

# Getting around

**Driving, transport and holiday guidance  
for people with MND or Kennedy's disease**








**"It is important to make the most  
of the time that you've got..."**

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# How can this booklet help me?

Motor neurone disease (MND) and Kennedy's disease can impact on mobility. Getting around for daily routines, appointments or wider travel can become challenging.

This booklet looks at the different ways you can get around when your mobility is impaired, from using adapted cars and public transport to travelling abroad. Whichever form of transport you use, and whether you're going to work or on holiday, there are ways to plan ahead and adapt.



This symbol is used to highlight our other publications. To find out how to access these, see *Further information* at the end of this booklet.



This symbol is used to highlight quotes from other people with or affected by MND.



# 1 How will my mobility change?

With MND or Kennedy's disease, your mobility, balance and posture are likely to be affected and symptoms do get worse over time.

You may:

- need help to do things
- support to get around
- be at risk of falls and injury.

Getting advice from your health and social care team can help you find support tailored to your needs. This includes how to adapt and manage falls, if they happen. Ask your GP or any of your professionals for referral to specialists, such as physiotherapists or occupational therapists.

Having to change the way you do things can feel difficult. However, accepting support can improve quality of life, and make a real difference for yourself and those close to you.



See our booklet on *Personal care*.

Exercise can be useful, including assisted and passive exercise where someone helps you. It can improve range of movement and relieve stiffness, but it cannot reverse your symptoms. A physiotherapist can assess you, give guidance and review your needs as symptoms change.



See our information sheet 6A - *Physiotherapy*.

It can be emotionally challenging to accept and use equipment in the home. You may not want to 'give in' to personal mobility aids, such as grab rails, walking aids, hoists, room conversions or installations like chair lifts and through-floor lifts.

However, this type of support can prolong independence and help your carers too. Ask for guidance from an occupational therapist, who can assess your needs within your own home.



See our resources on equipment and environmental controls and information sheet *10C - Disabled Facilities Grants and home accessibility*.

The earlier you plan ahead, the more likely you can:

- get suitable support in place by the time it's really needed
- feel confident and familiar with any new equipment.

Beyond personal mobility, you may have many questions about transport and travel, whether near or far. We hope this booklet helps you think about how to get around and who can help.



## 2 What do I need to do if driving or choosing a vehicle?

When diagnosed with MND or Kennedy's disease, you will face many challenges, changes and decisions. Much of the available support focuses on helping you continue your regular activities for as long as possible, including advice on driving.

### Can I continue driving?

If you currently drive, you will need to consider if your mobility or movement are affected. Deciding whether to continue driving can be emotional, as it impacts on your independence. However, this will depend on your symptoms, how fast they progress and the approach you wish to take.

In **England, Wales and Scotland**, you are legally required to tell the Driver and Vehicle Licensing Agency (DVLA) that you have been diagnosed with a medical condition. See **[www.gov.uk](http://www.gov.uk)** for the list of conditions, including MND, that must be reported. Search for *medical conditions, driving and disabilities* for more information.

In **Northern Ireland**, you will need to tell the Driver and Vehicle Agency (DVA). Search for *driving with a medical condition* at **[www.nidirect.gov.uk](http://www.nidirect.gov.uk)** for more information.



See *Other organisations* in section 4 for driving agency contact details.

The DVLA or DVA might ask you to fill out a medical questionnaire and, in some cases, undergo an assessment. These forms are available on the DVLA and DVA websites. The assessment looks at whether you can continue driving safely or need an adapted vehicle. You do not need to pay for the assessments or any future reviews.

If you are worried about this process, get advice from your GP or your nearest regional Driving Mobility Centre. They can provide guidance about alternative options and advice on driving with a disability.

Discuss with your GP about whether you should continue driving while waiting for an assessment or for a decision from the DVLA or DVA. Once the DVLA or DVA has the information it can decide to issue:

- an unrestricted licence
- a licence restricted to a certain length of time
- a licence restricted to a particular vehicle with adaptations.

## **What is a driving assessment?**

A driving assessment is different to a driving test. Trained assessors will review your driving to advise on adaptations that can prolong driving independence.

If you are approved to continue driving by the DVLA or DVA, it is still your decision if you want to continue driving or not. You can also choose to have your driving assessed at any time. You have to pay for any additional assessments you request yourself, but it could help with better decision making when you feel the time is right.



See *Other organisations* in section 4, as Driving Mobility hubs across the country can help arrange assessments of your needs.

## **What about my car insurance?**

Always tell your car insurance company of any new diagnosis or change in your condition. If you don't, you may find your policy is invalid if you need to make a claim.



Insurance companies need to take all reasonable steps to ensure their services are accessible for disabled people. They are not allowed to refuse car insurance to disabled drivers or charge extra unless there is a reason to do so.

## Can I get help with the costs of using a car?

**Road tax exemption** may be claimed, by you or your nominated driver, if you receive certain DLA or PIP mobility benefits. Contact the PIP or DLA helpline and ask for an application form. Search for *road tax exemption* at **[www.gov.uk](http://www.gov.uk)**

**London congestion charge exemption** can be claimed if you have a Blue Badge, whether you are the driver of the vehicle or not. There is a £10 registration fee and this will need to be renewed at the same time as your Blue Badge. If you renew within 90 days of your Blue Badge expiry date, you will not need to pay for renewals. Contact Transport for London for more information or visit **<https://tfl.gov.uk/modes/driving/discounts-and-exemptions>**.

