

TRAVEL

*Helpful tips for people
with ME/CFS and Long Covid*



Including:

Planning your trip

Choosing the right destination and accommodation

Surviving the journey

Help at the airport, railway station or port

Travel insurance and pre-travel vaccinations

Travel checklists



Travel - Helpful tips for people with ME/CFS was written by Russell Fleming, Head of Communications, and Caroline Cavey, ME Essential Editor, ME Association.

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DISCLAIMER

We recommend that the medical information in this leaflet is discussed with your doctor. It is not intended to be a substitute for personalised medical advice or treatment. You should consult your doctor whenever a new symptom arises, or an existing symptom worsens. It is important to obtain medical advice that considers other causes and possible treatments. Do not assume that new or worsened symptoms are solely because of ME/CFS or Long Covid.



TRAVEL: *Helpful tips for people with ME/CFS*

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IS IT POSSIBLE TO TRAVEL WHEN YOU HAVE ME/CFS OR LONG COVID?



The short answer is 'yes'. Of course you can. The slightly longer answer is that it's not as easy to travel with a chronic illness as it is for a healthy person. But if you plan properly, consider your limitations and perhaps make changes to the way you travel, with the right preparations in place you can still go out there and discover the world - just do it differently to how you used to.

WHERE TO GO

The key to travelling with a chronic illness is research.

Choose quality over quantity. A few days somewhere ideal will be better for you than a cheaper trip for a longer time in a not-so-perfect place.

Be prepared: Make sure that the place you plan to stay can cater to your needs. If you have mobility issues and/or require mobility aids, choose accommodation that is fully accessible, both around the accommodation and around the local area.

Local area: Those narrow, cobbled streets in pretty French and Italian towns are beautiful, but not if you need a wheelchair or walking aids to get around and certainly not if they're hilly and require an exhausting climb every time you go out. So study the area well to make sure that it is a terrain that you can manage.

City breaks: Look for a hotel in the city centre, within walking distance of almost everything. It might be cheaper to stay further out, but do you want that long commute every day? Adding the extra travelling to your days out may limit how much you get to see.

Fly-and-flop: Look carefully at the accommodation before you book. Will it be crowded? Might it be noisy? Are there lots of steps? Try to choose somewhere peaceful and flat. If it's a warm destination make sure there are plenty of loungers and parasols for relaxing in the shade.

How long to go for: Always choose quality over quantity. A few days somewhere ideal will be better for you than a cheaper trip for a longer time in a not-so-perfect place.

Final review: Once you've chose your accommodation and you're confident that it's the right place, have a final review of the accommodation access and living space. Check out the bathroom to ensure there are sufficient aids to ensure you'll be comfortable getting in and out of the shower/bath, using the loo and accessing the sink.



WHERE TO GO



Remember that a beautifully deep, roll-top tub looks stunning, but isn't necessarily very practical!

A slower pace of travel means you'll need rest days. You may find that you'll need some full days relaxing in your hotel room or apartment. So pick a nice one!

PLANES, TRAINS AND AUTOMOBILES

Whichever way you travel make sure you are super-comfortable. Whether that means pyjamas, a flowy dress, track suit or shorts and t-shirt, ignore everyone else and do what's right for you. Wear your comfiest shoes - and perhaps take your slippers too.

By car:

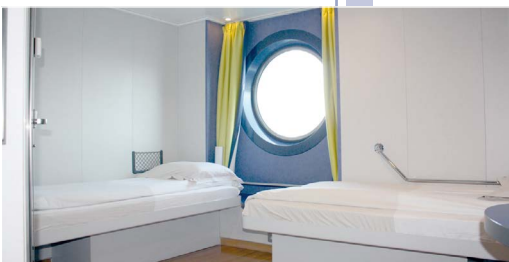
- Plan where to take your comfort breaks and food/drink stops.
- Get out of the car and stretch when you stop and take in some fresh air if you can. Even a few deep breaths can help.
- Take a small hypoallergenic pillow and/or blanket so you can stay comfortable on the journey.
- Take a sun visor for the window and sun glasses for if it's very bright.
- Water and snacks to keep you going.
- Travel at a time that suits you, so that it doesn't interfere with rest times.
- If you're travelling a long way, consider having an overnight stay on the way.

By coach:

- Book your ticket with the bus company that best caters to your travelling needs (cheapest might not be best).
- Check the routes before you book and try to find one with no changes or take longer than most.
- Ask the coach company about any special assistance you require.



Pack a small bag with everything you'll need to take with you when you leave your car - remember you won't be able to access your car once the ferry leaves the dock.



Commodore cabin and wheelchair-accessible cabin with Brittany Ferries

PLANES, TRAINS AND AUTOMOBILES

- Wear comfortable clothes and shoes.
- Pack light and try not to take anything unnecessary.
- Take a small hypoallergenic pillow and/or blanket so you can stay comfortable on the journey.
- Take a sun visor for the window and sun glasses for if it's very bright.
- Take water and snacks. Check that you can eat and drink on the coach before you book (some companies don't allow it).
- Take some ear plugs to block out the noise.
- Remember to stretch when you can.

