

Getting around

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





“The wheelchair was great, but it’s heavy, impossible to push. With the support of my amazing occupational therapist, I successfully applied for a grant for attendant controls. As my hands get weaker friends or carers are able to ‘drive’ the chair for me.”

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This symbol highlights quotes from people living with or affected by MND.



Patient Information Forum

This information has been evidenced, user tested and reviewed by experts.

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, whether you're the driver or the passenger.

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.

See *Further information* in section 4: *How do I find out more?* for a list of our resources and how to order them.



1: Driving and choosing a vehicle

When diagnosed with MND or Kennedy's disease, you will face many challenges, changes and decisions. Much of the support available looks at ways to prolong your usual activities, including guidance on driving.

Can I continue driving?

If you drive, you will need to consider if your mobility or movement are affected. This can be an emotional time, as it impacts on your independence. However, much will depend on your symptoms, how fast these progress and the approach you wish to take.

In England and Wales, you are legally required to tell the Driver and Vehicle Licensing Agency (DVLA) that you been diagnosed with a medical condition. In Northern Ireland you need to tell the Driver and Vehicle Agency (DVA). **www.GOV.UK** lists the conditions that must be reported, including MND. Search for *medical conditions, driving and disabilities* for more information.

See Useful organisations in section 4 for driving agency contact details.

The DVLA or DVA might ask you to have an assessment and fill out a medical questionnaire. The forms are available on the DVLA and DVA websites. An assessment looks at whether you can safely drive 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 Driver Assessment Centre. They can provide guidance about alternative options and driving with a disability.

Discuss with your GP if you should continue driving while waiting for an assessment, or for confirmation 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. Its purpose is to review your driving. Trained assessors can advise which adaptations could prolong your driving independence if needed.

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 whenever you want. You have to pay for any additional assessments you request yourself, but it could help with decision making when you feel the time is right.

See *Useful organisations* in section 4, as *Driving Mobility* can help arrange assessments.

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.

Insurers need to take all reasonable steps to ensure they do not make it difficult for disabled people to use their services. They are not allowed to refuse car insurance to disabled drivers or charge extra unless there is evidence to justify the decision.

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**

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 charge to register, and this will need to be renewed at the same time as your Blue Badge. As long as this is done within 90 days of your Blue Badge expiry date, you will not need to pay for renewals. Contact Transport for London for more information.

Toll concessions for people with disabilities at river crossings, bridges and tunnels can help reduce the costs of getting around. Before any journey check 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.

What options do I have when choosing a car?

Discuss how your travel requirements have changed with your health and social care team, or an occupational therapist experienced in MND. Keep in mind your needs will continue to change as MND progresses, before making any decisions about vehicles. Car dealerships will have knowledge about available adapted cars, but not about MND or Kennedy's disease. If you have had a driving assessment the conclusions from this can help them source and advise on appropriate options for you.

What is a wheelchair accessible vehicle? (WAV)

You can hire or purchase a wheelchair accessible vehicle (WAV) to travel as either a passenger or the driver, without having to transfer from seat to seat. Always get advice from a reputable WAV specialist.



“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?

Whether you're the driver or the passenger, adaptations to suitable existing vehicles could improve access and support, get professional advice before buying anything. For example, if you want to store a wheelchair, will there be enough room? Some adaptations can be costly, and powered adaptations may drain your vehicle's battery, so you might need to use an external charger between journeys.

Adaptations can help you use your existing vehicle for longer, including:

- ways to get in and out of the car more easily, such as swivel seats and easy release handbrake controls
- new ways to manage the driving controls, such as steering wheel aids and alternative foot controls or pedal guards
- ways to store your wheelchair or mobility scooter and wheelchair hoists and winches.

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

Motability may be able to help you find a local venue where you can sit in an adapted vehicle or try out the controls. They also hold regional events for this purpose. Search online to find these and other events in your area.