**Toll concessions** for people with disabilities may be available at river crossings, bridges and tunnels. Check before any journey to see what schemes and discounts might be offered. Search for the name of the toll road you will be using online to see if you can apply for any exemptions. Find out more at **[www.gov.uk/toll-concessions](http://www.gov.uk/toll-concessions)**.

## What options do I have when choosing a car?

Discuss with your health and social care team or an occupational therapist experienced in MND. They can help you understand how your travel needs may change over time as MND progresses. Keep this in mind when making any decisions about vehicles.

Car dealerships will know about the available adapted cars, but they may not be familiar with MND or Kennedy's disease. If you have had a driving assessment, the results from this can help them find the best options for you.

## What is a wheelchair accessible vehicle? (WAV)

This type of vehicle allows you to either store a wheelchair or remain seated in your chair as a passenger or driver. Always get advice from a reputable WAV specialist, whether hiring or buying.



**“We had to wait for an electric wheelchair before we could even think about having a WAV as obviously the height and width had to be taken into consideration.”**

## Can I adapt my existing car?

Yes, get professional guidance to ensure this meets your changing needs. For example, will there be enough space to store or seat a wheelchair? Some adaptations can be costly and if powered, may drain your vehicle battery and need an external charger between journeys.

Adapting your own car can help you use it for longer, with:

- easier access in and out, like swivel seats
- new driving controls, to help with steering and foot pedals
- hoists, winches or lifts to help store a wheelchair or scooter.

Ask if the original car controls can still be used by other drivers and if adaptations can be removed when no longer needed.

Motability can guide you to a local venue to test an adapted vehicle and the controls. They may have returned cars for quick access, depending on your needs.

## Questions when choosing an adapted car

- If you will be driving, do you want to carry passengers?
- What adaptations might you need, now or in the future?
- If driving, do you want to enter by the driver's door or at the rear?
- As a passenger, do you want to sit in the front or the rear?
- Will the chosen vehicle have the right dimensions if you use a wheelchair?
- Do you need a lift, winch or hoist for a wheelchair?
- Is it easy to secure or tie down the wheelchair in the vehicle?
- Will the vehicle take the weight of the chair?
- How much visibility will you have when seated in the car?



## Can the Blue Badge Scheme help me?

If disabled, you can use a Blue Badge to help you as a driver or passenger, across the UK. Unless there are specific local exceptions, use your Blue Badge to park:

- free of charge and with no time limit in street areas with parking meters, or pay and display parking
- in specific spaces reserved for valid Blue Badge holders
- on single or double yellow lines for up to three hours, unless there are loading or unloading restrictions.

Local authority, hospital or retail car parks have separate rules, but may have spaces for Blue Badge holders. In London, look for disabled parking bays for Blue Badge holders and search for *Blue Badge* at: **<https://tfl.gov.uk>**

You qualify for a Blue Badge if you are blind or receive:

- Personal Independence Payment (PIP)
- higher rate mobility for Disability Living Allowance (DLA)
- a War Pensioners' Mobility Supplement.

Other disability benefits do not automatically qualify you for a Blue Badge but you can still be assessed for one. Ask your GP to refer you or:

In England, Wales and Scotland, contact your local authority or apply online at: **[www.gov.uk/apply-blue-badge](http://www.gov.uk/apply-blue-badge)**

In Northern Ireland, contact the Blue Badge Unit, at the Department for Infrastructure:

**[www.nidirect.gov.uk/articles/apply-or-renew-blue-badge](http://www.nidirect.gov.uk/articles/apply-or-renew-blue-badge)**



## Can the Motability Scheme help me?

You can lease an adapted vehicle or Wheelchair Accessible Vehicle (WAV) from the Motability scheme, in exchange for some or all of your mobility allowance.

You qualify if you receive the higher rate mobility component of Personal Independence Payment (PIP) or Disability Living Allowance (DLA). You must have at least 12 months left on your PIP or DLA award.

Other disability benefits, such as Attendance Allowance, cannot be used for the Motability scheme.

Find out whether you qualify at:

**[www.motability.co.uk/get-support/faqs/am-i-eligible/](http://www.motability.co.uk/get-support/faqs/am-i-eligible/)**

You can be the driver or passenger of the leased vehicle. Two other people living within five miles of your home can be named drivers. You can pay for a third named driver.

The agreement with Motability is usually for three years with an adapted vehicle, or five years for a WAV.

If your PIP or DLA award runs out during the contract period and is not renewed, the vehicle will have to be returned. If you lose the mobility component of DLA after being reassessed for PIP, you may be able to keep the car for up to seven weeks after DLA is stopped.

### What's included?

Before leasing any type of vehicle from Motability, it's recommended that you get an independent assessment of your needs. Ask your GP for advice.

The contract usually includes:

- road tax, insurance and personal accident cover, with full breakdown assistance
- servicing, maintenance, and wear and tear repairs
- free replacement tyres, and window and windscreen replacement
- 60,000 mileage allowance over three years, or 100,000 over five years
- some adaptations at no extra cost.