By ferry:

- Book a cabin (wheelchair-accessible if you use a wheelchair), even if it's a daytime crossing - it will mean you have somewhere to retreat to that's private, quiet and comfortable.
- Take your own food and drink - the cafeteria might not cater to your taste, or there could be long queues or noise.
- Tell the ferry company if you need any special assistance onboard.
- Pack a small bag with everything you'll need to take with you when you leave your car - remember you won't be able to access your car once the ferry leaves the dock. Include listening books, music, water, medications, etc.
- Make a list for the duty-free shop so you spend as little time there as possible - or send someone else to purchase for you.
- Take a short walk around or stretch out when you can.
- Don't forget your 'Go-Bag' - see page 8. Also see our full travel checklist on page 22.

By train:

This could be the trickiest way to travel as you only have your booked seat and no control over who is around you. But if the train is the easiest way to get to where you're going:

- Pack as light as you can. Everything has to be dragged or carried.



PLANES, TRAINS AND AUTOMOBILES



- Take a separate bag with your headphones (anything you listen to will help to drown out the noise in the carriage), food, drink, eye-mask, a water spray for if it's stuffy, a light blanket for if it's a bit cool.
- Wear layers that you can take off or put on.
- Book your seat well ahead so that you can face the front (or back).
- Sunglasses are a must - even on the train the sun can get in your eyes.

Contact your departure station/ airport if you require special assistance at the train station or at the airport and while boarding the plane.

- Take some ear plugs to block out the noise and an eye mask for if you need to sleep.
- Stretch your legs when you can.

By plane:

- Ask the airline about any special assistance you require on the plane. Also see the advice given by the UK Civil Aviation Authority:

<https://tinyurl.com/yc8zvb9k>



- Contact the airport if you require special assistance in the airport and boarding the plane.
- Drink more water and avoid alcohol. Hydration is vital when you fly.
- Pack a good travel-size moisturiser to help with dry skin, and eye drops, especially if you wear contact lenses.
- Beat off infections with disposable wipes and hand sanitiser.

- Move around. Immobility can increase the risk of deep vein thrombosis (DVT) and flying is known to increase the risk. So walk around every hour, keep tapping your feet and rotate your ankles to keep the blood flowing.
- Try to sleep for some of the journey. Book a window seat if you can as you won't get disturbed by other people getting up to move about.
- Keep the space under the seat in front of you as free as possible so you have the maximum amount of leg room you can get.

PLANES, TRAINS AND AUTOMOBILES

- Wear comfortable clothes and layers, take some warm, fluffy socks or slippers. Compression socks will help with circulation.
- Take a soft neck pillow and perhaps an inflatable footrest and/or body pillow to help you stay comfortable in economy seats.
- Don't forget your 'Go-Bag' - see page 8. Also see our full travel checklist on page 22.



By Cruise Ship:

- Tell the cruise company if you need any special assistance during boarding and whilst onboard.
- Book a cabin (wheelchair-accessible if required), midship - you'll feel less movement if there is inclement weather.
- Book anytime-dining so that you can eat flexibly. Research and select the right drinks package according to your needs.

Do your research regarding excursions to ensure you can manage the length of time, terrains, sun, etc.



- Make sure your cabin is near, but not too close, to the lifts, and book a cabin with a balcony if you can (outside space all to yourself).
- Choose an itinerary that will be easy for you to enjoy the shore days.
- Plan your rest days well ahead. Allocate days off between shore excursions. There are lots of places onboard a ship to rest and relax.
- Book shore excursions before you go (they'll be cheaper) and do your research to ensure you can manage the length of time, terrains, sun, etc. Go on your excursions prepared with a small 'Go-Bag'.

You may feel that you'd rather wait to book excursions on the day. The trip may be more costly, but the benefit is that you won't have outlaid the money and then find you don't feel well enough to go. This is a decision for you to make according to how your own personal symptoms are.

- Ask to have an early boarding time so that you won't feel rushed. This also gives you time to explore the ship while it's quiet, get your bearings and have a rest before you sail.
- Pack a small bag with everything you'll need to take with you when you board the ship. You won't be able to access your main luggage until they get delivered to your cabin, which might be much later in the day. Include listening books, music, water, medications, a change of clothes, etc.



“I find that nuts, raisins, natural liquorice, fruit gums and plain biscuits can really help with travel nausea”



PLANES, TRAINS AND AUTOMOBILES

- Don't forget your 'Go-Bag' - see below. Also see our full travel checklist on page 22.
- Don't miss the sail-away (when your ship leaves the dock)!

SIGHTSEEING

Be realistic about what you are capable of when you plan your trip. Today you may feel on top of the world, perhaps you have the most energy you've had in a long time and that's why you're planning your trip. Just don't forget that you'll need time to recuperate from the days (or even just a couple of hours) of sightseeing. Plan a rest day after excursions. Look at the places you'd like to visit and be honest with yourself about what you'll be able to do. You know your body better than anyone and if two hours is what you can manage then so be it. Short bursts of somewhere you really want to visit are better than not going at all. Then rest.

EATING OUT

If you have food allergies check out the menus at the local restaurants before you go to avoid the stress of finding somewhere suitable when you get there. Pre-book your table and be on time to avoid having to wait around. Plan your day carefully, remember how long you can keep going before you need to rest, so plan where you'll be able to take your rest stops. Eat early in the evenings so you don't get overtired.

