



Before Booking

When it comes to long distance travel people with MND have a range of special needs that may change with time. When considering long distance travel it is essential that you contact the airline or holiday company to discuss your requirements with them and to explore any limitations on the service they can offer. As an added precaution against disappointment you might find it helpful to use a form such as ABTA's *Checklist for Disabled and Less Mobile Passengers* which can be downloaded from www.abta.com, or requested on 020 3117 0500, before you contact your airline, holiday company or travel agent. In July 2008 an EU law making it compulsory for airlines to provide a service appropriate for an individual's disabilities came into force. More information on this is available from The Equality and Human Rights Commission, Tel 0845 604 6610 or downloadable from www.equalityhumanrights.com/airtravel.

Airlines might place limitations on the carriage of mobility equipment or oxygen cylinders. For example, wheelchairs powered by lead-acid batteries will need special precautions and some airlines might insist that you change them for a non-spill or gel-filled type instead. If you intend to take a machine powered in this way you will need to tell the airline about it, even if the employee you are dealing with doesn't specifically ask about it as there are special rules for the carriage of powered scooters and wheelchairs, including weight limitations.

If you are a wheelchair user and you need to slide from a wheelchair onto an aircraft seat confirm with the airline directly whether or not the seat-type used on that aircraft and likely to be allocated to you has a fixed arm rest or one that can be raised to facilitate transfers. If the seat has a fixed arm rest you might not be able to transfer from one to the other and may need lifted across the arm rest. If that is the case bear in mind that cabin crew will probably not be willing to help lift you back out during the flight if you need to visit the toilet. If none of the staff you are speaking to can tell you about the arm rest insist that they should contact someone at their engineering base to confirm as this could make the difference between a successful trip and having to get back off the plane before departure and costly delays for the airline while they unload your luggage from the hold.

Once you have made your booking, confirm your needs in writing with the relevant companies such as the airline, hotel, holiday company or travel agent and ask them to confirm by return what arrangements they have made. You could include a completed copy of the ABTA Checklist to ensure that they have an exact record of your needs

At The Airport

Arrive at the airport in plenty of time and make yourself known to airline staff in order that they can make or confirm any necessary special arrangements to get you on board the aircraft. If you use a wheelchair and passengers are boarded via the aircraft steps staff will have to

MND Scotland is the working name of the Scottish Motor Neurone Disease Association, the only charity funding research and providing care and information for those affected by MND in Scotland.

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make arrangements for a vehicle with a height adjustable platform to get you on board. In all probability you will need to transfer from your own wheelchair to one provided by the airline at the point of entry to the aircraft in order that your own can be safely stowed for the journey.

You may also need a little extra time to clear airport security, particularly if you are carrying medications in your hand luggage or are using crutches, canes or some orthoses. As the regulations surrounding what can and cannot be taken on board an aircraft are constantly changing it is worth checking with your departure airport before-hand if there are restrictions on anything you might need in-flight, such as crutches or liquid medications.

This remainder of this factsheet is based on a report by a very experienced traveller who has been affected by MND for a number of years, yet has travelled solo, with his motorised wheelchair to Japan, North America, Europe and Australasia.

“Travelling alone, while having advanced MND, and flying long distances is perfectly possible given a bit of thought and preplanning. Obviously it would be a great help if someone can travel with you from door-to-door. Indeed, this would be ideal, but we don’t often have the resources to finance an ideal situation.

However, many airlines or their handling agents are unwilling to accept solo passengers who are unable to fasten their own seatbelt, leave their seat or evacuate an aircraft unaided and may insist that such passengers are accompanied by someone who can help them. Similar restrictions may apply for passengers who need help with breathing, feeding using the toilet or medication. You

should declare your personal circumstances with your chosen airline at the time of booking to ensure that there are no unexpected barriers to a successful journey.

Someone who hasn’t developed bulbar symptoms has a great advantage over those who have, they can ask for help and directions. Those who have speech problems might need to prepare some anticipatory cards in advance of their journey and carry something they can write on (assuming they can write) or prepare something saying that they cannot speak or write, but will spell things out on a prepared page of letters and words.

For any independent travel the journey breaks down into either three or four components;

- *Getting from home to the airport, complete with luggage,*
- *Making the flight itself and then*
- *Transfers, if the flight is not direct, or*
- *Getting from the airport to the final destination.*

Friends or family can deal with the UK end of the journey and likewise the people you are visiting or holidaying with can deal with the other end of the journey. The tricky bit could be the actual flights and transfers in between.

With a bit of preplanning and consultation the airlines are actually very helpful for those who are disabled and they will be able to facilitate transfers, including handling the luggage. Normally you should give the airline as much notice of this need as you can and can ask for pre-booked assistance to be listed on the ticket or itinerary. You should also contact someone from the airline at the airport 48 hours prior to departure to ensure something has been put in place for you. Some airlines are much better than others in this regard but the one thing that absolutely

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none of them will entertain is helping someone in the toilet.

They will help someone to get from the seat to the toilet and back but that will be it. If the person is unable to use his or her hands and arms to even undo zips or buttons then they will have to resort to one or two possibilities:

In some ways the simplest solution is to wear a heavy duty adult nappy or incontinence pants for the entire journey despite the potential discomfort.

Bearing in mind that the journey could be as long as two days if flying from the UK to Australia or New Zealand, this may be aesthetically unappealing but it could work, especially if the person is careful to cleanse their bowels before setting out on the journey and careful with their fluid intake during the total journey.

The person would then not have to leave their seat at all except to change planes.

Many ALS/MND patients have done this successfully.

Another alternative is to wear what is called in the USA a "Texas catheter". An externally fitted catheter which drains into a bag fitted on the inside of the thighs or calves. The downside is, of course, that until you reach your final destination you can't defecate and

can only urinate and people need to know you are wearing it if they are helping you to move. (So much for dignity!)

In-flight meals do not have to be an issue; adjacent passengers are often willing to help. This is where having adequate speech or an alternative communication strategy is pretty much essential.

People, however willing, can be, understandably, a bit reluctant if they don't clearly understand what they are helping with.

A well known Dutch gentleman, Jan, used to come to international MND meetings, travelling on his own. He couldn't speak at all but he could write copious notes in very good English so he didn't have an issue with asking for such help.

As for personal care and support when abroad: Contact a suitable agency at your destination, with the help of the local MND Association, and hire an aid to help with the personal things, morning and night.

Australia, Canada and the USA, unlike the UK, are quite well set up with this sort of thing, especially in the major cities.

This strategy could be a very practical solution for a solo MND traveller although there would inevitably be costs involved."

Useful Contacts

Access to Air Travel for Disabled Persons and Persons with Reduced Mobility:
Code of Practice Tel 0870 1226 236 or 0870 1226 237

The Equality and Human Rights Commission, Tel 0845 604 6610
www.equalityhumanrights.com/airtravel

Foreign and Commonwealth Office 0845 850 2829

ABTA Ltd 020 3117 0500, Email - abta@abta.co.uk Website www.abta.com

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