

Travel and Cardiomyopathy

Helpful guidance on planning your holiday

- Taking a break or a holiday can be important for both our mental wellbeing and physical health.
- For people with cardiomyopathy, going on holiday may need additional planning.
- We would advise you to discuss your travel plans with your healthcare professional so that you can plan in advance and find the holiday that is right for you.

Taking a break

Taking a break or a holiday away from home is important to many people. A 'change of scene' and 'getting away from it all' can help us to feel relaxed and re-charged. And it can be important for our emotional wellbeing as well as our physical health. For some people with cardiomyopathy, going away on holiday may not be easy, may raise questions and concerns, and may need careful planning. Here we look at some of the things to consider that people with cardiomyopathy, and their families and loved ones, tell us were important when planning a holiday.

How do I explain my condition to people?

There are times when it is helpful to tell people about your medical condition, in case you need medical help while you are away. This might include an airline, a tour operator or your accommodation provider.

Cardiomyopathy is a condition that not many people know about, and it can be difficult to explain it. You may like to ask your GP, nurse or cardiologist to write a letter explaining your condition, your symptoms and your current medication. You could also download and print our information resources about cardiomyopathy. You can then carry this with you in case you need to explain your condition. It might also be helpful to take your most recent clinic review letter and ECG, if you have one.



Taking photos on your phone might help to explain your condition, particularly if there is a language barrier. For example, a picture of a heart, or of your medication. This might also be a way to communicate other common things such as asking for directions to the hospital (or the toilet!)

Choosing your destination

For many people, deciding where to go on holiday is part of the enjoyment. Whether it is a relaxing beach break, a cultural destination or adrenalin-filled activity holiday. For a person diagnosed with cardiomyopathy, deciding on a destination may need a little more thought. For example, some people may decide to only visit countries that have modern healthcare systems, or where they can access a cardiac device clinic.

Visit www.gov.uk/foreign-travel-advice for details of healthcare in individual countries.

Where is the nearest hospital?

You may want to check where the nearest hospital or healthcare services are, and how you get to them.

If you have an implanted device (such as an ICD or CRT) you may also want to check whether there are pacing clinics in the area you are visiting.

Contact your device company about pacing clinics.

How do you call for help?

Look up local contact numbers before you travel so that you know what the relevant emergency contact number is, including the local chemist and local GP surgery. You can translate a letter explaining your condition using Google Translate.

Visit www.translate.google.com/

What is the environment like?

When thinking about the environment, it may be



helpful to think about any symptoms you experience and if anything makes these worse.

- Is it at a high altitude? The reduced oxygen levels may cause breathlessness or chest pain.
- Is it very hot? Extreme heat may affect symptoms such as dizziness or fainting, and risk dehydration.
- Is it hilly or will you have steps to climb? What fitness level do you need if there will be lots of walking?
- Are there enough amenities (for example, if you take diuretics and need to use the toilet frequently)?
- What is your accommodation like? will you need assistance with your luggage?.

Getting to your destination

Advice about flying will vary from person to person, depending on how their heart condition affects them. If you are considering traveling by air, you may be advised to notify the airline, travel agent or tour operator, at least two days in advance (some airports suggest longer), about your condition. The airline will be responsible for your wellbeing during your flight, and the airport can help you plan your arrangements.

Contacting them in advance can be helpful if:

- you need special assistance around the airport (for example, help with your luggage, disabled access or mobility assistance such as transport to the departure gate); or
- you may need medical help during the flight, such as access to oxygen.

You can find more information from individual airports and airlines.

During the flight, it is also helpful to:

- keep hydrated with non-alcoholic and non-caffeinated drinks; and
- regularly move around out of your seat to help blood flow and avoid blood pooling in your legs (to reduce the risk of DVT or deep vein thrombosis). Wearing flight stockings could help with your blood flow during longer journeys.
- you may also want to talk to your doctor about whether taking aspirin before the flight would be helpful, to reduce the risk of DVT.

Travelling with an implanted device

If you have an implanted device (ICD or a CRT device) you may have concerns about passing through the

airport security. Security checks at airports include scanners that check for any hidden prohibited items. Some scanners are metal detectors and others use 'millimetre wave' technology (a type of radio wave). Although the Medicines and Healthcare products Regulatory Agency (MHRA) consider that you can safely use airport security scanners if you have implanted devices, the following may be helpful.

