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Travelling and MSA

Introduction

This factsheet has been developed for people with MSA to help highlight some of the key considerations that need to be taken into account when planning to travel or go on holiday, whether it is in the United Kingdom, Ireland or further afield. It is not an exhaustive guide but its aim is to help you organise a holiday that is as enjoyable and stress-free as possible.

It can benefit everyone to have a change from their daily routines and even more so when coping with the challenges of living with MSA. It is all too easy to put off going away because of the worry about managing daily needs in different and unfamiliar surroundings. However, careful planning and being prepared will help to ensure a positive and enjoyable holiday experience.

Choosing a destination

Before looking at any of the accessibility aspects in detail, have a think about the sort of destination, resort and budget that appeal to you and what suits your personal likes and interests. Once you have decided on a destination, you can then explore the practicalities to try and ensure that they meet your individual requirements.

Many hotels and guesthouses in the UK and overseas have disabled facilities such as hoists, electric beds and wet-rooms. If holiday accommodation does not already have the equipment you require, it may be possible to rent it for the duration of your break (see section on 'Equipment' below).

Some people with MSA find that a sea cruise is a practical way to take a holiday and these days many cruise ships offer accessible facilities, including wheelchair-adapted cabins, a wide range of specialist equipment and often have experienced medical staff on board.

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In helping you to reach your final decision, it might be worth checking the accessibility of the bedroom in relation to the rest of the hotel facilities and the street for example, are the lifts reliable and able to take wheelchairs? You might also wish to establish whether your chosen resort can provide facilities such as:

- Step-free access
- Wheelchair ramps
- Access to disabled toilets
- Electric beds
- Bed rails
- Hoists (fixed room hoists and/or mobile hoists)
- Riser recliner chairs
- Shower chairs
- Wet rooms
- Hoists for swimming pool.

Bear in mind that disabled facilities in some parts of the world might not be up to the standard that you are used to at home. It is certainly worth asking lots of detailed questions at the planning stage. It is also worth looking up any recent reviews for the accommodation you are considering.

If your holiday is booked through a tour operator, the latter should be able to help you with many of these preparations, but it is important to make them aware of your possible needs. Some people prefer to book disabled rooms as they generally have more space.

In order to get the most out of your travels, you might find it helpful to contact one of the accessible holiday organisations specialising in disability, accessibility and travel (please see 'Accessible Holidays' list below).

Transport and Travel

Air

At the time of making your booking, ensure that the airline on which you are travelling is fully aware of your level of mobility and remember to tell them whether you will be using a wheelchair. It is a good idea to contact them again shortly before your departure date to make sure that the right level of assistance will be available. You might find it helpful to request an aisle seat with good leg room on the plane, ideally close to the toilet. If you are particularly worried about toileting needs and you have a long flight, you may want to consider wearing pads just for the journey in case of accidents or difficulty getting to the toilet. It is also possible to discuss with your District Nurse or Continence Nurse about the use of a catheter or convene just to assist you over this time. Remember that aircraft toilets are not easily accessible for disabled passengers. It is also a good idea to wear in-flight compression stockings throughout the flight.

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Power wheelchairs often have to have the battery removed (it's helpful to have your wheelchair toolkit with you) to store in the hold and you will be transferred to a manual wheelchair to get to your seat. If you need a hoist to get into your seat then just inform your airline in advance.

Most airlines will allow you to take extra luggage, free of charge, if you need to take essential medical supplies and equipment, so ask your airline about this before you travel.

It is best to request full assistance for all your travel as this will enable you to have wheelchair assistance or buggy pick up. This will help you get around the airport with your luggage so you are not exhausted before you even start your holiday. Also, with this assistance you will avoid long stands in the security queue, not be expected to stand unaided in the X-ray machine and avoid the hassle getting to the aircraft.

Sea

It is essential that you provide details of your mobility level to the cruise or ferry company at the time you make your booking. Make sure that the ship has appropriate facilities, e.g. disabled toilets and lifts to all floors and contact them again nearer the departure date to update them and double check that the required assistance will be provided. There are a limited number of cabins suitable for people with disabilities on each vessel so do book early for the cruise you are considering.

Rail

Many mainline rail stations in the UK and Ireland and most trains are suitable for wheelchair use. If you require assistance with boarding and leaving a train, for example using wheelchair ramps, it is a good idea to contact the individual train company the day before your journey to ensure that someone is on hand to help with boarding and alighting from the train. For general information on rail journey planning in England, Scotland and Wales, contact National Rail Enquiries on 08457 484950 or www.nationalrail.co.uk.

You may be entitled to a disabled person's railcard which could save up to a third on the cost of rail travel. For further details visit www.disabledpersons-railcard.co.uk or call 0845 605 0525.

For travel in Ireland go to www.transportforireland.ie/accessible-travel/.

Taxi

If you need to book a taxi remember to specify that you will need a wheelchair accessible vehicle, either because you are wheelchair dependent or because it is easier to travel in your wheelchair.