What to consider when choosing a car.

Think about the following:

- If you will be driving, do you want to carry passengers?
- What adaptations might you need, now or in the future?
- As the driver, would you prefer to enter through the rear of the vehicle or through the driver's door?
- If you are a passenger, do you want to sit in the rear or the front of the vehicle?
- If your wheelchair is heavy, will a lift, winch or hoist system be needed?
- Is it easy to secure the wheelchair in the vehicle?
- How much visibility will you have when seated in the car?



Can the Blue Badge Scheme help me?

The Blue Badge scheme provides parking benefits for disabled people who travel either as a driver or a passenger. The scheme operates across the UK. Unless there are specific local exceptions, you can use your Blue Badge to park:

- free of charge and without time limit in street areas with parking meters, or pay and display
- in street areas reserved for valid Blue Badge holders
- on single or double yellow lines for up to three hours, unless there is a ban on loading or unloading.

The Blue Badge is intended for on-street parking only. Off-street car parks, such as those provided by a local authority, hospital or supermarkets have separate rules. They may have spaces for Blue Badge holders.

Different rules apply in London, but many disabled parking bays are available for Blue Badge holders. For more information search for *Blue Badge* at: <https://tfl.gov.uk>

Will I qualify for a Blue Badge?

You may automatically qualify for a Blue Badge if you:

- receive the enhanced or standard rate of Personal Independence Payment (PIP)
- receive the higher rate of the mobility component of Disability Living Allowance (DLA)
- receive a War Pensioners Mobility Supplement
- are registered blind.

Other disability-related benefits, such as Attendance Allowance do not automatically qualify you for a Blue Badge. You will need to be assessed by an independent assessor. Ask your GP to refer you or see next heading, *How do I apply for a Blue Badge?*

**For more about benefits, see information sheet
10A – Benefits and entitlements**

How do I apply for a Blue Badge?

For an application form, contact your local authority in England and Wales or apply online at: **www.gov.uk/apply-blue-badge**
In Northern Ireland contact Transport NI or search *Blue Badge* at:
www.nidirect.gov.uk

Can the Motability Scheme help me?

The Motability scheme can lease you an adapted vehicle or WAV, in exchange for some or all of your mobility allowance. See **www.motability.co.uk** for more information.

You don't have to be the driver of the leased vehicle. You can be the passenger and name two other people living within five miles of your home to be the named drivers. You can also pay extra 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 the PIP or DLA award runs out during the contract period and is not renewed, the vehicle will have to be returned.

Get assessed before leasing a car. The contract usually includes:

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



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

Will I qualify for the Motability scheme?

You may be eligible for the scheme if:

- you receive the higher rate mobility component of Personal Independence Payment (PIP) or Disability Living Allowance (DLA)
- your PIP or DLA award has at least 12 months left.

Attendance Allowance cannot be used to lease a car through the Motability scheme. See, www.motability.org.uk/faq for information on benefits that do qualify.

How do I apply for the Motability scheme?

To take part in the Motability scheme:

1. Choose the vehicle that is right for you.
2. Make an appointment with a Motability scheme dealer to get advice and arrange a test drive.
3. Submit your application to order your new car.

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 agree to a new vehicle being leased. There is usually a fee. If adaptations or further adaptations are needed to continue using the vehicle, only Motability approved installers should make them.

If you are leasing a Motability car, but lose your award for the mobility component of DLA after being reassessed for PIP, you may be able to keep the car for seven weeks after DLA is stopped. Contact Motability to check what happens next.

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 two weeks, but they must inform Motability before using the government Tell Us Once service. This is because Tell Us Once contacts other departments about the death, including the DVLA, which results in cancellation of the vehicle's road tax. A Motability form can be completed online and someone will contact you within 3 days. Someone else can also help and contact Motability on behalf of other named drivers. Search for *Tell Us Once* at **www.GOV.UK** for more information about how this service works.