YOUR 'GO-BAG' CHECKLIST

However you travel, always pack a 'go-bag' that you keep near you. Pick the contents according to your needs, including:

- Purse/wallet.
- Passport and travel documents.
- Spare clothes and a clean set of underwear and socks.
- Water bottle and snacks.
- Medications (always carry these with you, along with your GP's letter).
- Headphones, magazines, a book or Kindle, puzzle book, etc.
- Sunglasses, hat or sun visor.
- Eye mask and earplugs for light and noise control.
- Comfort items such as: slippers, blanket, pillow or neck support.
- Tissues, water spray, hair ties.



If you're going anywhere abroad, where you won't be covered by the NHS, travel insurance is an absolute must.



TRAVEL INSURANCE

If you are going on holiday in the UK and have pre-booked travel or accommodation, travel insurance is well worth thinking about. If you're going anywhere abroad, where you won't be covered by the NHS, travel insurance is an absolute must.

More information can be found at:

Travel Abroad: Step by Step (Gov. UK website):

<https://www.gov.uk/travel-abroad>

Applying for Healthcare Cover Abroad (NHS website):

<https://tinyurl.com/w8yh8e69>

A few key points

- Don't leave arranging your travel insurance until the last minute.
- If a new health problem occurs shortly before departure that requires assessment, investigation or treatment, you may find that it is very difficult to get this covered. Obtaining straightforward standard cover may also become more difficult.
- It is advisable to take out your cover as soon as you book the holiday. And, if you have an annual policy, arrange to renew it at least a month before you normally go away.

If you take out a standard policy that automatically excludes problems relating to pre-existing medical conditions, this means what it says. Problems relating to ME/CFS will not be covered.

Some insurance providers change their underwriters quite frequently. Never assume that, because you told an insurer last year about a medical condition and this was accepted, this year's insurance with the same company will still cover you. If the underwriter has changed, you may not be covered.

Some banks and financial service providers include free travel cover as part of their contract – but do check the small print. You will need to check what it says about pre-existing conditions and what you need to say about your state of health.

Feedback to the ME Association suggests that many of the major insurance companies that offer travel insurance are willing to cover people with ME/CFS for problems that might arise as a result – but this

TRAVEL INSURANCE

often means having to speak to a health assessor and then paying a small surcharge to make sure that everything related to ME/CFS is fully covered. You might also be asked to obtain a letter from your GP saying that you are 'fit to travel'.



If you have difficulty obtaining cover, there are insurance brokers who specialise in dealing with people who have disabilities. They can be found by typing 'insurance for people with disabilities' into an internet search engine.

It would not be sensible to omit the fact that you have ME/CFS when you answer questions about your health on the application document. Failing to mention that you have a chronic health problem such as ME/CFS could invalidate the policy.

If you are taking expensive disability aids or equipment with you (like a wheelchair), make sure this will be covered for use outside the UK, or that it is already covered by another policy.

You may find that you can extend the existing cover for a small extra fee to cover use overseas.

If you have difficulty obtaining cover, there are insurance brokers who specialise in dealing with people who have disabilities. They can be found by typing 'insurance for people with disabilities' into an internet search engine.

Services provided by insurance and travel companies are covered by Part 3 of the Disability Discrimination Act. This means there are limitations to the way in which insurers can 'bend the rules' when it comes to disabled people. Simply refusing to provide cover on the grounds that you have ME/CFS might constitute discrimination – but this has not been tested in the courts.

If things go wrong with an insurance company and internal procedures do not resolve a dispute, you can contact the Association of British Insurers for advice:

<https://tinyurl.com/u8ynwhrk>

Tel: 020 7600 3333

If the problem remains unresolved, the Financial Ombudsman Service may be able to help:

www.financial-ombudsman.org.uk

Free phone from a fixed line:
0800 023 4567



TRAVEL INSURANCE



Ensure your travel insurance will meet your needs. If you travel more than once a year, look at annual cover policies as these may be better value.



Six things to know before you go

Always make sure it is safe to travel. Always check current Foreign, Commonwealth and Development Office (FCDO) advice, especially as travelling against FCDO advice is likely to invalidate your travel insurance. Be aware of any quarantine requirements on your return to the UK – travel insurance will not cover costs associated with quarantining in Government-provided accommodation.

Buy travel insurance and make sure that it best meets your needs. The main reason for travel insurance is to cover the costs of emergency overseas medical treatment which, together with any repatriation required back to the UK, can easily run into tens or even hundreds of thousands of pounds.

Check and be aware of any COVID-19 exclusions in your travel insurance. All ABI travel insurers will continue to provide cover for emergency medical treatment needed overseas, including emergency medical treatment related to COVID-19. There are many providers that can be found by using an online search engine.

Try the Post Office:

<https://www.postoffice.co.uk/travel-insurance>

or look at Money Helper:

<https://tinyurl.com/45r2zrs4>

If you are travelling to a country in the EU, Iceland, Liechtenstein, Norway or Switzerland, check out the information available of the Government website:

<https://tinyurl.com/32x4w7yu>

Be aware of, and comply with, travel requirements for entering overseas countries. It is your responsibility to comply with any border restrictions in place at your destination country (i.e. negative COVID-19 test, vaccines, visa, etc). If you do not comply with these requirements, then you will need to return home at your own cost.