**“The Motability car has given Dad a new lease of life and so much freedom.”**

### **How do I apply for the Motability scheme?**

If you qualify and wish to apply:

1. Choose the vehicle that is right for you.
2. Make an appointment with a Motability scheme dealer to get advice.
3. Submit your application online to order your new car and they will contact you within 3 days.

### **What if my needs change during my contract?**

If the vehicle no longer meets your needs during the contract period, Motability may agree to cancel your contract or lease a different vehicle. There is usually a fee. If additional adaptations are needed for your vehicle, only Motability approved installers should make them.

A Motability vehicle contract only applies to the person who has the contract. This means that the Motability vehicle will need to be returned if they die. Other named drivers can continue to use it for up to two weeks, but they must inform Motability before that point.

Search for *Tell Us Once* at **www.gov.uk** for the service that notifies relevant departments about the death, including the DVLA, for cancellation of the vehicle's road tax.

### **Do Motability lease powered wheelchairs or scooters?**

Yes. You can lease a powered wheelchair or scooter from Motability and a single monthly payment can be taken from your PIP or DLA mobility allowance. The lease includes breakdown cover, insurance and maintenance.

## **Walking aids, wheelchairs and mobility scooters**

**Walking aids** can help if your mobility is slightly affected. You can buy walking sticks, crutches and frames online or from mobility shops. Some types of walking sticks and frames are available to borrow from the NHS for a small deposit. Ask your GP or physiotherapist for more information.

**Standard manual wheelchairs** can help you continue doing what you enjoy for longer periods, especially on outings. Fold-up wheelchairs are useful for short trips. You can move the wheels yourself or you can be pushed by someone else. Larger, supportive manual wheelchairs help with posture support but may not fold.

**Powered wheelchairs** offer more independence with control options like joysticks and attendant controls. Most powered chairs also feature a tilt-in-space function to support posture and relieve pressure. Various types of these chairs are available on the NHS, but your needs have to be assessed. Ask your GP or physiotherapist to refer you to your local wheelchair service.

**Mobility scooters** are not available on the NHS, but can be purchased from mobility shops. Ask an occupational therapist if a scooter is suitable and safe for you. Help may be available through Motability (see previous section) and many shopping centres offer short-term scooter hire.

Find out more about mobility support on the NHS website.  
Select *Care services, equipment and care homes* at:  
**[www.nhs.uk/social-care-and-support](http://www.nhs.uk/social-care-and-support)**

We offer a range of information resources on personal care, home adaptations, equipment, wheelchairs and environmental controls.

### **Do I need to register a wheelchair or mobility scooter?**

Manual wheelchairs do not need to be registered. Mobility scooters or powered wheelchairs do not require a licence but you may need to register them with the DVLA or DVA.

Powered wheelchairs and mobility scooters have different rules depending on what 'class' they are in, although some are not in a class.

**Class 2:** these have a max speed of 4mph or less and you do not need to register them. They can be used on pavements and other pedestrian areas, but **cannot** be used on the road or cycle lanes.

**Class 3:** these have a max road limit of 8mph. They can be used on roads but **not** in cycle lanes. You must register them but won't have to pay vehicle tax.

**Not in a class:** these can go more than 8mph, wider than 0.85 metres and weighs more than 150kg (without equipment attached). They can **only** be used on the road, must be registered and require a valid driving license.

You can find out further details on each of the classes, and how to insure or register your vehicle at: **[www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules/classes](http://www.gov.uk/mobility-scooters-and-powered-wheelchairs-rules/classes)**

Check with the DVLA in England, Wales and Scotland, or DVA in Northern Ireland, if your scooter or wheelchair meets the necessary requirements to be able to safely drive on roads if necessary.



## Do I need insurance for a mobility scooter or wheelchair?

Although it's not required legally, you are strongly recommended to get insurance as with any motorised vehicle.



**"Having the scooter that the MND Association helped fund has made an enormous difference because I can now access places independently which for so long I had been unable to do."**



# What else could help me to get around?

## Community transport services

These not-for-profit schemes are run by local drivers, offering door-to-door accessible transport if you are ill or disabled. Your local authority can advise in England, Wales and Scotland. In Northern Ireland, ask your local health and social care trust.

## Patient transport services (PTS)

These services provide free, non-emergency transport to and from hospital appointments, if you need mobility or other support. Ask your GP or the healthcare professional for more information in England or Northern Ireland.

In Wales, see: <https://ambulance.nhs.wales>

In Scotland, see: [www.scottishambulance.com/our-services/support-with-appointments](http://www.scottishambulance.com/our-services/support-with-appointments)

## ShopMobility

This scheme loans or hires out wheelchairs or mobility scooters to help you get around local towns and shopping centres.

In England, Wales and Scotland, see:  
[www.gov.uk/community-transport-services-shopmobility](http://www.gov.uk/community-transport-services-shopmobility)

In Northern Ireland see: [www.shopmobilityni.org](http://www.shopmobilityni.org)

## Disabled Person's Freedom Pass

If you are a Londoner, this pass gives you free travel across London and free bus journeys nationally.

Search for *Freedom Pass* at: [www.londoncouncils.gov.uk](http://www.londoncouncils.gov.uk)



## Access to Work

The Access to Work scheme may help fund taxi fares if you find it difficult to drive or access public transport.