Do Motability lease powered wheelchairs or scooters?

Yes. If you wish to lease a powered wheelchair or scooter from Motability, a single monthly payment can be taken from your PIP or DLA mobility allowance. The lease includes breakdown cover, insurance and maintenance. An independent assessment can help work out what is likely to suit you now, and in the future as your symptoms progress.



Wheelchairs and mobility scooters

Mobility equipment can make it easier to get in and out of vehicles, such as leg lifters, hand holds, transfer boards, hoists and swivel cushions. If your mobility is slightly affected, walking sticks, crutches and rollators can help when out and about.

Mobility scooters are useful if you can use the controls safely. Discuss with an occupational therapist if you think you will benefit from one as they can be costly. See previous section, *Can the Motability scheme help me?* Or read on in this section about renting scooters from shopping centres for short periods.

Standard manual wheelchairs could help you get around easier for longer and enable you to continue doing what you enjoy. For example, if you get tired during days out, try taking a manual fold up wheelchair with you on trips so you can carry on with your day if you get tired.

A highly supportive manual wheelchair offers better support for your posture, but they are larger than a standard wheelchair and may not fit as easily in vehicles.

Powered wheelchairs can offer more independence if you can't use a manual wheelchair. You can use various control options to drive. There are many different types of powered wheelchair and assessment is needed to find one that matches your needs.

Ask if your local wheelchair service can assess your wheelchair needs. See information sheet 11C - Equipment and wheelchairs.

Do I need to register a wheelchair or mobility scooter?

Manual wheelchairs, which you move yourself or someone else pushes, do not need to be registered in any way. You do not need a licence to drive a mobility scooter, or powered wheelchair, but you may need to register it with the DVLA or DVA. There are 2 classes of wheelchair and mobility scooters.

Class 2: powered wheelchairs and mobility scooters cannot be used on the road (unless there is no pavement). They have a max speed of 4mph and you do not need to register them.

Class 3: powered wheelchairs and mobility scooters can be used on roads if necessary. They have a max road limit of 8mph and 4mph off road and you do need to register them. You do not have to pay vehicle tax on class 3 powered wheelchairs and mobility scooters.

Check with the DVLA in England or Wales, or DVA in Northern Ireland, which features your scooter or wheelchair must have to be able to safely drive on roads if necessary.



“My husband’s powered wheelchair gave him an enormous amount of independence. It enabled him to travel much more easily than a manual chair, and for a longer period of time.”

Do I need insurance for a mobility scooter or wheelchair?

Although it’s not required legally, you are strongly recommended to get insurance for any mobility scooter or powered wheelchair, as with any motorised vehicle.

What else could help me get around?

Community transport services are usually run as not-for-profit schemes. They’re run by local people, offering door to door accessible transport for people who are ill or disabled.

Patient transport services (PTS) may provide free, non-emergency transport, to and from hospital appointments for people who have reduced mobility. If you live in England or Northern Ireland, ask your GP or the healthcare professional who referred you for the appointment about patient transport services. In Wales you can check if you qualify for the service here:

www.ambulance.wales.nhs.uk/en/406

Shopmobility loan or hire out wheelchairs and mobility scooters to help you get around shops when visiting local towns and shopping centres. In England and Wales contact your local council for more information on schemes in your area, or search online at: www.gov.uk/community-transport-services-shopmobility
In Northern Ireland see: www.shopmobilityni.org

The Freedom pass offers Londoners free travel across London and free bus journeys nationally. Search for *Freedom Pass* at www.londoncouncils.gov.uk

The Access to Work scheme may be able to help fund taxi services if you commute to work but are unable to drive, or you find using public transport difficult. See: www.gov.uk/access-to-work to find out more. If you live in NI search for *access to work* on: www.nidirect.gov.uk

For more about the Access to Work Scheme see, information sheet 10E – *Work and MND*.