TRAVEL INSURANCE



Get as much information as you can so that, in the event of any travel problems, you know what you are entitled to

If you hold a current European Health Insurance Card (the EHIC entitles you to access state-provided health care when visiting the EU) this remains valid until its expiry date. After that, or if you do not have an EHIC, you will need to apply in the same way (through NHS online) for a Global Health Insurance Card (GHIC).

To apply for healthcare cover abroad (EHIC and GHIC), visit the Government website:

<https://tinyurl.com/bddr9vuj>

Neither the EHIC or the GHIC is a replacement for travel insurance as it will not cover you for all medical costs, or the cost of emergency repatriation back to the UK.

Know your rights

Get as much information as you can, so that, in the event of any travel problems, you know what you are entitled to.

For example, check the refund policy of any accommodation provider, what you are entitled to if booking a package holiday, and what the legal obligations of the airline are if your flight is disrupted or cancelled.

By Dr Charles
Shepherd



The **Vaccinations and Travel Health**, **Travel Vaccinations**, and **Other Health Considerations** sections were written by **Dr Charles Shepherd**, Trustee and Hon. Medical Adviser for the MEA.



Check what the weather and humidity is going to be like in more exotic locations if you are already heat-sensitive.



VACCINATIONS AND TRAVEL HEALTH

Never leave pre-travel health planning to the last minute. It's important to check on vaccination advice and requirements before making a booking if you are intending to travel to a tropical or more remote location.

Accurate and up-to-date information and advice about health requirements for overseas travel can be obtained from:

- NHS Fit for Travel: www.fitfortravel.nhs.uk
- Netdoctor: www.netdoctor.co.uk
- Medical Advice Services for Travellers Abroad (MASTA): www.masta-travel-health.com

This organisation provides reliable advice on food, water, general hygiene, risks from specific infections, and appropriate methods of protection on a country-by-country basis.

Contact your GP or practice nurse: Some GP surgeries have travel clinics where information and advice can be obtained and arrangements made for any vaccinations, anti-malaria drugs, etc, that are going to be required. You will need to pay for some of these drugs, vaccinations and possibly certificates.

There are also private travel clinics run by companies such as MASTA and BUPA.

Advice contained in travel company brochures, and from travel agents, about health and vaccination requirements abroad can be deficient or inaccurate and should not be relied on.

Homeopaths and other complementary practitioners may recommend other forms of disease protection but there is insufficient evidence of effectiveness to recommend their use.

Regular medication

Make sure you have an adequate supply of any regular medication and keep a written list of names of any important drugs you take in case anything goes missing. Always keep any essential drugs with you in your cabin baggage.

Keep a written note of the foreign translations for any important drugs you use and any medical conditions you have.

VACCINATIONS AND TRAVEL HEALTH

Covid-19

This infection has not gone away and is unlikely to do so in the near future. Although the level of infection in the UK has fallen to much lower levels there are other parts of the world where the risk is significantly higher. So it's worth checking to see what level of Covid infection is present in the country/countries you are intending to visit.



Pre-travel vaccinations

Vaccinations can occasionally trigger or exacerbate pre-existing ME/CFS. This is something to bear in mind if vaccinations are advised or are compulsory.

If you have ME/CFS and want to travel to a country where specific vaccinations (including Covid) are strongly advised, or are even made compulsory with a certificate (as with yellow fever), it would be foolish to avoid the high level of protection that most forms of vaccination provide.

If you are well enough to travel outside most of Europe, USA, Canada, Australia and New Zealand, where travel vaccinations aren't usually required, it's highly likely that you will have to consider the pros and cons of one or more vaccinations.

If you are well enough to travel outside most of Europe, USA, Canada, Australia and New Zealand, where travel vaccinations aren't usually required, it's highly likely that you will have to consider the pros and cons of one or more vaccinations.

Key points:

- All travel vaccines are capable of producing side-effects in perfectly healthy people – fairly common ones include fever, fatigue, headache, joint pain, rash. Fortunately, these reactions are normally limited to a few days. Serious reactions, including neurological ones, are far less likely but can occasionally occur with vaccines such as yellow fever.
- A decision on whether or not to have a particular vaccine should take individual circumstances into account as well as the official printed guidance. For example, where rabies is present abroad, vaccination would be vital for travel to remote areas away from medical attention but may not be necessary if your stay is confined to a hotel.
- Travel vaccination protocols may require more than one appointment in order to complete a course of vaccinations. A course of travel vaccinations should therefore be planned a couple of months before travelling, and be completed at least two weeks before departure – in case side-effects occur.



As with any vaccination and ME/CFS, travel vaccines should normally be deferred if you are having a lot of flu-like symptoms or a relapse.



TRAVEL VACCINATIONS

■ As with any vaccination and ME/CFS, travel vaccines should normally be deferred if you are having a lot of flu-like symptoms or a relapse.

Cholera: This is a gastrointestinal infection that is mainly found in parts of Africa and Asia where there is a lack of clean water and sewage systems. This infection can cause very severe diarrhoea. Vaccination, which is given as a drink, requires two doses several weeks apart and provides protection for up to two years. Vaccination is normally only recommended if you are travelling to a country where this disease is active.

