



# Travel and Accommodation

*ASSISTANCE, AIDS AND ADAPTATIONS THAT MAY BE REQUIRED BY PEOPLE WITH ME/CFS (MYALGIC ENCEPHALOMYELITIS/ CHRONIC FATIGUE SYNDROME) IN RELATION TO ALL ASPECTS OF TRAVEL AND ACCOMMODATION*

## To whom it may concern

### Date as postmark



I have been asked to provide some information on ME/CFS in relation to travel and accommodation.

This is designed to ensure that people and organisations involved in transportation and provision of accommodation are aware of the health and disability problems that this illness can cause.

The guidance also covers what can be done by the travel industry to try and ensure that appropriate assistance and/or aids are available where and when required.

### WHAT IS ME/CFS?

People with ME/CFS have a number of symptoms that affect their ability to cope various aspects of travel, as well as the type of accommodation that may be required at the end of the journey.

The following ME/CFS symptoms are particularly important in relation to travel and accommodation:

- **Activity-induced muscle fatigue, weakness and pain.** This means that, while most people with ME/CFS are able to walk, they may not be able to cope with walking longer distances to, for example, an airport departure lounge, or be able to walk the length of a long platform at a railway station. They may therefore require temporary assistance in the form of a wheelchair or driver-operated buggy. People with more severe ME/CFS may require wheelchair assistance for most or all of the time they are travelling.
- **Cognitive dysfunction, meaning they have problems with concentration, short-term memory word-finding ability and information processing.** This can cause problems with understanding information and instructions, especially in busy or unfamiliar surroundings.
- **Problems with balance.** This means that a person with ME/CFS will require somewhere to sit down. If more severely affected, they may require somewhere to lie down.

- **Orthostatic intolerance and hypotension (low blood pressure).** This means people with ME/CFS are unable to stand for long periods, especially in hot weather. This may be linked to a pronounced fall in blood pressure on standing, which then results in a fainting episode. As a result, they will again require a place where they can sit or lie down if necessary.
- **Sensitivity to loud noise and bright lights** – both of which are likely to be a problem in a busy transport terminal.
- **Sensitivity to chemicals.**
- **Problems with temperature control, including sensitivity to both hot and cold external temperatures.** In hot climates, rooms with air conditioning should therefore be available.

## WHAT CAN THE TRAVEL INDUSTRY DO TO HELP?

Based on feedback from people with ME/CFS, who have both good and bad experience of travel, the list below contains some of the most important practical ways in which the travel industry can help people with the disability and health problems associated with ME/CFS cope with travel.

One important point here is that having a disability is not necessarily the same as having a health problem. In the case of ME/CFS, most people have what is normally regarded as a disability in relation to mobility but they also have health problems, as listed below, which affect their ability to cope with travel and the requirements they may then have in relation to suitable accommodation.

### ***Airports, airlines, train/coach stations and train/coach companies***

- Providing reliable, easy to understand and up-to-date information about access, facilities and assistance at airports, coach and train stations. This should occur on location websites, by phone, and by post. By phone and by post is important because some people with disabilities do not use the internet.
- Providing contact details for enquiries about how and where to book and collect/make use of any mobility aids - eg wheelchair, staff-driven buggy that may be required on a journey, at both departure and arrival points.
- Having a member of staff at a specific and easy to find location who can deal with any queries.
- Making sure people know where to go for assistance and collection of wheelchairs, etc.
- Having a low counter where people in wheelchairs are able to deal with any paperwork and make proper eye contact with a member of staff.
- Providing a quiet room with disabled facilities at airports and large train/coach stations.
- Providing designated/priority seating areas at the points of departure and arrival as well as on the method of transport.

- Allowing early or priority boarding on planes, trains and coaches.

### **Accommodation**

- Making it clear in brochures and in website information where accommodation is likely to be noisy, or where there may be problems relating to access for people with disabilities or mobility problems. The introduction of some form of disabled friendly rating system for hotels would be useful.
- Providing ground floor accommodation, or good access via a lift, to bedrooms on upper floors.
- Making sure that bedrooms designed for people with disabilities have wide enough doors to cope with wheelchairs and that any information is placed at eye height for someone in a wheelchair.
- Provision of bedrooms with disabled toilet and bathroom facilities for more severely affected travellers. This should include being able to provide information before booking about bedrooms with disabled access, bath and shower facilities.
- Avoiding the use of chemical products – air fresheners in particular – in bedrooms.

I would be happy to answer queries relating to any aspect of this information.

Feedback from the travel industry is always welcome because helping people with disabilities and health problems to travel and find suitable accommodation should be a two way process.

**Dr Charles Shepherd**  
**Hon Medical Adviser, ME Association**  
**8 April 2018**