2: 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 must offer an accessible service to people with disabilities. In reality this service can be limited by timings and staff availability. Planning ahead can help providers make 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. This could be helpful depending on your current symptoms. You don't have to display this symbol to get assistance, but the sunflower symbol is widely recognised in airports, railway and coach stations, venues and leisure facilities as well as by highways agencies. You can wear a lanyard, carry a card, or put a sticker in your car window. The use of the sunflower symbol is being adopted across the UK in other sectors. Find out more at:

<https://hiddendisabilitiesstore.com>

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



Make journeys easier by:

- researching transport websites when choosing your route, using search terms like *accessibility* and *help*
- asking direct questions to a travel provider to find out how they can meet your needs and what they mean by 'accessible'
- planning each stage of your trip from your door to returning home
- find out where accessible toilets will be on your route or equipment such as ramps
- keeping a note of the weight, size and height if you have a wheelchair, both when sitting in it and empty
- making sure any personal equipment is in good working order before setting off
- booking any larger equipment you need in advance, so it will be ready at your destination
- carrying a small repair kit for punctures and emergency repairs if you use a wheelchair, and note the nearest repair facility to your destination
- taking our *MND Alert Card* or *MND Alert Wristband* with you, which explain you have MND and may be at risk with oxygen (the MND Alert can also be downloaded 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.”

To gain access to thousands of accessible service station public toilets you can purchase a RADAR key. Keys can be purchased at Disability Rights UK. Some local authorities also have schemes to offer these at reduced rates.

See *Useful organisations* in section 4 for contact details, including *Changing Places* to help find accessible toilets.

For more about personal care and toilet accessibility, see our booklet, *Personal care*.

By road

By car

Plan your route, including where and when to stop for comfort breaks. Motorway service stations provide disabled parking and accessible toilets, but service stations on smaller roads may not.

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

By taxi

If a taxi company is wheelchair accessible (including London black cabs), they may only be able to carry smaller wheelchairs, so check when making the booking.

Knowing the size and weight of your wheelchair, as well as its height with you sitting in it, can be helpful when booking a taxi. 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. Contact your local council for advice on local taxi firms who can meet your needs.

Uber Assist are unmodified Uber taxis who can assist customers with foldable wheelchairs or mobility difficulties. **Uber Access** provide taxis that are modified for wheelchair access. There is no price increase for Uber Access or Uber Assist. Find out more at: www.uber.com/gb/en/ride/uberwav

The London Taxicard scheme offers disabled residents of London discounted journeys in licensed taxis and private hire vehicles. See more at: www.londoncouncils.gov.uk/services/taxicard

By bus or tram

Most buses have designated wheelchair spaces and can be lowered or have ramps for getting on and off.

Various UK cities offer tram services that have level access. Check tram accessibility with the relevant local authority before you set off on your journey.

You can ride a mobility scooter onto some low level bus and tram services. Check with the service provider first, including the size and type of scooter allowed.

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

If you live in Northern Ireland and receive certain benefits, you may be able to get a reduced price with Translink, which includes the Glider bus service. Search for *SmartPass* on www.nidirect.gov.uk for more information.

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:

- if the coach is fully booked or not
- if the wheelchair lift can safely accommodate the combined weight of the wheelchair and passenger
- that the wheelchair lift can be safely used at the boarding and final stop point.

If you use a mobility scooter, it can usually be stored in the hold of a coach but check before booking. Reasonable support is usually available from the driver to help you safely to your coach seat, along with grab rails.

By rail

By train

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

Most trains are suitable for wheelchair and mobility scooter users and have designated wheelchair spaces located near accessible toilets. As with all forms of transport, it is essential to book any support offered in advance.

The Passenger Assistance app allows you to quickly book the support you need for your rail journey. It will save your details so you can simply update them when needed. Find out more, and see a subtitled animation at: [**https://passengerassistance.com**](https://passengerassistance.com)

If you use a wheelchair you may be entitled to a Disabled Person's Railcard – find out through your local train company. If you don't qualify, check if there are any other discount schemes for people with reduced mobility.