Hepatitis A: This is an infection that can cause a severe relapse of ME/CFS symptoms and can occasionally trigger ME/CFS in previously healthy people. Outbreaks of hepatitis A infection occur quite frequently in less developed countries – even in hotels and holiday resorts. The vaccine provides long-lasting protection.

Hepatitis B: This is an infection that can be caught from sexual contact and blood transfusions. It can cause a very serious and long-term liver disease. If you are travelling to high-risk countries, vaccination – which requires a course of three doses – will need to be considered. However, it should be noted that this is a vaccine that from patient evidence appears to be more likely to trigger ME/CFS.

Polio: If there is a risk of polio in the country being visited it would be very foolish to avoid having up-to-date protection. A list of countries with a high incidence of polio can be obtained from www.travax.nhs.uk.

Tetanus: Up-to-date protection is important if you are taking part in activities that could involve exposure to tetanus infection.

Typhoid: Protection should always be considered if you are travelling to a high risk country – especially India, Pakistan and Bangladesh.

Two vaccines are available to prevent typhoid fever:

- Vi vaccine is given as a single injection
- Ty21a vaccine is given as 3 capsules to take on alternate days

Combined typhoid and hepatitis A: Injections are available for people aged 15 or over. Protection against hepatitis A lasts 12 months and protection against typhoid lasts three years.



TRAVEL VACCINATIONS

Yellow fever: This is a potentially fatal infection that is present in parts of Central and South America and the Caribbean.

Countries affected are likely to require an International Certificate of Vaccination and you may have to go to a special centre to have this vaccine. Surrounding countries may also require a certificate if you have recently travelled through a country at risk. So do check on vaccination requirements well before departure. The protection should last for 10 years –as does the certificate.

Side-effects include headache, fever, fatigue and stiffness, which may occur 4-7 days after vaccination. Less common side-effects include muscle pain, enlarged glands and a rash. Neurological complications such as meningoencephalitis, and an unusual multisystem illness, have been reported.

Up-to-date protection against diphtheria and tuberculosis may be necessary as well.

For travel to more exotic locations, particularly in Africa, the list of recommendations may be quite long and include vaccination against rabies, meningitis and encephalitis.

Malaria protection: The main high-risk area for malaria is Africa but cases have also been reported in Florida USA this year. So if you are travelling to this part of the USA check on preventative measures.

Various anti-malarial drugs are available on prescription. These drugs are normally very effective but have to be started before entering an at-risk country and continued after leaving.

Simple self-help measures - effective insect repellents, covering up exposed areas of skin and the use of impregnated mosquito nets at night - are also very important.

Using the right drug, or combination of drugs, on a regular basis is absolutely vital – so do obtain accurate, up-to-date information on which drugs are currently being recommended for which country you intend to visit.

Lariam, also known as mefloquine, is an effective anti-malarial drug but needs to be used with caution (or not at all) if you have had neurological or psychiatric health problems. For people with ME/CFS, if there is a suitable and equally effective alternative, this would probably be a better option.



The main high-risk area for malaria is Africa...



OTHER HEALTH CONSIDERATIONS



Air travel:

Along with checking in and moving through the various security procedures at an airport, this can turn out to be the most stressful part of an overseas trip.

Airports and aeroplanes are high-risk areas for picking up infections. So it's worth using antiseptic gel on surfaces like tables on planes and consider wearing a face mask in crowded areas or even on the plane.

Allow 24-48 hours to recover from the journey. Avoid napping as soon as you arrive at your destination – even if you're tired after a long flight, try to stay active until the correct time to sleep; this will help your body adjust more quickly.

Prolonged sitting in a plane on long-haul flights makes the blood flow in the legs sluggish and increases the risk of developing a blood clot or deep vein thrombosis (DVT) in the legs. Inactivity associated with moderate/severe ME/CFS may increase this risk – as can being overweight.

If you have an increased risk of developing DVT, you should see your GP before you travel. Don't leave it until the last minute in case you need to obtain medication, compression stockings or anything else for your flight.

You can reduce your risk of DVT occurring during a long-distance flight, train or car journey by:

- wearing loose, comfortable clothes
- wearing flight socks
- doing anti-DVT stretching exercises
- walking up and down the aisle every hour whenever you can
- drinking plenty of water
- not drinking alcohol or take sleeping pills

Wearing properly-fitting compression stockings, which speed up blood flow in the leg veins, can significantly reduce the risk of DVT, as well as leg swelling. These stockings come in a variety of sizes and can be purchased from pharmacies such as Boots. Stockings exerting a pressure of 14-17 mmHg at the ankle are generally sufficient for air travel. Take advice on size and proper fitting from a pharmacist or another health professional.

More detailed information on DVT prevention can be found here on the NHS Choices website:

<https://tinyurl.com/mr232r38>



OTHER HEALTH CONSIDERATIONS

Heat sensitivity:

Sensitivity to changes in temperature, especially excessive heat, are a common feature of ME/CFS – so it's worth checking what the weather and humidity is going to be like in more exotic locations if you are already heat-sensitive.



Taking a relaxing holiday in a warm, dry location may be beneficial for ME/CFS. Taking a holiday in a very hot climate could well cause serious problems if you have ME/CFS.

