

Travelling and travel insurance

Living well with AL amyloidosis Infosheet

This Infosheet outlines a few things to help make your trip as an AL amyloidosis patient safer and more enjoyable, including what to do before you go on holiday, while you are away and when you return. It also covers getting travel insurance and lists some travel insurance companies.

COVID-19 and travel: please see information at the end of this Infosheet.

Going on holiday is often one of the highlights of the year – offering a welcome break from routine and a change of scenery. This does not necessarily need to change after a diagnosis of AL amyloidosis. With careful planning and a few sensible precautions, you can still enjoy holidays both in the UK and abroad.

Before you go

Driving

Whether or not you can drive is generally a personal decision based on how well you're feeling. However, your doctor may advise you against driving, for example if you're on particular treatments that can cause drowsiness, such as thalidomide.

If you are intending to drive, you do not have to tell the DVLA that you have AL amyloidosis, however you must do so if it will affect your ability to drive. In particular, you are required by law to tell them if you develop peripheral neuropathy. They will judge on a case by case basis whether they feel it is safe for you to continue driving. You should check with your doctor (and the DVLA if necessary) in advance of your holiday plans.

Letters and medicines

It is always advisable to chat through your holiday plans with your doctor, especially if you are receiving treatment for your AL amyloidosis. Check that they are happy for you to travel before you make arrangements.

If you are currently receiving treatment, it may be necessary to wait until you've finished treatment before you travel.

Most doctors will be happy to write a letter for you to carry with you, outlining your previous and current treatment and details about your condition. This could be invaluable should you fall ill whilst you are away.

It is very important that you have enough medication with you to last for your whole trip and it is sensible to carry some extra in case of any unforeseen delays.

Speak to your doctor about taking a course of emergency antibiotics with you, so if you pick up an infection you can treat it. As an added precaution you may also want to take some 'just in case' medication with you – for example to deal with the onset or increase of diarrhoea, constipation or pain.

When travelling, the Home Office advise that all prescription drugs should be carried:

- In their original packaging
- In your hand luggage
- With a copy of your (repeat) prescription, or a note from your doctor detailing any medications that you are taking with you

Restrictions

If you are travelling abroad and taking any controlled drugs with you (e.g. opiate pain killers), you will need a letter of ownership to prove you own the drugs. If you are travelling for three months or more, or you have enough drugs to last you three months or more, you will need to apply for an export licence from the Home Office. You may also need to check with the Embassy or High Commission of the country you are visiting, or with Home Office, in case they have any restrictions on taking your medications into the country.

Check the security guidelines of any airlines you are travelling with, particularly if you are carrying syringes, as you may need an accompanying doctor's letter.

Funding for treatment abroad

If you know that you will need to have treatment (e.g. infusions or injections) whilst you are away in a country within the European Economic Area (EEA) or Switzerland, one option is to apply for an S2 form. The S2 form entitles you to state-funded treatment in these countries. Treatment will be provided under the same conditions of care and payment as for residents of that country. This could mean you have to pay a percentage of the costs personally.

Alternatively, you can apply for funding for treatment in the EEA via the EU Directive route. If you choose to do this however, you will usually need to pay for treatment up front and claim the cost back once you are in the UK. You may also need to apply for permission to have certain treatments in advance. The treatment can be given in the country's state or private sector, but you will only be reimbursed up to as much as the treatment would have cost on the NHS.

You should speak to your GP or consultant haematologist about how to apply for funding for your treatment abroad.

Brexit: There are no changes to access to planned treatment in Europe up to 31 December 2020. You can still apply for the S2 funding route or the EU Directive route. If you have requested authorisation for your treatment by 31 December 2020, it can go ahead once it is authorised, even if the date of treatment is from 1 January 2021. However there are no new arrangements in place yet for access (new applications) from 1 January 2021 onwards.

Vaccinations

Depending on which country you are planning to visit you may need to have vaccinations before you go. There may be restrictions on which vaccinations are safe for you to receive. Again it is worth discussing this with your doctor or nurse well in advance of your proposed departure date.

Travel insurance

You may find it harder, or more expensive, to get travel insurance when you have had a diagnosis of AL amyloidosis as some insurance companies assume that you

are more likely to make a claim. However, to avoid any unforeseen financial costs, it is very important to get travel insurance if you are going on holiday or travelling abroad.

There are several specialist companies who provide tailored insurance for people with existing medical conditions such as AL amyloidosis. It is vital that you tell your insurer about your condition and treatment; if you do not provide this information your insurer can refuse to pay for medical care even if it is not related in any way to your condition.

