

Travel

Advice and insurance

Fact sheet for Myelodysplastic Syndrome (MDS) Patients

Travelling and pre-existing medical conditions

If you have a pre-existing medical condition like MDS it is important to consider taking some extra steps to prepare for your trip:

- Always **consult your haematologist first** - ask how the trip might affect you, whether you will need any additional treatments (such as extra top-up transfusions) before you go, whether it is safe for you to have recommended travel vaccinations.
- **Research your destination, local conditions and the facilities that are available**, and consider how you may be affected. Find out the local emergency services numbers, nearest MDS specialist centre and the number of the local hospital. Some countries may have higher risk of infections or a lower standard of medical facilities. For country specific travel information visit: www.gov.uk/foreign-travel-advice
- When contacting holiday providers, airlines, hotels etc., **clearly state your needs** and what assistance you require. Just telling people you have a particular disability does not mean that they will understand your needs, so clearly explain them.
- **Ensure you have all necessary documentation** before you travel. Depending on your circumstances you may be required to have a 'Fit to travel letter' or clearance from the airline for air travelling. In case of emergency ensure that you also carry some documentations describing: what MDS is, what your particular MDS issues are (low haemoglobin/feeling weak; low platelets/risk of bleeding; low neutrophils/risk of infection) your exact MDS diagnosis, your usual or latest blood results, your medication list, information about what assistance you may need, Next of kin. For remote and non-English speaking destinations, consider having these documents translated.
- **Take enough medicines** to last throughout your trip plus some extra in case of delays. Speak to your doctor or nurse for the best advice on transporting your medication. Find out if you need a letter from your doctor explaining your need to carry certain medicines, syringes or portable medicine pumps, (and any necessary receptacles to carry and store them), to satisfy foreign customs authorities, or to facilitate obtaining fresh supplies in the visiting country. Some GPs charge for writing such letters, so if you travel frequently, ask them to write it in such a way that it can be used more than once. Always keep clearly labelled medication and any medical documents in your hand luggage or in a place you can get to them easily.
- For travel within the European Economic Area (EEA) or Switzerland, you should **have a European Health Insurance Card (EHIC)** to entitle you to free, or reduced cost, medical care in the visiting country. The card does not cover the costs of any medical treatment that you have planned in advance, but will cover you for unforeseen medical needs or if you need continued treatment for an ongoing illness while you are abroad, such as regular injections. You can apply for the EHIC online through the NHS Choices website, by phoning the automated service on 0300 3301350, or at your local Post Office. The EHIC is free of charge.
- Ensure you have a **comprehensive travel insurance** that is appropriate to your needs.

Blood counts and flying

The UK Civil Aviation Authority encourages all people who wish to fly to assess whether they are fit to fly in an aeroplane. People with low blood counts (of any kind) may be advised against flying or against flying for long periods of time. In particular, anaemic patients may be affected by flying because of reduced oxygen levels at high altitudes, which do not affect those with a normal haemoglobin range. In their guidelines for health professionals, the UK Civil Aviation Authority state: *Patients with haemoglobin of greater than 8 g/dl may travel without problems assuming there is no coexisting condition such as cardiovascular or respiratory disease. If the haemoglobin is less than 7.5 g/dl, special assessment should be made and the use of supplemental oxygen should be considered.*

Please check with your doctor before booking flights whether you are fit to fly in an aeroplane. You and your doctor may be required to complete a Medical Information Form (MEDIF), before flying. The form is only valid for one trip and can only be used on the flights and dates shown on your ticket. Frequent travellers may be able to obtain a Frequent Travellers' Medical Card (FREMEC).

Travel insurance tips for MDS patients

It can often be difficult for MDS patients to get the right travel insurance policy at a reasonable price. Below are some tips on how to overcome the most common challenges:

Always declare MDS as a pre-existing medical condition. If you don't, the insurer can make your policy void or refuse to pay for any claim related to your medical condition. Be aware, if the insurer does not ask about any pre-existing conditions, your condition almost certainly will not be covered by the policy. This also applies to travel insurance provided with some credit cards and bank accounts.

Travel insurance covers more than medical costs and should also cover anything else that may happen on the trip: cancellation; the trip being cut short; medical expenses and repatriation; lost and stolen possessions including hand luggage, money, passports and other belongings. Always ask what exactly is included and excluded in the policy, how much you will be charged and how much excess you will have to pay in various circumstances.

Typically medical screenings for travel insurance are done over the telephone. Be aware **the charges for phoning insurance companies vary and may be high.** Rates from mobile phones are considerably higher. The website www.saynoto0870.com may help you find cheaper phone numbers to call. Check if you can complete your medical screening online, which is an useful option to patients whose MDS is not particularly problematic e.g. watch & wait category.

You can **avoid costs and hassle by insuring all people travelling with you on the same policy**, so that if you need claim on the insurance, the rest of the group are also covered e.g. if the holiday needs to be cancelled because of your medical condition then all of the travelling party are eligible for a refund.

Get a 'fit to travel letter' from your haematologist, which will confirm that although you have the diagnosis of MDS, it is safe for you to travel to your chosen destination. Some insurers will ask for this letter.

Before you answer any questions, ask the insurer if it has a **specific 'code' for MDS**, as opposed to a general code for cancer, blood cancer or leukaemia. If the insurer does not code MDS specifically, most likely they do not understand what MDS is. Same applies to online screening questions. Be aware that the questions you may be asked on the telephone may not be the same as those on an online form and may differ significantly between different insurance providers. Increasingly, more MDS patients are asked whether their diagnosis is 'terminal'. **MDS is generally not considered as a 'terminal illness'** as defined by the Association of British Insurers. Therefore, you should answer 'No' to this question, unless you have specifically been told otherwise by your haematologist.

Get at least 3 quotes for the same trip from 3 different insurers. This takes time and effort but will be worthwhile. Consider using comparison websites specifically for those with pre-existing medical conditions. For example: www.moneysupermarket.com/travel-insurance/pre-existing-medical-conditions/

Your choice of destination will affect the cost of your cover. If you travel several times a year, and it is an option to you, consider purchasing an annual travel insurance cover. Equally, if you currently require active treatment or blood transfusions ask for a single trip cover, which will be cheaper and easier to obtain.

'Travel Insurance - General advice and recommendations' on MDS UK Forum

Check our MDS online chat forum for MDS specific and practical travel advice from other MDS patients, including details of recommended insurance companies. If you have found the information helpful, please return the favour and share your good or bad experiences on the Forum. Please visit the MDS UK website to join the forum discussion on travel insurance at www.mdspatientsupport.org.uk.

If you haven't got access to internet, please call us on 020 7733 7558 for the latest advice and recommendations from fellow patients or to have your story shared on our Forum, for the benefit of others.

References and further sources of travel insurance information

Assessing fitness to fly Guidelines for health professionals from the Aviation Health Unit, UK Civil Aviation Authority (2012) Travel Health, Foreign and Commonwealth Office: www.gov.uk/foreign-travel-for-disabled-people and

www.gov.uk/government/publications/disabled-travellers

Association of British Insurers: www.abi.org.uk

The Macmillan website: www.macmillan.org.uk/Cancerinformation/Livingwithandaftercancer/Practicalissues/Travel

Please note this fact sheet is a guide and should not replace the advice of your clinical team. Date Published: May 2015