By Tube (The London Underground)

Transport for London produce guides showing tube stations where you can use lifts, escalators or ramps between the street and the platform, and which stations have level access. Search for *transport accessibility* at [**https://tfl.gov.uk**](https://tfl.gov.uk) to find which modern stations have gap free access to tube trains and which older stations need a ramp to safely board.



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

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

Staff can accompany you to the train and help you on board. 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 offer assistance with checking in, boarding and getting off the train. You need to advise them 48 hours before your trip of any help you might need. They ask that you arrive at least an hour before your train is due to depart.

Eurostar wheelchair spaces accommodate a 70cm x 120cm wheelchair. Spaces are limited so pre-booking is essential.

If you don't use a wheelchair but have reduced mobility, you will be provided with a wheelchair to travel through the station to the train. You will need to walk from the door to your seat. There may not be a ramp to help you board the train and the discounted rate does not apply. They may be able to store mobility scooters in the luggage hold for free. It is important to contact Eurostar in advance to ensure there will be enough space in the luggage hold before your journey and they do have restrictions on the types of battery they allow. Eurostar produce a guide for people with disabilities, for more information see: www.eurostar.com/uk-en/travel-info/travel-planning/accessibility

By air

If you want to travel by air, discuss specific needs before you book. All airlines are different, and it could help you decide who you 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 shows what specific assistance you might need. Some airlines also require a *Medical Information Form (MEDIF)* to confirm you are fit to fly, which needs to be completed by your doctor. However, the airline has the final say. They can refuse to let you travel with them if they don’t feel you are fit to fly.

Allow plenty of time to see your doctor before making any arrangements or payments for travelling, as you might need breathing tests which can take time to arrange. A member of your respiratory team will usually assist if breathing tests are required.

You can use training facilities to try out boarding a plane, before you decide to travel. A trained occupational therapist will guide you through boarding the aircraft, wheelchair transfer options and using support systems available on the aircraft. There will 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 who is disabled. This includes support with:

- reaching check-in on arrival at the airport
- registering at check in
- moving through the airport
- getting on and off the plane
- free carriage of medical equipment and up to two items of mobility equipment.

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

When going through security, if you use a wheelchair you will be searched manually, due to the metal detectors. You can request the search takes place in private.



Airport services vary greatly outside of Europe. Ask your destination airport 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 if they can assist.

What happens if I'm a wheelchair user?

You should be able to travel all the way to the plane in your own wheelchair, before it's put in the cargo hold. The airline supplies a transfer chair when you're ready to board. This is a narrow chair which can fit down the plane aisles. Some airlines use hoists to help disabled passengers transfer to a seat. Always check with the airline in case you need to book support or equipment for either the outward or return flights.

Airlines carry most wheelchairs in the hold, although a weight and size limit may apply. If parts of your wheelchair are easily removed, do so, to reduce risk of damage, or you may be able to buy a wheelchair travel bag. There might be safety restrictions on some powered wheelchair batteries, check with the airline well in advance.

If the battery does cause an issue, find out if an 'airsafe' plug can be used to safely immobilise the wheelchair during the flight.

This can prevent costly damage such as wires being cut or disassembly of the chair to remove the battery. Search for *airsafe wheelchair plug* online.

If you lease your powered wheelchair check with the hire company what their policy is for taking it abroad. Check with your travel provider if there are any specific rules about using a powered wheelchair or mobility scooter at your destination.

Can I use the toilet on a plane?

Toilet accessibility varies on planes, but most airlines supply narrow wheelchairs for use onboard. Some larger planes have wheelchair accessible toilets. If you are concerned about using the toilet on a flight, get advice from your medical professional about discreet portable toilet equipment.

For more information about portable toilet aids, see our booklet *Personal care*.