Some types of medication (e.g. antidepressants, antihistamines, decongestants, blood pressure treatments) have a potential to exacerbate problems with temperature regulation.

If you are visiting a country where it is going to be hot, or very hot, make sure you keep well hydrated, wear loose, cotton clothing, use plenty of sunscreen and stay cool during the hottest part of the day.

Avoid napping as soon as you arrive at your destination – even if you're tired after a long flight, try to stay active until the correct time to sleep.

Jet lag, time changes and sleep disturbance

Long-distance flights that involve a considerable number of time zone changes are likely to exacerbate any form of pre-existing sleep disturbance which already occurs in ME/CFS. So it's worth checking on what the time-zone change is going to be at your destination.

Jet lag refers to a range of symptoms that are experienced while adapting to a different light-dark schedule following a flight to a new time zone. This is the result of your internal body clock not being able to quickly adjust to a new time zone. Jet lag can disturb your sleep at night and make you feel drowsy and lacking in energy during the day. It can exacerbate cognitive dysfunction and cause digestion problems.

- Check what the time zone change is going to be at your destination.
- Follow the established general advice on how to cope with resetting your body clock when travelling.
- Allow 24-48 hours to recover from the journey.

Crossing six to 12 time zones usually results in more severe jet lag than crossing three to six time zones. Crossing one or two time zones doesn't usually cause any problems. People usually report more severe jet lag flights heading east compared with flights heading west across the same number of time zones.



OTHER HEALTH CONSIDERATIONS



As soon as you board your flight, adjust your watch to the time of the country you're heading to.

There are several things you can do to help reduce the effects of jet lag when you arrive at your destination.

Before you arrive:

- Have plenty of rest before you travel. You could start going to bed and getting up earlier or later than usual (and more like the time zone of the place you're travelling to).
- During the flight try to sleep if it's night time at your destination and use an eye mask and earplugs if they help you sleep.

- As soon as you board your flight, adjust your watch to the time of the country you're heading to.

When you arrive at your destination:

- Establish a new routine and try to get used to it as soon as possible – eat and sleep at the correct times for your new time zone, not when you usually eat and sleep at home.
- Avoid napping as soon as you arrive at your destination – even if you're tired after a long flight, try to stay active until the correct time to sleep; this will help your body adjust more quickly.
- Spend time outdoors – natural light will help your body adjust to a new routine.
- The use of **melatonin**, which may be helpful for reducing jet lag, could be discussed with your GP.

Melatonin is a hormone that is released in the evening to let your brain know that it's time for your body to sleep. Your body stops producing melatonin at around dawn to help you wake up. It has been found to help people sleep and reduce general feelings of jet lag in some (but not all) research studies. However, melatonin is not currently licensed in the UK for the prevention of jet lag. So this is not a drug that a GP would normally prescribe for jet lag.

Purchasing melatonin on the internet is not without problems because it's difficult to be certain how much melatonin the products contain and whether other substances are present.

OTHER HEALTH CONSIDERATIONS

Boots has a fee-paying on-line doctor service for melatonin prescriptions:

<https://onlinedoctor.boots.com/jet-lag>

Melatonin is contra-indicated if you have an autoimmune disease such as rheumatoid arthritis or lupus. Side-effects can include headaches, nausea, dizziness and irritability.

The NHS website has useful information on melatonin, including how to use it for jet lag:

<https://www.nhs.uk/medicines/melatonin>



If you are flying a very long way – to Australia for example – it's worth looking at the pros and cons of doing this in one go, or having a stop over half way in somewhere like Hong Kong

Traveller's diarrhoea

The most common cause of illness amongst travellers, including in Europe, is diarrhoea. This can be caused by bacterial or viral infections and is likely to cause an exacerbation or relapse in ME/CFS, especially if you already have irritable bowel-type symptoms.

The most effective ways to avoid traveller's diarrhoea are to:

- Wash your hands with soap and water regularly, especially after using the toilet and before preparing food or eating
- Only drink tap water that's been boiled or bottled water
- Brush your teeth using bottled or boiled water
- Not eat uncooked fruit and vegetables (including salads) that you have not washed with bottled or boiled water and prepared yourself
- Not eat shellfish and seafood
- Not eat ice cream or have ice in your drinks

The most important self-help form of treatment for diarrhoea is rehydration - replacing lost fluids, and using an oral rehydration salt and electrolyte replacement such as Dioralyte.

The most important self-help form of treatment for diarrhoea is rehydration



OTHER HEALTH CONSIDERATIONS



Loperamide/Imodium (available over-the-counter from pharmacies) will quickly help to stop very loose bowel movements – but do read the cautionary notes in the instructions. It's worth buying some before you depart.

An antibiotic called ciprofloxacin, at a dose of 500mg twice daily for three days, is one of the treatments of choice for a more severe infection. If you are travelling to somewhere that's remote and where traveller's diarrhoea is a strong possibility, your doctor may be willing to prescribe this drug on a 'just in case' basis.