The following is a list of points to consider when planning a holiday and shopping for travel insurance:

- A good starting point would be to discuss with your consultant whether they think you are fit enough to travel. Most travel insurance companies will need confirmation from a doctor stating you are fit to travel. It may save time and money if you ask for a 'fit for travel' letter from your consultant or GP before contacting travel insurance companies
- Allow enough time (at least a month) before you travel to apply for insurance as it may take some time to find the best cover

- Many travel insurance companies use a 'medical screening' system to determine whether they can offer you an insurance policy. This is usually done over the phone and will mean you are asked a series of questions about your AL amyloidosis and any treatment you have had or are having. You must also declare any other health conditions to the insurance company, otherwise they will be able to declare your policy invalid should you need to make a claim
- It may be cheaper to look into an annual insurance policy if you are planning to travel more than once a year
- It is advisable to have at least one of your travelling companions insured on the same policy as you. This should ensure that someone could accompany you home, should you become unwell
- Your choice of destination will affect the cost of insurance. If you are travelling to the USA, insurance will be more expensive and can be more difficult to arrange than for within Europe

Some countries in Europe have reciprocal health arrangements with the UK. This means you will get the same care as the people who live in the country you're visiting,

but this may not be the same as the care you'd expect to get from the NHS. To access this you need a free European Health Insurance Card (EHIC). You can apply for this from the NHS, either online at www.nhs.uk/ehic, or by calling **0300 330 1350**. The EHIC entitles UK residents to free or reduced-cost emergency treatment when temporarily visiting European Economic Area (and certain other European) countries. The EHIC is not an alternative to travel insurance. It will not cover any private medical costs nor help getting back to the UK should you become unwell while on holiday.

Brexit: The current type of EHIC cards can only be used up to 31 December 2020, which is the end of the transition period following the UK leaving the EU. It is hoped to set up a new arrangement, but this has not yet been done. If the transition period ends without a deal, the EHIC system will no longer be valid. For travel from 1 January 2021 onwards, you should check the NHS website link nearer to the date of travel for more information.

Getting travel insurance

When applying for travel insurance it is important to read the 'small print' of a proposed policy. In particular, it is essential to check:

- The cost of the insurance (the premium) and the amount you have to pay if you make a claim (the excess)
- Exactly what is included and excluded in the policy
- Make sure that the company will not just cover you as an AL amyloidosis patient, but will cover any claims resulting directly from your AL amyloidosis
- That any medical equipment and drugs you need to take on holiday with you are covered
- Whether the policy offers cancellation cover

Travel insurance companies vary considerably in their price and the level of cover they provide, so it is worth considering different options. You should be prepared to answer a range of questions about your AL amyloidosis and your treatment. Some companies may refuse you cover, only provide you with partial cover or only provide cover with increased premium or excess. Contacting travel insurance companies can be a difficult and time consuming process. Try to be patient and persevere – you may want to consider contacting one company at a time. There is also the option of contacting an insurance broker who can shop around for a suitable insurance company for you.

See following sections for a list of travel insurance companies and brokers that specialise in providing insurance for people with existing medical conditions.

Travel arrangements

When planning your trip it is important to make sure that your travel plans are realistic and that you will not arrive at your destination exhausted or in extreme pain. It is advisable to think about any assistance that you may need whilst travelling. Most travel and airline companies will have a medical officer who should be contacted before your journey. They can then help with any special arrangements that you may need to make your trip more comfortable.

Travelling to Europe after Brexit

After the UK left the EU on 31 January 2020, we entered a transition period which is expected to last until 31 December 2020. During this period, arrangements for travel in the EU are unchanged. There may be changes after this however, depending on whether we reach the end of the transition period with or without a deal. The following information may be helpful:

- You may need to renew your British passport earlier if you are planning to travel after

1 January 2021. Your passport will need to have at least 6 months left and be less than 10 years old

- It is advisable to check with the company you are travelling with for information about anticipated delays or disruption, and factor in extra time for travel
- If you are planning to drive abroad you may need extra documents after 1 January 2021
- The Government website www.gov.uk/visit-europe-1-january-2021 provides up-to-date information. Check the website before planning your travel, and check again for updates nearer to your travel dates.

Travelling

Long haul flights

Before you go on a long haul flight, you may want to discuss preventative measures to help reduce the risk of DVT (deep vein thrombosis or blood clots) with your GP. During the flight it is important to try to exercise your feet/legs as this will help prevent stiffness and can reduce your risk of DVT.

All flights

It is important that you keep hydrated throughout your flight. You may find it handy to have your own supply of bottled water rather than relying on the catering on the flight. However, you should remember that there are restrictions on the liquids you can take through the security checks at airports – bottled water can usually be purchased in the shops in the departure lounge after you have passed through security. It may also be worthwhile taking a small travel cushion or neck collar with you for extra comfort, particularly if your journey is quite long.