Can I take medical equipment onto a plane?

If you use ventilation, 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 additional documentation.

Oxygen is not routinely recommended for people with MND. Most airlines provide oxygen when medically required. You cannot take your own oxygen supply on to the plane. Advise the airline if you're likely to require oxygen beforehand as there may be a charge and you may be asked to provide your own mask.

For more about ventilation and air travel see: *information sheet 8E – Air travel and ventilation for MND*.

Prescribed feeds and fluid supplements can be taken through security as long as they have the original packaging as given by a pharmacy. The pharmacy can mark the prescription as

'Essential medication'. An accompanying letter from your GP, consultant or dietitian is also helpful to take, as are details of the ingredients in case a new prescription is required whilst abroad.

Can I take non-prescribed supplements on a plane?

If you use supplements such as fortified drinks or thickeners, it may be possible to have them delivered to a pharmacy located beyond the airport security area. This means your supplements would have been security checked already and therefore allowed on the plane. If you order supplies online they will be sent to a pharmacy before security, which could cause delays. Order by phone and ask for delivery to the branch after security. They may also be able to arrange for extra fluids that are not needed in-flight to be sealed in a transit bag for additional onward flights. Ask about this when ordering your supplements.

In the USA you will not be allowed to carry any fluids in hand luggage on forward connecting or internal flights. Check the security rules for the country you're visiting before travelling.

The Equality and Human Rights Commission have produced a guide with tips for air passengers who are disabled. It explains your rights and how to best prepare for a journey. You can find the guide on their website. See, **www.equalityhumanrights.com** and search for *Disability and Air Travel*.

By sea

Modern ferries and cruise ships are often well adapted and accessible to all. Let the ferry or cruise company know of your specific needs before booking so you can be sure you'll get the help you need.

Keep in mind the movement of the sea can make it difficult to keep your balance if you are unsteady on your feet. Companies usually suggest travelling with someone who can assist you. You may find travelling on larger ships more comfortable.

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 ferry companies offer varies greatly, so check what is available when making your booking. This may include assistance with:

- registering at check-in and checking in your luggage
- getting seated and storing your luggage
- retrieving your luggage and leaving the ferry at the end of your journey.

In many ferries, cabins designed to accommodate wheelchairs are limited and assigned 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 making a booking.

On a cruise ship

With cruises, all facilities are in one place and you can visit several destinations while only unpacking once. Ships often have accessible cabins, with level access wet rooms. If you have specific diet requirements, you may need to arrange these in advance.

Operators must carry any medical or mobility equipment you need that is reasonably necessary 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 information relating to your needs.

Find out which ports on the cruise are accessible, as some may have ship-to-shore boats which can be difficult with limited mobility or if you use a wheelchair.



3: Planning a day out and holidays

To get the most out of your holiday or day out, decide where you'd like to go first. Then think about accessibility and take your planning from there.

Search websites about accessible venues and destinations to get ideas. Euan's Guide lists reviews from around the world by people who are disabled: **www.euansguide.com** and carers may be offered free or discounted admission to help support the person they care for when visiting sporting venues or theatres.

Wherever you decide to go, seek recommendations from accessible travel specialists and other people with reduced mobility.

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 get past steps or to other floors. Always ask a trained member of staff to help operate lifts. Accessible bedrooms and bathrooms vary in support, so find out what's on offer. For example, you may need a hoist, adjustable bed, level access shower or 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 what support travel operators can provide. For example, special diets or sleeping arrangements. Let each operator know about your needs as airports, airlines, hotels and other transport providers all work independently.

Equipment: if you plan to take equipment, could you rent somewhere already equipped, or hire the items you need in advance? If going abroad, you might be able to hire a beach wheelchair if needed. For non-prescription diet requirements, ask the manufacturer if they are sold in that country to save taking supplies with you.

Care services: does your chosen holiday provider offer care services, or can you arrange support?