In England and Wales, see: **[www.gov.uk/access-to-work](http://www.gov.uk/access-to-work)**

In Northern Ireland, search for access to work at:  
**[www.nidirect.gov.uk](http://www.nidirect.gov.uk)**

In Scotland, see:  
**[www.disabilityscot.org.uk/info-guide/access-to-work](http://www.disabilityscot.org.uk/info-guide/access-to-work)**



See our information sheet *10E – Work and MND*.



### 3 What do I need to think about when planning journeys?

Whether you're travelling alone or with others, by road, rail, air, or sea, you may need support at some points on your journey.

Public transport in the UK is required to offer an accessible service for people with disabilities. These services can be limited by timings and staff availability. Planning ahead can help make sure your journey as smooth as possible.

**The Hidden Disabilities Sunflower symbol** discreetly lets trained staff know you may need extra support or a little more time due to a hidden disability. While it's not necessary to display this symbol to receive assistance, it can be helpful depending on your current needs and symptoms.

The sunflower symbol is widely recognised in shops, airports, railway and coach stations, venues, tourist spots, leisure facilities and by highways agencies. You can wear a lanyard, carry a card, or put a sticker in your car window to identify yourself. For a small charge, the cards can be personalised. Find out more at:

**<https://hdsunflower.com/uk/>**

For government information about accessible travel by road, air or train see their online guidance at: **[www.gov.uk/transport-disabled](http://www.gov.uk/transport-disabled)**





## Make journeys easier by:

- researching transport websites when choosing your route, searching terms online like *accessibility* and *help to travel*
- asking travel providers how they can meet your needs and what they mean by 'accessible'
- planning your trip door to door, and home again
- finding where accessible toilets or support equipment will be available on route
- keeping a note of the weight, size and height if you have a wheelchair, both when sitting in it and empty
- checking equipment is working before setting off
- booking onsite equipment in advance, for when you arrive
- taking a small kit for punctures and quick repairs with a wheelchair, and note the nearest repair facility to your destination
- using our *MND Alert Card* or *MND Alert Wristband*, to explain you have MND and may be at risk with oxygen, and download the *MND Alert Card* to your phone.



**“We took with us, a small zimmer frame, dismantled in a suitcase, along with a pair of suction grab handles to help in the walk-in shower. I also emailed the hotel to request a shower stool to make life easier.”**

Access thousands of public toilets at service stations and other public places by purchasing a RADAR key. Disability Rights UK and some local authorities offer them at reduced rates.



See *Other organisations* in section 4, including Changing Places to find accessible toilets. For more about toilet access, see our booklet, *Personal care*.

## By road

### By car

When planning your route, consider where and when to stop for comfort breaks. Motorway service stations provide disabled parking and accessible toilets, but smaller service stations may not.



See *Other organisations* in section 4, including AccessAble to check accessible facilities on your route.

### By taxi

Wheelchair-accessible taxis, such as London black cabs, may only be able to carry smaller wheelchairs. Always check with the company when making the booking.

When booking a taxi, it helps to know the size and weight of your wheelchair, as well as its height with you sitting in it. This is because taxi companies need to be sure there is adequate space between the top of your head and the roof for safety reasons.

For advice on accessible taxis in your area, contact your local council.

### Uber WAV

There are a range of Uber vehicles available if you require additional assistance. Check first to make sure they are available near you or at your destination.

**Uber Access** provides forward-facing wheelchair accessible vehicles for customers with non-foldable wheelchairs.

**Uber Assist** is available for those who need additional assistance in a standard vehicle. This includes mobility difficulties, hearing or visual impairment and foldable wheelchairs.

**UberX** is a standard vehicle that can also take foldable wheelchairs and assistance animals.

All three services are priced the same as regular Uber rides. Find out more at: **[www.uber.com/gb/en/ride/uberwav](https://www.uber.com/gb/en/ride/uberwav)**

**The London Taxicard** scheme offers London residents with long-term mobility difficulties or sight impairment discounted journeys in licensed taxis and private hire vehicles. See more at: **[www.londoncouncils.gov.uk/services/taxicard](https://www.londoncouncils.gov.uk/services/taxicard)**

## **By bus or tram**

Most buses have designated wheelchair spaces and ramps that can be lowered for getting on and off. Many UK cities also offer tram services that have level access. Always check accessibility with the relevant local authority before you set off on your journey.

Some low-level buses and tram services will allow mobility scooters. Check with the service provider first about the size and type of scooter allowed.

In England and Wales, you may be entitled to a free bus pass for off-peak hours. Contact your local authority for details.

In Northern Ireland, certain benefits may entitle you to get reduced fares with Translink, which includes the Glider bus service. For more, see **[www.nidirect.gov.uk](https://www.nidirect.gov.uk)** and search for *SmartPass*.

In Scotland, free bus and tram passes are available for those who have disabilities and need extra assistance. Find out more and how to apply at **[www.mygov.scot/transport-help](https://www.mygov.scot/transport-help)**

## By coach

You may not have to book in advance to use a wheelchair on a coach, but check with the provider to find out:

- **availability** - if the coach is fully booked or not
- **wheelchair lift capacity** - check the lift can safely carry both you and your wheelchair's combined weight.
- **lift accessibility** - check the wheelchair lift can be used safely at both the boarding and final stop point.