Car

If you are planning to hire a car whilst on holiday consider booking a more spacious one that is easier to get in and out of. It may help to pack a 'turntable' seat and a slide sheet in your main luggage. Some vehicle hire companies have wheelchair accessible vehicles for hire. Don't forget your blue badge if you have one, this can be used in any vehicle you travel in.

If going overseas, check with the resort or tour operator about hiring a wheelchair accessible vehicle.

Several UK companies have wheelchair accessible vehicles for hire, including:

Queen Elizabeth's Foundation for Disabled People

T: 020 8770 1151 | W: www.qef.org.uk

Adapted Vehicle Hire Ltd

T: 0845 257 1670 | W: www.adaptedvehicles.com

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Allied Mobility

T: 0800 916 0015

W: www.alliedmobility.com/accessible_rentals

Pre-departure preparation

About a month before departure, it might be worth getting a reassessment from your Physiotherapist, Occupational Therapist, Speech and Language Therapist and Continence Nurse. They may have tips about things they anticipate could need planning for and ways to manage any 'hurdles' they think may occur.

Obtain a letter from your Consultant or GP setting out your current situation and your medication – keep one copy with you in English for getting through airport control with medicines and, if possible, one copy translated into the appropriate language for the destination.

Write up a list of contact telephone numbers and email addresses, including your Consultant and MSA Health Care Specialist, so that you can contact them whilst away and can pass on details to any medical team that might need advice.

Ensure that you have a couple of copies of the Trust's 'Guide to Multiple System Atrophy' to take with you to show to any health professional you may need to be in contact with while you are away. Remember it is likely that they may have no experience of MSA.

If staying in a hotel, contact them again before departure to ensure that they are fully aware of your requirements e.g. bedroom and bathroom facilities that are accessible as well as specialist equipment, such as hoists.

Ensure that you have appropriate travel insurance (please see 'Travel Insurance' section below) and consider insuring any specialist equipment you are taking too.

What to pack

Remember to pack any special eating and drinking utensils and adapted cutlery if you use these at home. Alternatively, think about adapting the cutlery provided, e.g. foam grips to fit over standard cutlery are a good idea, particularly as you won't be able to take a knife in your hand luggage if travelling by plane.

An element of MSA can be episodes of sudden low blood pressure so it's important to be careful not to get overheated in showers and baths or by sitting in direct sunlight. Always take particular care if visiting a hot country, take salt tablets with you and whilst away ensure you drink more fluids.

Take all the medication that you will need while you are away plus at least one extra week's medication. All medication must be in correctly labelled and in its original packaging and any food or drink supplements must be in sealed, labelled and original packaging.

If you use a Convene or catheter, ensure you have spares with you and you may find using a leg bag for the journey reduces the need to find and access toilets. If you have a disabled toilet/RADAR key, ensure you have it in your hand luggage.

If you use a powerchair it is useful to have information on the size and weight as this may be required by some travel companies to ensure they can accommodate the chair in transit.

Some people have a small bag with suction fit grab rails, a fold down bed lever, slide sheet and lifting belt that they keep together for trips away from home.

Accessible holiday accommodation

There is a wealth of information online about accessible holiday accommodation of which the services listed below are a small selection. Please note the MSA Trust does not necessarily endorse any of these services, but we hope you will find them useful.

Accessatlast

Accessible travel and accommodation in the UK and overseas, with detailed reviews

T: 01772 814 555 | W: www.accessatlast.com

Can be Done Limited

Wheelchair-accessible holidays in the UK, Europe and worldwide - Also cruises

T: 020 8907 2400 | W: www.canbedone.co.uk

Disabled Holidays.com

Accessible holidays in the UK and abroad, including cruises and respite holidays

T: 0800 993 0796 | W: www.disabledholidays.com

Disabled Holiday Information

Information on accessible holiday accommodation, attractions and activities

W: www.disabledholidaysinfo.org.uk

Enable Holidays

Customised accessible holidays in Europe and the US

T: 0871 222 4939 | W: www.enableholidays.com

Open Britain

Accessible travel in England and Wales

T: 0845 124 9971 | W: www.openbritain.net

Revitalise

Holidays and respite breaks for people with physical disabilities and their carers at purpose-built centres in England

T: 0845 345 1970 | W: www.revitalise.org.uk

WheelMate

This site (also available as a smartphone app) gives you an overview of your nearest wheelchair-friendly toilets and parking spaces throughout the UK

W: www.wheelmate.com

Limitless Travel

Provides tour packages, accessible accommodation and transport for holidays in the UK and Europe

W: <https://www.limitlesstravel.org>

For general information about accessible places to go in the UK and Ireland visit -
www.disabledgo.com/

Travel insurance

Below is a small selection of the many travel insurance companies that provide cover for pre-existing medical conditions. Bear in mind that they may not have MSA listed as a condition, if not try “Parkinsonism” or “Shy-Drager”. Feel free to give the company the Trust’s contact details if they wish to discuss your medical condition in more detail. Please note that the MSA Trust does not necessarily endorse any of the services listed.