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TRAVEL CHECKLIST

Documents

- Passport, visa
- Tickets for airline, boat, train, coach, etc
- Tickets for excursions
- Copies of passport, tickets, etc
- Boarding pass
- Drivers licence, insurance
- Health insurance card
- Medical folder containing a list of

medications, letter from your GP confirming your prescribed medicines (especially if you need to carry quite a lot) and any other vital information

- Vaccination certificate
- Travel insurance
- Student card (if applicable)

Financial

- Foreign currency
- Emergency money
- Credit card, debit card, holiday money card, currency
- Money belt

Medical

- All medication, medical equipment and medical information must stay in your hand luggage.

Do some research about where you're going. You need to ask:

- Is the medication I take allowed in the country I'm visiting?

- Am I allowed to bring more than a 30-day prescription?
- Hydrocortisone cream or ointment - this can be purchased over-the-counter
- Antibiotic cream
- Paracetamol and/or ibuprofen
- Antiseptic cream
- Sunscreen and Aftersun
- Antihistamines
- Plasters
- Face mask
- Nebuliser or inhaler
- Personal equipment (oxygen tank, epi-pens, etc.)

Walking aids when flying

- Most airlines will allow you to bring one walking aid on board but do double-check the regulations for the specific airline that you're using.

- If you need assistance at the airport, call the airline you're flying with in advance to book a wheelchair. If you are already using a wheelchair, and/or you are bringing your own, make sure you tell the airline.

They will need to know:

- If you can walk at all.
- How much assistance you need.
- Whether you require a special wheelchair to board the plane.



If you need assistance at the airport, call the airline you're flying with in advance to book a wheelchair.

Try to be organized when you travel by writing out your plans. It will also help keep your loved ones calm if your trip is mapped out.



TRAVEL CHECKLIST

Medication

There's always a chance you'll run out of meds while you travel, so make sure you have enough for the whole trip – plus an extra three days for safe measure.

Don't try to save space by putting medication in smaller boxes. Keep everything in their original boxes (so it's labelled properly). These are not vitamins you're taking – if you mix them up, it's a big problem.

Keep your medication in a Ziplock bag that you can use to grab and go at any time.

Health

- Medications, pain relief
- First aid kit
- Insect repellent and bite cream
- Oral Rehydration, such as Dioralyte
- Mosquito repellent
- Birth control
- Self-administered vaccines
- Vitamins
- Hand sanitizer and hand wipes

A schedule to help with brain fog

Try to be organised when you travel by writing out your plans. It will also help keep your loved ones calm if your trip is mapped out.

Include:

- The dates and times you'll be travelling.
- Where you are coming from and going to.
- Your flight details (airline name, flight number, airport, terminal).
- Names and phone numbers of the key people you'll be dealing with in each place you visit.

Top tip: transfer all this information to your phone as well, so it's easy to share with others as you travel.

- List of nearby hospitals, doctors and pharmacies.
- Taxi services that you can call in case of emergency.
- Emergency contact details.
- Medical aid or insurance contact details.
- A brief explanation of your medical condition, especially if there's also other illnesses to consider alongside ME/CFS.

Give a copy to everyone you're travelling with and keep it on you at all times. If there's an emergency and you cannot communicate, everyone will know what to do.

If the place you're visiting uses a different language, write it down in that language as well as in English (use Google Translate).



Tailor your clothing to the climate at your destination. Try not to over-pack - you never need as much clothing as you think, especially if it will be hot.



TRAVEL CHECKLIST

Cruising

A lot of the rules that apply to flying will apply here as well.

Also check the following:

- How disability-friendly the cruise ship is.
- How many pieces of medical equipment they allow.
- Their policy on travelling with medication.

Clothes

Tailor your clothing to the climate at your destination. Try not to over-pack - you never need as much clothing as you think, especially if it will be hot. Pack comfortable clothes and footwear.

- Underwear
- Socks
- Sleepwear, slippers
- Shirts, polos, t-shirts, tops
- Jeans, trousers, shorts
- Dresses, skirts
- Evening wear
- Shoes, trainers, flipflops, sandals
- Jacket, coat
- Belts, ties
- Scarves, hats, gloves

General activities

- Swimwear
- Towels (if not provided)
- Comfortable walking shoes
- Sunglasses
- Sunscreen
- Day bag
- Books, e-books, magazines, etc

Travel aids

- Itinerary
- Maps and directions
- Language guide
- Travel guide
- Travel pillow, sleeping mask, earplugs
- Travel locks
- Luggage tags
- Snacks, drinks
- Travel clothes line
- Magnetic hooks for cruising

Appliances

- Mobile phone and charger
- Camera and accessories
- Laptop, iPad/tablet, E-reader, chargers
- Travel adapter and converter
- Travel iron or steamer (not for cruise ships, they will be confiscated at boarding!)
- Torch
- Headphones

Toiletries

- Toothbrush, toothpaste, floss
- Deodorant
- Tweezers, nail scissors and nail files
- Soap, shampoo, conditioner
- Skincare
- Tissues
- Feminine hygiene
- Makeup, makeup remover
- Shaving supplies
- Brush, comb, hair products
- Glasses, contact lenses, solutions



“Thank you for producing such a helpful magazine. The standard is consistently high and each edition is interesting and varied. I need all the help I can get and this magazine is consistently encouraging, realistic, and helpful.”