Mobility scooters can usually be stored in the coach's hold. Always check with the provider before booking to make sure this is possible. Drivers usually offer reasonable assistance to help you safely to your seat, along with grab rails for support.

## By rail

### By train

Many trains and stations across the UK have been adapted to make rail travel easier for people with reduced mobility. If you are travelling abroad, check what specific facilities will be available in your destination country.

**Train accessibility:** Most trains are suitable for wheelchair and mobility scooter users. They have designated spaces often located near accessible toilets.

**Booking assistance:** It is essential to book any required support in advance. The *Passenger Assistance app* allows you to quickly book the support you need for your national rail journey. You can save your details for future trips and update them when needed. Find out more, and see a subtitled animation at: <https://passengerassistance.com>



**Disabled Person's Railcard:** If you use a wheelchair you may be entitled to a *Disabled Person's Railcard*. Check with your local train company for more details. If you don't qualify, ask if there are any other discount schemes for people with reduced mobility.

## **By Tube (London Underground)**

Transport for London (TfL) offer guides showing which stations have lifts, escalators or ramps between the street and the platform, and which stations have level access. To find which modern stations have gap free access to tube trains and which older stations need a ramp to safely board visit: **<https://tfl.gov.uk/transport-accessibility>**



**“There is a London Underground Map showing which stations have lifts.”**

When planning your journey, be aware you cannot remain seated in a wheelchair on any escalator, even if assisted. Your wheelchair must be transported separately, but many tube stations have lifts.

Staff are available to help you get on and off trains. They can also arrange for you to be met at your destination. To use this service, ask any member of staff. They are trained to look for people who need help to get on or off the train and offer assistance.

All London Underground trains have priority seats for people with disabilities. London residents with limited mobility can apply for a *Please Offer Me a Seat* badge or card from Transport for London at: **<https://tfl.gov.uk/transport-accessibility/please-offer-me-a-seat>**

## **By Channel Tunnel (Eurostar)**

Eurostar provides assistance with check-in, boarding and getting off the train. You need to notify them at least 24 hours before your trip of any help you might need. It is also recommended to arrive at least an hour before your train is due to depart.

**Wheelchair spaces:** Eurostar offers wheelchair spaces with maximum dimensions of 70cm x 120cm. These spaces are limited so pre-booking is essential.

**Reduced mobility:** If you don't use a wheelchair but have reduced mobility, Eurostar will provide you with a wheelchair to travel through the station to the train. However, you will need to walk from the door to your seat. There may not be a ramp available to help you board the train.

**Mobility scooters:** Eurostar may be able to store foldable mobility scooters in the luggage hold free of charge. It is recommended to contact Eurostar in advance to make sure there will be enough space in the luggage hold. There are restrictions on the types of battery they allow. See their guide for people with disabilities at: [www.eurostar.com/uk-en/travel-info/travel-planning/accessibility](http://www.eurostar.com/uk-en/travel-info/travel-planning/accessibility)

## By air

Before booking a flight, it is important to discuss your specific needs with the airline. Each airline has different disability and mobility services so it could help you decide the right airline to fly with.



**“We went on holiday as soon as my husband was diagnosed, but whilst away he found he couldn't walk far. I had to organise help at the airport both ends before going home. All was done with no problem.”**

Some airlines ask for an *Incapacitated Passengers Handling Advice Form (INCAD)*, which outlines the specific assistance you might need during your flight. Some airlines may ask for a *Medical Information Form (MEDIF)* to confirm that you are fit to fly. This form needs to be completed by your doctor. However, the airline has the final decision to allow you to travel.

Ask if your GP provides help for travel assessments and allow plenty of time for this support before arranging travel or payments. If you need breathing tests, these can take time to book and may need help from your respiratory team. If there is a waiting list, ask if you can book these privately, which would mean paying a fee.

If you are interested in finding out more about the process required to board a plane, there are schemes like QEF's Tryb4uFly or special days held at various airports that run through the experience before your trip. A trained occupational therapist will guide you through boarding, wheelchair transfer options and the support systems available on the aircraft. There may be a charge for this service.



For more on training facilities see QEF in *Useful organisations* in section 4: How do I find out more?



**“Travelling can be rewarding but requires a lot of planning.”**



## What happens at the airport?

In European airports, assistance is usually available free of charge for anyone with a disability. This assistance includes support with:

- reaching check-in on arrival
- support during check-in registration
- assistance moving through the airport
- help getting on and off the plane
- free carriage of medical equipment and mobility aids.

It is essential to book support with your chosen airline at least 48 hours before you are due to fly.

If you use a wheelchair, you will need to have a manual search during the security screening due to the metal detectors. You can ask for a private search if preferred. See more details on your airport rights and services at: **[www.gov.uk/airport-rights](http://www.gov.uk/airport-rights)**

Services at airports outside of Europe can vary. Ask your destination airport in advance to find out what type of support will be available.

## What happens on the plane?

Airlines will usually require you to have someone with you at the airport and on the flight if you need support to:

- evacuate the plane in an emergency
- use the toilet
- eat and drink
- communicate with staff.

If you will need help to put your bags in the overhead locker on the plane, ask the airline in advance if they can assist.



