become progressively weaker to the point that the ability to walk, speak, swallow and ultimately breathe is lost. MND affects each person differently with respect to initial symptoms, rate and pattern of progression and survival time.

Average life expectancy for people living with MND is 27 months from diagnosis. A third of those die within one year and more than half within two years of diagnosis. There are no known causes for MND, apart from the up to 15% per cent of cases which have a genetic basis. There are no effective treatments and there is no cure. There are no remissions and progression of MND is usually rapid and relentless, creating high levels of life-limiting disability, regardless of the age at onset, and a consequent need for a wide range of changing supports based on the person's complex needs. In 2025 there were an estimated 2,752 people with MND in Australia.¹

MND and air travel

Because the progression of MND varies by individual, the challenges that people face in air travel also varies. Many people with advanced MND are reliant on wheelchairs. Many use a feeding tube (a percutaneous endoscopic gastrostomy, or PEG) as they lose the ability to swallow. As MND progresses, many people use a specialised ventilation machine to assist with breathing. As people lose their ability to speak, some use eye gaze technology or text-to-voice. In these situations, air travel requires accommodation for essential life-sustaining equipment, limitations in being able to transfer to an aisle wheelchair, and understanding how to communicate with the passenger, who may be non-verbal.

For other people with MND, however, their disability may not be so obvious. Some struggle to stand or walk but do not yet need the use of a wheelchair. For some people, their initial symptom is the loss of use of their arms and hands. They may be unable to use cutlery, carry a suitcase, or open a door.

In sum, the feedback points to the need for better information and coordination. When the person living with MND provides information on their needs at the time of booking, this information should be shared across the key points of need – that includes having the information ready to hand at the check in counter, the security checkpoint being aware of the equipment and capabilities of the person travelling, and being ready at the gate with an aisle chair and understanding how the person would like to be transferred.

Other recurring feedback includes roomier bathroom facilities, particularly on board the flight, and understanding the capabilities of each individual, even if they don't appear to have reduced capability.

It was the observation of the group that it is largely up to the individual flying to solve most of their problems. However, attentive and informed ground and flight crew can make all the difference. Many people had positive experiences and these were attributed to good communication and thoughtful interactions.

Response to the consultation

Common themes that were raised by the MND Lived Experience Network include the following.

Advance planning for travel can be time-consuming and not always respected by the airlines.

Respondents told us that they understand the need to let the airline know in advance what their equipment needs are when flying, and for most people filling forms online, either at the time of booking or to cover a 12-month period of time, was considered a reasonable additional step. However, several people told us that they often needed to repeat all the information again at the airport at the time of check-in. This means planning for extra time in advance of the flight, which is not always easy for someone living with MND.

More concerning, one respondent told us that she needed to take regional flights to visit her neurologist. It had happened more than once that the plane had been changed and was no longer able to fit her power wheelchair in the hold. This necessitated a family member returning the power chair to the house and returning with a smaller, portable chair while she waited at the airport. This not only has implications for missing a flight, but it also means reduced independence and mobility on arrival at the destination. Some international airlines are experimenting with prototypes wherein a power wheelchair can be boarded and locked

in place on the plane. This would be an ideal travel situation for people who rely on their power wheelchair for their independence.

Recommendations:

- a. Ensure that information logged in advance is available and understood by ground staff, reducing providing information multiple times.
- b. At a minimum, a courtesy call should be made as early as possible where a plane change results in equipment no longer being accommodated.
- c. Introducing the ability to lock a power wheelchair in place on the plane would be very welcomed by all people who rely on wheelchair use for their independence.

Security clearance procedures can be problematic.

Respondents told us that clearing their equipment can lead to delays or difficulties when going through security. This includes power banks, breathing equipment, and feeding tubes (a percutaneous endoscopic gastronomy, or PEG).

One respondent was traveling overseas with her underage children and was separated from them at the security checkpoint. She was wheeled away for her separate security clearance while her children were left to navigate security on their own, without parental supervision.

Recommendations:

- a. Security screeners should be made aware in advance of specialised equipment, including feeding tubes.
- b. Where it is necessary to take a person living with MND to a separate place for security screening, family members should be allowed to attend them. This is particularly important in the case of underage children.

The boarding process can be onerous.

People living with MND who use a wheelchair said the onboarding process can be difficult. Specifically, transferring to and from an aisle chair can be very difficult; one person told us that her husband was barred from assisting with the transfer, which led to difficulties in transferring because the airport staff were not understanding of her limited capabilities. As MND advances, people develop paralysis in their limbs and they are unable to stand for even brief periods of time and/or cannot hold their weight using their arms. Transferring to and from the aisle chair also caused bruising for many people. For larger aircraft, the use of the Eagle 2 lifter would minimise these difficulties, but not all airports have them. One person also related that an aisle chair was not brought to the gate despite being booked in advance, which delayed boarding by 30 minutes for the entire plane.

Recommendations:

- a. Airports and airlines should ensure there are an adequate number of aisle chairs and that they are at the right place at the right time.
- b. Airport and airline staff should actively engage with people with disabilities and their family members, including asking their preferences for assisting with wheelchair transfers.

- c. All airports should have an Eagle 2 lifter (or similar) available for use where appropriate.

Bathroom sizes and accessibility are poor on most planes.

Regardless of the stage of progression, people living with MND often need help with toileting. Bathrooms, particularly on airplanes, are generally so confined that many people sought ways to avoid using the toilet across their travel time. Strategies included fasting, deliberately dehydrating and/or wearing absorbent underwear. Other people risked the humiliation of having the bathroom door open while they were assisted by a carer or family member. One person informed us that she and her partner pay the extra for business class, because the cabin has fewer passengers and the flight attendants are more helpful.

One respondent told us, however, that she had been on international flights with very roomy bathroom facilities, where her carers could comfortably attend to her with the door shut.

Recommendation: That airplanes provide at least one accessible (double) bathroom. Accessible bathrooms should be available to all people with a disability regardless of where on the plane they are seated.

Flight attendants should be made aware of needs in advance of the flight.

People who consulted with us for this submission experienced a broad range of restricted function. Some required a specialised wheelchair and breathing assistance. For others, the restrictions they experienced on their functional capabilities was not obvious. For example, two people were losing the use of their arms and hands. Both said that they had to adjust for their own needs when traveling by plane. This included traveling with a range of straws of various sizes and widths for eating, needing help with luggage, and needing help with using the bathroom.

Recommendation: Flight attendants should be made aware in advance of passengers with restricted function.

MND Australia would be happy to provide any further information or to discuss our submission with Taskforce Members.

We look forward to hearing about the outcome of the consultation process.

Kind Regards,



Clare Sullivan
Chief Executive, MND Australia

¹ MND Australia and Evohealth (2025). *Every moment matters. Addressing the human and economic toll of motor neurone disease in Australia*. Canberra. https://www.mndaaustralia.org.au/getmedia/e5df789a-3318-4fb5-89c2-ed4935e3ebae/Every-Moment-Matters-report_MND-Australia.pdf