HOW WE CAN HELP

■ **COMMUNITY:** We provide a safe and welcoming community for people affected by ME/CFS and Long Covid who come together and benefit from sharing their experiences. We provide membership, an essential support service, excellent website resources and we host engaging discussions on the most popular social media channels. Knowing that you are not alone can be a great comfort and we are happy to answer your questions and share helpful tips.

■ **MEMBERSHIP:** We put the interests of members at the heart of everything we do. Your subscription means that we can support more people, campaign more effectively and fund more medical research. Members receive the exclusive ME Essential magazine which carries the latest news, medical information, personal stories, and feature articles. **Join us today!**

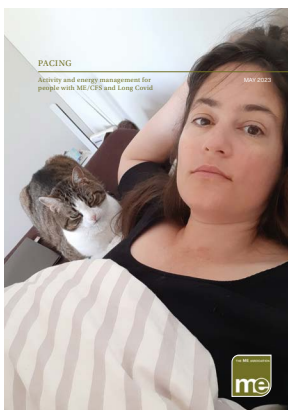
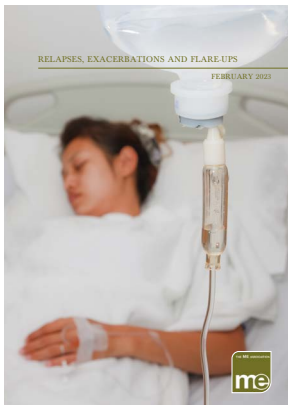
■ **SUPPORT:** ME Connect is the charity's support and information service. We listen and we understand. We provide a personalised service and we're here when you need us most. Most of us have personal experience of these medical conditions, or care for a loved one who does. To view the ME Connect telephone helpline opening hours please visit: <https://www.meassociation.org.uk/me-connect>

■ **INFORMATION:** We produce reliable and timely information written by topic experts and have the **largest range of literature covering all aspects of life with ME/CFS and Long Covid**. We can show you how to recognise and manage symptoms, to get an accurate diagnosis, a referral to specialists, and to obtain the healthcare that you deserve. We also provide an **e-newsletter** and free access on the website to **Medical Matters** and other relevant information.

■ **RESEARCH:** We fund medical research via the **Ramsay Research Fund** and are especially interested in research that can find diagnostic markers, causes, and treatments. We support the UK ME/CFS Biobank and the Manchester Brain Bank, and have invested over £1m in medical research in the last 10 years.

■ **MEDICAL EDUCATION:** We arrange training for healthcare professionals, offer a medical magazine, ME Medical, and are working with the Government, NHS, Royal Colleges of Medicine, and Local Authorities to implement the recommendations from the 2021 NICE Clinical Guideline on ME/CFS – the successful result of 14 years lobbying and hard work.

“The MEA is doing exactly what it said it would by providing support, actively lobbying for recognition, improvements to health and social care, and funding biomedical research.”



HOW WE CAN HELP

■ **LOBBYING:** We campaign to raise awareness and bring about positive change. We believe in collaboration and work with the NHS and social care services, the Department of Health and Social Care, the British Association of Clinicians in ME/CFS (BACME), Forward-ME, the ME Research Collaborative (MERC), DecodeME, the All-Party Parliamentary Group (APPG) on ME, Physios4ME, the Chronic Illness Inclusion project (CII), Hidden Disabilities Sunflower, and Long Covid initiatives.

■ **HEALTH & SOCIAL CARE:** The charity works with healthcare providers to successfully implement the NICE Guideline recommendations on ME/CFS and Long Covid to ensure that everyone receives the very best healthcare, wherever they live in the UK. We want well-trained healthcare professionals providing excellent services because timely intervention can lead to better health outcomes and improved quality of life.

■ **DONATIONS:** In order to help more people and invest in medical research we depend on your generosity. If you feel able to make a donation or want to raise funds in other ways, please get in touch with the fundraising team: fundraising@meassociation.org.uk or you can **make a direct donation via the website.**

WHAT ARE ME/CFS AND LONG COVID?

We answer key questions about these medical conditions and compare similarities and differences. You'll also find the NICE Guidelines reproduced in full in an easy to use **database**.

MEDICAL MATTERS

Medical Matters is an easy to use online supplement to the more detailed literature. The same topic experts provide answers to commonly asked questions.

NHS REFERRAL SERVICES

If you need to locate an ME/CFS specialist service or Long Covid Clinic then we can help. We have listed all secondary care referral services in an easy to use **database**.

THE ME ASSOCIATION



ME CONNECT

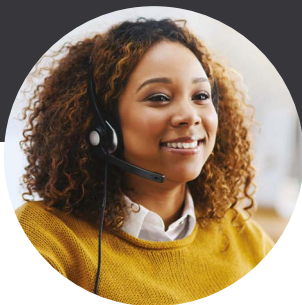
The Support and Information Service
for people affected by ME/CFS/PVFS
and Long Covid

3 WAYS TO GET IN TOUCH:
by phone, email
or social media private message



Freephone
0808 801 0484

For opening hours visit:
meassociation.org.uk/me-connect



HERE TO LISTEN

We are here to listen, validate and empathise with any issues you might be facing.



VITAL SUPPORT

We are here to help you reach an informed decision.



SAFE ENVIRONMENT

We provide a safe, confidential and understanding environment where you can be heard and understood.

We're here for you!



MEConnect@meassociation.org.uk



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