## What happens if I'm a wheelchair user?

Most airports will allow you to travel all the way to the plane in your own wheelchair before it's put in the cargo hold. Your airline will help you board the plane, which could include an Ambulift, Eagle hoist or narrow aisle chair to help you into your seat. Always check with the airline if you need to book support or equipment in advance for either your outbound or return flights.

**Wheelchair storage:** Airlines usually store most wheelchairs in the hold, or folding manual wheelchairs in dedicated cabin storage. Your wheelchair must fit within the maximum weight and size for travel with the chosen airline. If parts of your wheelchair are easily removed, do this and pack separately to reduce risk of damage. You may also be able to buy a travel bag for your wheelchair. Please check with the airline in advance of your journey.

**Battery restrictions:** Some airlines might have safety restrictions on powered wheelchair batteries. Check with the airline well in advance to confirm. If there are issues with your battery, find out if an 'airsafe' plug can be used to safely immobilise your wheelchair during the flight. This can help prevent costly damage such as wires being cut or the need to disassemble the chair to remove the battery. Search for *airsafe wheelchair plug* online for more information.

**Leasing a powered wheelchair:** Check the hire company policy for taking a leased chair abroad. Ask your travel provider if there are rules about using a powered wheelchair or mobility scooter at your destination.

## Can I access the toilet on a plane?

Toilet accessibility on planes can vary. Some airlines have an onboard wheelchair the cabin crew can use to escort you to the door of the toilet. However they will not assist with any personal care required. If you are not able to self-toilet, then an assistant or carer will be needed. Larger planes may have wheelchair accessible toilets, but do check with the airline first.

If you might need the toilet quickly during a flight, ask your doctor about discreet support such as continence pads.



See our booklet *Personal care* about portable toilet aids.

### **Can I take medical equipment onto a plane?**

If you use ventilation equipment, you may be allowed to take your own equipment on to the plane if it uses a dry cell battery. Ask the airline about this in advance and if they need any documentation.

Oxygen is not routinely recommended for people with MND. Most airlines provide oxygen when medically required, however this service will need to be booked in advance and requires medical clearance. Advise the airline in advance if you're likely to require oxygen as there may be an additional charge.



See information sheet 8E – *Air travel and ventilation for MND*.

### **Can I take prescribed supplements on a plane?**

Prescribed feeds and fluid supplements can go through security if they are in the original pharmacy packaging. It helps if the pharmacy can mark the prescription as 'Essential medication'. Carry proof of your prescription from your GP, consultant or dietitian and details of the ingredients in case you need more prescribed when abroad. It's worth exploring if your medication can be sent ahead to your destination.

### **Can I take non-prescribed supplements on a plane?**

If you use supplements like fortified drinks or thickeners, you may be able to have them delivered to a pharmacy beyond the airport security area. This means they are already security checked and allowed on the plane. If you order supplies online they will be sent to a pharmacy before security, which could cause delays. When ordering by phone, ask for delivery to the pharmacy after security.

They may also be able to arrange for extra fluids that are not needed during the flight to be sealed in a transit bag for additional onward flights. Ask about this when ordering your supplements.

Check security rules for the country you're visiting before travelling. For example, you are not allowed to take fluids in hand luggage for onward or internal flights in the USA.

The Equality and Human Rights Commission have produced a guide with tips for disabled air passengers. It explains your rights and how to prepare for your journey. Search for *Disability and Air Travel* at: **[www.equalityhumanrights.com](http://www.equalityhumanrights.com)**

### **What will the seating arrangements be?**

Seating on the plane can vary depending on the size of the aircraft. There may be different types of seating available, to help with posture or legroom.

Some aircraft accept a range of airline approved seat supports for the back, head and side to help make your journey more comfortable. These will need to be fitted by you or your travel companion, so please check with the airline before you make your booking.

## **By sea**

Modern ferries and cruise ships are often designed to be accessible for all. Let the ferry or cruise company know of your specific needs before booking your trip.

Keep in mind that the movement of the sea can make it difficult to keep your balance, especially if you are unsteady on your feet. Companies usually suggest travelling with someone who can assist you. Larger ships offer more stability and may be more comfortable if you have mobility concerns.

## **On a ferry**

Travelling by ferry can be a practical choice if you're also driving part of the journey. If you book tickets in advance you can often drive through the terminal and on to the ferry without leaving your car.

The level of support offered by ferry companies can vary, so check what is available when making your booking. This may include assistance with:

- registering at check-in and luggage handling
- help with seating and storing your luggage
- retrieving your luggage and leaving the ferry at the end of your journey.

Accessible cabins on ferries, in particular those designed for wheelchairs are often limited and allocated on a first come, first serve basis, so always book in advance. Most ferries will have lifts to all floors and disabled access toilets, but it is always important to check the facilities available when booking your trip.

## **On a cruise ship**

Cruises have the luxury of having all facilities in one place while visiting several destinations and only unpacking once. Many cruise ships have accessible cabins, often with level access wet rooms. If you have specific dietary requirements, you may need to arrange these in advance with the cruise line.

Cruise operators are required to provide necessary medical or mobility equipment for your trip. However, some items may not be allowed on board or may be subject to a size limit, depending on the size of the ship. Contact the travel company for specific details relating to your equipment needs.

Check which ports on the cruise are accessible. Some may require ship-to-shore boats, which can be difficult with limited mobility or a wheelchair.