Able2Travel

T: 0845 839 9345 or 01892 839501 | W: www.able2travel.com

Medici Travel Insurance

T: 0845 880 0168 | W: www.medicitravel.com

Freedom Insurance Services

T: 01223 446 914 | W: www.freedominsure.co.uk

Signa Insurance Services

T: 0330 100 9349 | W: www.cignainsurance.co.uk

Free Spirit Travel Insurance

T: 0845 230 5000 | W: www.freespirittravelinsurance.com

Chris Knott Insurance

T: 0844 576 0660 | W: www.chrisknott.co.uk

Orbis Insurance

T: 01274 518393 | W: www.orbisinsurance.co.uk

World First Insurance

T: 0345 908 0161 | W: www.world-first.co.uk

Fish Insurance

T: 0333 331 3900 | W: www.fishinsurance.co.uk

Just Travel (Over 65’s only)

T: 0800 294 2969 | W: www.justtravelcover.com

Insurance Choice

T: 0843 538 5336 | W: www.insurancechoice.co.uk

All Clear Insurance

T: 0808 281 0605 | W: www.allcleartravel.co.uk

Stay Sure

T: 0808 178 6087 | W: www.staysure.co.uk/travel-insurance

More information about travel insurance and pre-existing medical condition insurance can be found at: www.travelinsuranceguide.org.uk/medical-conditions.html.

Assisted holidays

If financial constraints make it difficult for you to fund a holiday, consider exploring local sources of funding such as Rotary Clubs, Round Tables or similar organisations. Other organisations that might be able to give help or advice include:

3H Fund

Organises subsidised group holidays for physically disabled children and adults with the support of volunteer helpers to enable family carers to have a break whilst on holiday

T: 01892 860 219 | W: www.3hfund.org.uk

Handicapped Aid Trust

Provide grants towards cost of holiday care assistants for people with disabilities

T: 01253 796 441

Holiday Care

Information on accommodation, respite care, reservations and details of trusts offering financial support towards holiday costs

T: 08451 249 971 | W: www.holidaycare.org.uk

Citizens Advice Bureau

Information and advice to help resolve legal, financial and other problems. They may know of funds in your local area that might be able to help in the event of an emergency

T: 0207 833 2181 | W: www.citizensadvice.org.uk

Equipment

For holidays abroad, ask the tour operator or resort about availability of mobility equipment or other aids for hire. It can be difficult organising specialist equipment whilst abroad, so it is advisable to plan well ahead and do this through your tour operator or travel agent who will have representatives who can communicate your needs in the local language.

If holidaying in the UK, it can sometimes be possible to arrange the loan of equipment such as wheelchairs or commodes, through your local British Red Cross or the branch that is local to where you are going. Alternatively, a local Occupational Therapist might be able to arrange short-term equipment loan for holidays or perhaps put you in touch with local representatives.

Think about separately insuring any expensive specialist equipment you are taking on holiday with you in case of loss or damage. If possible get any specialist equipment serviced before you go away and carry a puncture repair kit if you use a wheelchair.

National Federation of Shopmobility

Hire of wheelchairs and mobility scooters in the UK

T: 01933 229644 | W: www.nfsuk.org

Travel John

A Travel John disposable urinal might be worth considering – it is suitable for men and women and holds up to 600ml of urine which turns into a gel that can be disposed of in standard waste. They cost around £13 for three and can be ordered online at www.completecareshop.co.uk Reference code CCS996.

If you are going away for a longer period of time and require the use of bulky disposables e.g. continence products, oxygen, food for your gastrostomy etc. do contact the suppliers as they may be able to arrange delivery directly to the location you are going to.

The MSA Trust regrets that it is unable to provide individual advice on travel insurance services or destinations.

Key points to remember:

- Plan carefully, do plenty of research and be realistic and honest about your disability
- Ensure your resort, travel operator and transport service are fully aware of your individual needs
- Obtain several travel insurance quotes and ensure that MSA is covered - if MSA is not specifically listed and the insurance certificate says Parkinson's or Ataxia, ensure you have a copy of correspondence that shows you advised the company that you have MSA and they accept insuring this under Parkinson's or Ataxia
- If taking expensive equipment, arrange insurance cover for that too
- Take extra supplies of medication, catheters etc in case you are delayed.

If you have any questions about anything you have read in this factsheet, then please contact your MSA Health Care Specialist.

The Trust's contact details

We have MSA Health Care Specialists that support people affected by MSA in the UK and Ireland. If you would like to find the MSA Health Care Specialist for your area, contact us on the details below or use the interactive map here – <https://www.msatrust.org.uk/support-for-you/hcps/>.

MSA Trust, 51 St Olav's Court, Lower Road, London SE16 2XB

T: 0333 323 4591

E: support@msatrust.org.uk |

W: www.msatrust.org.uk

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References for this information sheet are available by contacting support@msatrust.org.uk.

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