The general recommendation from implantable device companies is to let the staff know that you have a device as soon as you approach the security desks and show them your device identification card.

- If the scanner is a walk-through one (an archway scanner), walk at a normal pace and do not pause or stop in the scanner.
- If the scanner is an electronic wand (that is passed over your body) ask the security staff to avoid passing it close to, or repeatedly over your heart.
- If the scanner is a full-body one (where you have to stop inside it to be scanned) these use 'millimetre wave' technology and are considered safe for people with medical implants.
- If you have any concerns, you may like to ask to be searched by hand instead.

Use our Symptom Diary to record details of your cardiac device - www.cardiomyopathy.org/newly-diagnosed

Carrying your medication

When travelling, it is often recommended that you carry all of your medication, in its original packaging, with you in your hand luggage. That way, you will have your medication with you if you get separated from your checked-in luggage. It is also important to carry a copy of your prescription, and a letter from your doctor explaining what medication you take and for what condition. This can help to explain why you are carrying medication in case you get asked at security. This is also helpful if your medication is not available, or has a different name, in the country you are travelling to.

It may be worth taking more medication than you need for your entire stay, in case of any travel delays.

If you are going away for several weeks, you can talk to your GP about whether they can give you a prescription for an extra supply of medication to cover the time you are away.



Crossing time zones

Most people with cardiomyopathy take some form of medication. Taking medication at around the same time each day can be helpful to keep the level in the blood as stable as possible. If you are travelling to a different time zone, you may want to consider changing the time you take your medication to fit in with the new time zone.

- If your destination is within a couple of hours time difference, sticking to your usual time may be preferable if it does not interfere with your holiday.
- If your destination is more than a couple of hours difference, this may make taking your medication at your usual (UK) times difficult. This may depend on where you are going, and how long you are away for. Gradually adjusting the time that you take your medication may be helpful. Your doctor, nurse or pharmacist may be able to help you with planning this, and planning for your return home.

Travel insurance

Travel insurance is important for everyone, particularly for people with pre-existing medical conditions, who may need medical assistance while travelling.

It is worth contacting several companies to compare the cost and level of cover. Companies will ask for details of any medical conditions, and giving as much information as you can helps to find cover that meets your needs. It is important to check what is included in the cover, and what is excluded. Quotes may be high because they are calculated on the likelihood of you needing to make a claim. Some companies exclude claims relating to pre-existing medical conditions, and some may cover them at an additional cost.

The UK Global Health Insurance Card (GHIC) lets you get state healthcare in Europe at a reduced cost or sometimes for free. If you have a UK European Health Insurance Card (EHIC) it will be valid until the expiry date on the card. Once it expires, you'll need to apply for a GHIC to replace it.

www.gov.uk/global-health-insurance-card

Applying for insurance

When describing your condition to insurance companies, you may find that different words are used to explain your condition. For example: typing in 'cardiomyopathy' into some insurance websites

will give you a list of types of cardiomyopathy. Some describe the effect on the heart, and some describe the cause of the condition.

For example:

- dilated cardiomyopathy;
- genetic cardiomyopathy;
- hypertrophic cardiomyopathy;
- idiopathic cardiomyopathy (where the cause of the cardiomyopathy is unknown);
- ischaemic cardiomyopathy (where the coronary arteries that supply blood to the heart are narrowed, reducing the heart's ability to pump properly);
- Takotsubo cardiomyopathy; and
- viral cardiomyopathy (caused by a viral infection).

This can make completing the application difficult if you are unsure which option to select (for example, if you have dilated cardiomyopathy but it is caused by a viral infection). If in doubt, you might like to ask your cardiologist what they suggest, or contact the insurance company directly by phone to explain your situation.

See our *Travel Insurance information sheet to find out more* - www.cardiomyopathy.org/living-cardiomyopathy/get-practical-support/travel-insurance

Travel vaccinations

When travelling abroad, you might be advised to have vaccinations, or medication such as anti-malarials, to protect you against infectious diseases. This will depend on where you are travelling to and the time of year.