## 4 What do I need to think about for days out and holidays?

To make the most of your holiday or day out, choose where you want to go first, then explore access and support for your trip.

Explore websites dedicated to accessible venues and destinations for ideas. *Euan's Guide* offers reviews from people with disabilities around the world. Visit the website at: [www.euansguide.com](http://www.euansguide.com).

Wherever you decide to go, seek recommendations from accessible travel specialists and other people with reduced mobility. Carers may be offered free or discounted admission at sporting venues or theatres to help assist the person they are supporting.

Be completely honest about your needs to get advice that feels right for you.



**“I asked for an accessible room when I booked. When I arrived, it was a very small room, and the toilet door did not fully open so I could not get my wheelchair in and there were no grab rails. (Lesson one – check that people understand what I mean by accessible.)”**

Things to think about include:

**Accommodation:** some venues may have equipment such as wheelchair lifts to navigate steps or to get to other floors. Always ask a trained member of staff to help operate lifts. Accessible bedrooms and bathrooms can vary in the level of support they provide, so it's important to find out what's on offer. For example, you may need a hoist, an adjustable bed, a level-access shower or sufficient turning space for a wheelchair.



**“There was an ordinary bed which I could manage but it wouldn't be suitable for everyone.”**





**“Our family had a fabulous time away and with the support of our friends I managed to enjoy time on the beach, in my wheelchair!”**

**Travel operators:** find out if an operators provides help, such as mobility support, dietary requirements or special sleeping arrangements. As airports, airlines, hotels and transport work independently, ask each operator about your needs in advance.

**Equipment and supplies:** if you need equipment on holiday, see if you can hire items in advance from your destination such as a beach wheelchair. If you use non-prescription supplements or tube feeds, check with the manufacturer to see if they are available in the country you are visiting.

**Care services:** does your chosen holiday provider offer care services, or do you need to arrange your own support?

**Communicating with medical staff:** if you are visiting a non-English speaking country, take key phrases about your medical care needs in their language. We have a range of information sheets about MND or Kennedy's disease in other languages which you could take with you. Find these at: [\*\*www.mndassociation.org/languages\*\*](http://www.mndassociation.org/languages)

For travel within the UK or to a country that speaks English, you can use our *Understanding my needs form* to write information for staff who may not be familiar with you or your condition.

**Travel insurance:** this usually costs more with a medical condition so explore several quotes. Check what the policy covers and that MND or Kennedy's disease has been specifically listed to ensure you have valid insurance before travelling. Insurance companies frequently change their offers, but our MND Connect helpline may have details about current holiday cover for people with MND or Kennedy's disease.



**"They said there was an insurance that covered MND. Yet, when I had to cancel the holiday, they refused to pay out. I did get the money back, but after nearly 18 months. So it's essential that MND is mentioned and understood."**

Since leaving the EU the European Health Insurance Card (EHIC) has been replaced with the UK Global Health Insurance Card (GHIC). You can continue to use an existing EHIC until its expiry date. You will then need to apply for a UK GHIC to replace it. Search for *GHIC* on **www.nhs.uk** for more information.



**“My wife made a daily diary of everywhere we went while abroad. When I became ill out there, the diary helped with the holiday insurance claim, making it easier to submit dates for hospital stays and expenses, with receipts attached.”**

### **Can I get financial support to have a holiday?**

You may be able to get help with holiday costs through your local branch at:

- Citizens Advice
- Family Holiday Association
- Rotary Clubs
- Round Table
- Benevolent charitable funds
- Lions Associations.

The MND Association offers financial support grants to people living with or affected by MND, or Kennedy’s disease. These grants can help towards the cost of a holiday, for you and your carer.

Visit **www.mndassociation.org/financialsupport** for more information or call MND Connect on **0808 802 6262**.

## Who can support me while my carer has a break?

- day centres and local hospices offer sessions such as complementary therapy, where your carer can join you or take a short break.
- extended family may already provide care support but might be willing to assist on a regular basis
- both you and your carer might benefit from a break together, away from the usual routines
- during a needs assessment or carer's assessment, ask adult social care services for recommendations on appropriate care cover in case you need support.



For more information about maintaining intimate relationships, see our booklet *Sex and relationships*.

## If I'm a carer, how can I take a break?

As a carer, your needs matter too and when facing the demands of support, you need rest. A holiday or even short breaks make a difference, to shop or meet friends. Respite care can help support the person with MND or Kennedy's disease during this time, but ensure the service understands the condition.



**"Exhaustion can creep up on you when you least expect it and tasks that would normally be easy or simple can become very fraught."**

Once registered as a carer, you may qualify for funding to help you and the person you support access respite care and other support services. Ask for both your needs to be assessed by adult social care services.

**In England or Wales:** contact your local authority.

**In Northern Ireland:** contact your local health and social care trust.

**In Scotland:** contact your council's social care department.



**“With funding, you can get help to take a break from home and the daily struggles of life with MND.”**

During your assessments, ask about support for carers to take a break and about appropriate respite care with relevant experience.



For more information on carer assessments, see our guide: *Caring and MND: support for you* and information sheet *10B – What is social care?*

To explore options, search for *respite care* at: **[www.nhs.uk](http://www.nhs.uk)** or get helpful advice on the Carers UK website: **[www.carersuk.org](http://www.carersuk.org)**.