Ask to sit near the toilet or for a seat with extra leg room if you think this may help. It is often helpful to get up and move around, at regular intervals throughout the flight, to minimise pain and discomfort.

While you are away

Food and drink

When away it is important to keep well hydrated. Remember that if you are in a hot climate you may need to drink more than you usually would. If you have been advised to limit your fluid intake (for example because of kidney problems), you should ask for advice about how much fluid you should drink per

day while you are in a hot climate. It is sensible to drink bottled water when away from home to minimise the risk of infection.

Many people can develop stomach upsets whilst abroad so it is wise to adopt some sensible safety precautions when eating out. Try to eat only in restaurants that serve freshly cooked foods and avoid salads, ice in drinks and any uncooked meat or fish.

Sun safety

You will need to be particularly careful in the sun especially if you are on, or have just completed, chemotherapy treatment, as your skin will be much more sensitive to the sun's rays. It is important to apply an adequate sun block liberally and regularly, especially to exposed areas. Staying in the shade, wearing a hat and loose cotton clothing can all help minimise the risk of burning.

Treatment away from home

If you do need to buy medicines abroad, be certain about what you are buying and do not take anything that you are unsure about. Do not bring any medicines bought abroad home with you.

If you are taking erythropoietin (EPO), or any other medicines that have to be stored below room

temperature, remember to check that the hotel/apartment you are staying in has a refrigerator and that they will be happy for you to store your medicines.

If you do become ill while you are away, make sure a doctor reads your letter detailing your medical history. Try to contact your insurance company as soon as possible – they should make all the necessary arrangements for you, and your travel companions, to get home safely.

Within the UK

If you are on holiday in the UK, take the phone numbers of your doctor, your nurse and the out-of-hours doctor at your hospital so that you can call them if you need any medical advice.

If a nurse normally administers regular treatment to you, it is often possible to arrange for a local nurse to do this whilst you are away. It is also possible to arrange dialysis away from home in the UK and even abroad. Your doctor or nurse will be able to tell you more about this.

When you return

You will hopefully return home rested and rejuvenated after an enjoyable time away. However, if you do start to feel unwell,

particularly if you have persistent diarrhoea, an infection or a nasty insect bite, it is important that you see your GP immediately to receive the appropriate treatment. If necessary, try to make any insurance claims as soon as you return home, as you are more likely to remember events clearly.

Further information and useful organisations

NHS website

www.nhs.uk

Provides up-to-date health advice for travellers, including on the S2 and EHIC forms.

Global Dialysis

www.globaldialysis.com

Provides comprehensive information on dialysis centres around the world.

Home Office Drugs Branch

www.gov.uk/guidance/controlled-drugs-personal-licences

020 7035 6330

Provides personal import/export licences for controlled drugs and further information about travelling with controlled drugs.

Specialist travel insurance companies

All the travel insurance companies listed below specialise in providing travel insurance for people with pre-existing medical conditions. No particular companies are recommended over any others: who you choose to take out insurance with should depend on who can provide the best policy for your needs.

Age UK Travel Insurance

www.ageco.co.uk/travelinsurance

Not currently providing travel insurance. Check website for changes to this situation.

All Clear Travel Insurance

www.allcleartravel.co.uk

0800 848 8608

Avanti Travel Insurance

www.avantitravelinsurance.co.uk

0808 281 3212

Cancellation Plan

www.cancellationplan.co.uk

02392 419 843

Explorer Travel Insurance

www.explorerinsurance.co.uk

FISH Insurance

www.fishinsurance.co.uk

0333 331 3770

Free Spirit Travel Insurance

www.freespirittravelinsurance.com

02392 419080

Freedom Insurance Services Ltd

www.freedominsure.co.uk

01223 446 914

Freedom Travel Insurance make a donation to Myeloma UK for each policy sold, at no extra cost to you. Quote 'Myeloma UK' when you speak to them so they know that you would like this donation to be made.

Get Going Travel Insurance

www.getgoinginsurance.co.uk

0333 999 2678

(urgent enquiries only)

Insurancewith

www.insurancewith.com

Insure Cancer (also trade as Medi Travel Cover Ltd)

www.insurecancer.com

01252 780 190

It's So Easy Travel Insurance

www.itssoeasytravelinsurance.com

No new insurance quotes at time of writing.

Just Travel Cover.com

www.justtravelcover.com

0800 294 2969

Just Travel Cover make a donation to Myeloma UK for each policy sold, at no extra cost to you. Quote 'Myeloma UK' when you speak to them so they know that you would like this donation to be made.