Medical staff: if 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

If you're travelling in the UK or to a country that speaks English use our *Understanding my needs form* to write information for staff who will not know you.

What if I'm taken seriously ill when I'm abroad?

Insurance will generally be more expensive when you have a medical condition. Shop around for the best quote but always make sure MND or Kennedy's disease is listed and look at the specifics of what the policy covers. Insurance companies can frequently change their offers, which makes it difficult to provide a list of those who support specific conditions. Our MND Connect helpline have contact details of companies currently offering holiday cover to people with MND or Kennedy's disease. Ensure you have valid insurance before travelling as any other schemes are not a substitute for correct insurance cover.



“Holiday insurance is a big issue...When booking, I kept telling them that my husband had MND and, after a few tries with the same company, 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). Search for *GHIC* on **www.GOV.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?

Financial constraints can make it difficult to have a holiday, but you may be able to get help with the costs of your break.

Contact your local branches of the following organisations to see if they can offer any support:

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

The MND Association offer financial support grants for people with or affected by MND, or Kennedy's disease. A grant could help towards the cost of a holiday, for you and your carer. Find more information at: www.mndassociation.org/financialsupport or call our helpline MND Connect on **0808 802 6262**.

Who can support me while my carer has a break?

- day centres and local hospices offer regular wellbeing sessions, such as complementary therapy – your carer can take a quick break or join you
- 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?

If you provide support to someone with MND or Kennedy's disease, the care demands can increase and make it difficult to take a break. Your needs matter too and there may come a time when you need some rest. Regular short breaks, to go shopping or meet friends, can help. At some point you may need a holiday to recharge. This may mean getting help for the person you support, through respite care.



“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 you are registered as a carer, you may be able to access government funding to help you take a break. Get a needs assessment for the person being cared for and a carer's assessment. Contact your local authority in England or Wales, or your local health and social care trust in Northern Ireland.



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

Ask during your assessment about schemes or ways to help carers take a break. Try to ensure the person you support gets appropriate respite support, from care workers who have relevant experience.

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

Find out more about breaks for carers, respite care and find places to visit through the Carers Direct online service, search for *respite care* at: **www.nhs.uk**

4: How do I find out more?

Useful 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: 07701 373565

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 or Wales.

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/medical-enquiries-driving-licences

Disability Rights UK

Information on how to purchase a RADAR key.

Telephone: 0203 687 0790

website: www.disabilityrightsuk.org/shop/official-%20%20and-only-genuine-radar-key

GOV.UK

Government website, including travel, driving and disabled rights.

Website: www.GOV.UK

Motability

For help with a scooter, powered wheelchair or adapted car, if registered as disabled.

Telephone: 0300 456 4566

Website: 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: <https://qef.org.uk/our-services/qef-mobility-services>

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**

Or write to: Information feedback, MND Association
Francis Crick House (2nd floor), 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)

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

8A - 8D: our sheets about breathing and ventilation

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

11C -Equipment and wheelchairs

Download our resources at: **www.mndassociation.org/publications**
or 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 grants for people with and affected by MND or Kennedy's disease.

Telephone: **0808 802 6262**

Email: **mndconnect@mndassociation.org**

MND Association website and online forum

Website: **www.mndassociation.org**

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

Equipment loans and MND Support Grants

We may be able to provide a support grant or some equipment on loan. Contact us to find out more:

Telephone: **0808 802 6262**

Email: **Support.services@mndassociation.org**

Website: **www.mndassociation.org/getting-support**

Benefits Advice Service

Find current contact details for England, Wales and Northern Ireland at: **www.mndassociation.org/benefitsadvice** or contact our MND Connect helpline for guidance: **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

You can also email your comments to us at:

infofeedback@mndassociation.org

or write to us:

MND Association Information feedback,
Francis Crick House (2nd floor), 6 Summerhouse Road
Moulton Park, Northampton NN3 6BJ.

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