## 5 How do I find out more?

### Other organisations

We do not endorse organisations, but these may help you begin your search. Contact our MND Connect helpline for support with finding services, (see *Further information*). See more organisations at:

**www.mndassociation.org/usefulorgs**

#### **AccessAble**

Guides on accessible venues and motorway services

**Telephone:** 01438 842 710

**Website:** **www.accessable.co.uk**

#### **Changing Places**

Find your nearest accessible toilet.

**Telephone:** 020 7803 4814 (England, Wales and Northern Ireland)  
01382 755389 (Scotland)

**Website:** **www.changing-places.org/find**

#### **Driving Mobility**

For driving assessments and regional mobility centres.

**Telephone:** 0800 559 3636

**Website:** **www.drivingmobility.org.uk**

#### **DVLA (Driving and Vehicle Licensing Agency)**

To declare a disabling condition in England, Wales and Scotland.

**Telephone:** 0300 790 6806

**Website:** **www.gov.uk/driving-medical-conditions**

#### **DVA (Driver and Vehicle Agency)**

To declare a disabling condition in Northern Ireland.

**Website:** **www.nidirect.gov.uk/articles/when-you-tell-dva-about-medical-condition**

## **Disability Rights UK**

Information on how to purchase a RADAR key.

**Telephone:** 0203 687 0790

**Website:** <https://shop.disabilityrightsuk.org/products/radar-key>

## **Google Maps (App)**

Download from your device's app store for wheelchair-accessible walking paths, stair-free routes, screen reader abilities and more.

## **GOV.UK**

Government website, including travel, driving and disabled rights.

**Website:** [www.gov.uk](http://www.gov.uk)

## **Motability**

For help with a scooter, powered wheelchair or adapted car.

**Telephone:** 0300 456 4566

**Website:** [www.motability.co.uk](http://www.motability.co.uk)

## **Queen Elizabeth's Foundation for Disabled People (QEF)**

Helping disabled people to be as independent as possible.

**Telephone:** 01372 841100

**Website:** [www.qef.org.uk/service/mobility](http://www.qef.org.uk/service/mobility)

## **Red Cross**

Easy and affordable wheelchair hire delivered straight to your door.

**Website:** [www.redcross.org.uk/get-help/hire-a-wheelchair](http://www.redcross.org.uk/get-help/hire-a-wheelchair)

## **ShopMobility**

Hire mobility equipment for getting around the local area.

**Website:** [www.shopmobilityuk.org](http://www.shopmobilityuk.org)

## **Transport for London - Accessibility**

Information on accessible travel in London.

**Telephone:** 0345 222 1234 **Textphone:** 0800 112 3456

**Website:** <https://tfl.gov.uk/transport-accessibility>

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## References

References used to support this information are available on request from email: **[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**

Or write to:

Information feedback, MND Association  
Francis Crick House, 6 Summerhouse Road  
Moulton Park, Northampton NN3 6BJ

## Further information

We have other resources related to the content in this booklet:

*Living with motor neurone disease (MND)*

*Living alone with motor neurone disease*

*Caring and MND: support for you*

*Personal care*

*Telling people about MND*

*Making the most of life with MND*

*Sex and relationships*

*Understanding my needs*

*3A - MND Care Centres and networks*

*8D - Air travel and ventilation*

*10A - 10G: our sheets on benefits support and social care*

We also provide information about equipment, wheelchairs, environmental controls and more.

Download our resources at: **[www.mndassociation.org/publications](http://www.mndassociation.org/publications)**  
or search for resources by need using our Care information finder at:  
**[www.mndassociation.org/careinfofinder](http://www.mndassociation.org/careinfofinder)**

Order printed copies from our MND Connect helpline.

### **MND Connect**

Our helpline team can provide emotional support and guidance. They can help you search for other organisations, our local branches, groups and volunteers, and explain our services and financial support for people with and affected by MND or Kennedy's disease.

Telephone: **0808 802 6262**

Email: **[mndconnect@mndassociation.org](mailto:mndconnect@mndassociation.org)**

### **MND Association website and online forum**

Website: **[www.mndassociation.org](http://www.mndassociation.org)**

Forum: **<https://forum.mndassociation.org>**

## **MND Association Benefits Advice Service**

For help to identify claims and how to apply. Find current contact details for England, Wales and Northern Ireland at:

**[www.mndassociation.org/benefitsadvice](http://www.mndassociation.org/benefitsadvice)**

or contact our MND Connect helpline: **0808 802 6262**

## **We welcome your views**

We'd love to hear what you think we did well and how we can improve the content for people with or affected by MND or Kennedy's disease. Your anonymous comments may also be used to support and influence, as they help us share real MND experiences and raise awareness in our resources, campaigns and applications for funding. Please use our online feedback form at:

**[www.smartsurvey.co.uk/s/Gettingaround](http://www.smartsurvey.co.uk/s/Gettingaround)**

You can also email your comments to us at:

**[infofeedback@mndassociation.org](mailto:infofeedback@mndassociation.org)**

or write to us:

MND Association Information feedback,  
Francis Crick House, 6 Summerhouse Road  
Moulton Park, Northampton NN3 6BJ



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