MIA Online

www.miatravelinsurance.co.uk

0800 999 3333

Nowicantravel

www.nowicantravel.co.uk

0203 829 3893

Nowicantravel make a donation to Myeloma UK for each policy sold, at no extra cost to you. Quote 'MYELOMA' when you speak to them so they know that you would like this donation to be made.

OK To Travel Insurance

www.oktotravelinsurance.co.uk

01223 446 920

Staysure Travel Insurance

www.staysure.co.uk

0800 033 4902

World First Travel Insurance

www.world-first.co.uk

0345 90 80 161

Insurance brokers

Insurance brokers do not supply insurance themselves; they shop around to try to find a suitable insurance company for you. The insurance brokers listed below specialise in providing cover for those travelling with a pre existing medical condition.

Able2travel Ltd (formerly CH Facilities Ltd)

www.able2travel.com

01483 806 826

JD Travel

www.jdtravelinsurance.co.uk

0344 247 4749

Medical Travel Compared

www.medicaltravelcompared.co.uk

General insurance companies

These are insurance companies that, although they do not claim to be specialists in travel insurance for people with pre-existing conditions, may still be able to provide cover for AL amyloidosis patients.

Bupa

www.bupa.co.uk/travel-insurance

0808 159 1392

Marks and Spencer

bank.marksandspencer.com

New travel insurance sales temporarily suspended.

Post Office Travel Insurance

www.postoffice.co.uk/travel-insurance

New travel insurance sales temporarily suspended.

Insurance standards and complaints

Information about insurance standards and making complaints can be found at:

Citizens Advice

www.citizensadvice.org.uk

England: 03444 111 444

Wales: 03444 77 20 20

Scotland: call your local office.

Northern Ireland: use Advice NI, visit www.adviceni.net

Citizens Advice offers free, independent and confidential advice about consumer issues including travel insurance.

Financial Ombudsman

www.financial-ombudsman.org.uk

0800 023 4567

The Office of the Financial Ombudsman is set up to help settle complaints about businesses providing financial services, including insurance companies.

Summary

- With careful planning you should still be able to enjoy holidays in the UK and abroad as an AL amyloidosis patient
- Discuss your travel plans with your doctor before booking
- You may find it harder or more expensive to get travel insurance, but it is very important to be covered to avoid the risk of high medical costs while you are on holiday
- Allow enough time (at least a month) to organise insurance
- A number of insurance companies specialise in insuring people with pre-existing medical conditions, but the cost and the level of cover vary considerably, so it is worth phoning a number of companies
- Other things to consider before travelling include: drug treatment you may need while you are away; air travel; and food and drink

To our knowledge this information was correct at the time of printing. Please let Myeloma UK know if you find any particular company helpful (or unhelpful), or if you have used a company that does not appear on this list, as we regularly review and update our information. We hope you find a suitable insurance policy and we wish you a happy holiday.

About this Infosheet

The information in this Infosheet is not meant to replace the advice of your medical team. They are the people to ask if you have questions about your individual situation.

For a list of references used to develop our resources, visit myeloma.org.uk/references

We value your feedback about our patient information.

For a short online survey go to myeloma.org.uk/pifeedback or email comments to myelomauk@myeloma.org.uk

Other information available from Myeloma UK

Myeloma UK has a range of publications available covering all aspects of AL amyloidosis,

its treatment and management.

Download them from myeloma.org.uk/publications

To talk to one of our Information Specialists about any aspect of AL amyloidosis, call the Myeloma UK Infoline on **0800 980 3332** or **1800 937 773** from Ireland.

The Infoline is open from Monday to Friday, 9am to 5pm, and is free to phone from anywhere in the UK and Ireland.

Information and support about AL amyloidosis is also available around the clock at myeloma.org.uk/amyloidosis

COVID-19 and travel

- Visit www.gov.uk/coronavirus for information on restrictions to travel
- Visit www.gov.uk/foreign-travel-advice before planning any future travel abroad. As a result of the coronavirus (COVID-19) outbreak, at the time of writing the Foreign and Commonwealth Office (FCO) was advising against all but essential international travel, except to some exempted countries. This advice is being kept under constant review
- If you are looking for insurance to cover future travel plans, it is very important to check what the available policies will cover in the light of COVID-19
- During the COVID-19 outbreak, some insurance companies are not contactable by phone, or there may be long wait times if you do phone. It is best to check contact arrangements on the website first if possible

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We're here for everything a diagnosis of myeloma brings

Get in touch to find out more about how we can support you

Call the Myeloma Infoline on

 **0800 980 3332**

Email Ask the Nurse at

 **AskTheNurse@myeloma.org.uk**

Visit our website at

 **myeloma.org.uk**

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