You may want to talk to your GP or pharmacist about whether there are any contraindications (medical reasons to not take) any particular vaccinations or medication. This might be because of your underlying condition or because of the medication you are taking (due to possible drug interactions). If you are planning a holiday where you may need vaccinations, it is a good idea to talk to your GP or practice nurse a few weeks prior to travel about which travel vaccinations or medications might be advised for you. You may wish to ask for advice on using insect repellents and avoiding being out in the hottest part of the day.

For more information

The following websites can provide further information on which vaccinations are recommended for each country.



- www.nhs.uk and search 'travel vaccinations'.
- www.fitfortravel.nhs.uk which also has information leaflets on different vaccines.

Checklist of documents

It may be helpful to carry the following with you in your hand luggage:

- your passport;
- your GHIC card (if appropriate);
- your insurance documents;
- your prescription and your medication;
- a letter from your GP or specialist explaining your condition, symptoms and treatment; and
- any tests results you think might be important (such as a recent ECG recording).

While you are away

On the next page are some things that you might want to think about and plan for in advance of going away. These may not apply to everyone.

Exposure to the sun

It is important for everyone to take precautions when exposed to the sun, and this is even more important for people taking certain medications.

Some medications can increase how sensitive skin is to sunlight, and exposure to the sun can cause serious sunburn or blisters. The drug amiodarone (an anti-arrhythmic medication used to treat heart rhythm problems) causes sun sensitivity, and so it is very important to use protection if you are taking this drug (see below). Other medication that can cause increased sensitivity include some diuretics (water tablets).

If you are taking medication that increases sun sensitivity, it is important to protect your skin from sunlight. Using high factor sunscreen (at least factor 30), wearing clothes that cover your arms and legs, using a wide-brimmed hat, and staying out of the sun when it is at it's hottest (usually between 12 and 3pm), are all useful precautions. For some people, exposure to the sun even when it is cloudy or overcast, can be harmful.

Skin sensitivity can also continue for several months after you stop taking the medication.

You can check the patient information leaflet that comes with each packet of medication to see whether this may be an issue. You can also talk to your GP or pharmacist about any precautions to take when using the medication.

Alcohol

Alcohol is a depressant and can affect how well the heart functions. For some people diagnosed with cardiomyopathy, alcohol can also cause blood pressure to increase and can bring on abnormal heart rhythms.

Alcohol can interact with some medications. For example, it is known to interact with the anti-coagulant (blood thinner) warfarin, and increases the effects of warfarin. For some people this could put them at an increased risk of bleeding. It can also cause dehydration.

You can check the patient information leaflet that comes with each packet of medication for guidance on drinking alcohol.

Dehydration

Keeping hydrated (drinking enough water) is important for your heart as it makes it easier to pump blood around the body. Dehydration, where you are not getting enough water, can cause tiredness, swelling in the ankles and feet, dizziness and headaches. It can also lead to heat-stroke, which can be life-threatening.

Dehydration can be caused by air travel, physical activity, hot climates, and not drinking enough water. Keeping hydrated can be challenging when you may be out of your usual routine, doing more activities than usual, or out in hot weather.

You can avoid dehydration by drinking regularly, (perhaps carrying water with you), and avoiding caffeinated drinks and alcohol. It can also be helpful to look out for any early signs of dehydration such as feeling thirsty.

If you are on diuretics you may want to ask advice from your GP or cardiac nurse about keeping hydrated.

Sauna

Saunas, jacuzzis and steam rooms all use heat (either dry or wet heat). This heat causes vasodilation (widening of the blood vessels), and can affect blood



pressure and in turn, cause dehydration. These may affect some people diagnosed with cardiomyopathy more than others, especially if you have a lower blood pressure or you are taking medication which helps the heart by increasing the size of blood vessels in the body. If you are unsure you can talk to your GP or cardiac nurse for advice.

Terms used in this information sheet

- **DVT (deep vein thrombosis)** – where a blood clot forms in the deep veins within the leg. Although it is rare, the clot can travel to the heart and block an artery in the lung.
- **ICD (implantable cardioverter defibrillator)** – a device which monitors the heart rhythm and gives a shock to the heart if it detects a dangerous rhythm.
- **CRT (cardiac resynchronisation device)** – a device which coordinates the heart's pumping action.
- **MHRA** – the organisation that regulates the safety of medicines and medical devices in the UK.

We are here for you

At Cardiomyopathy UK we offer help and support for you and your family. You can call our helpline to talk to our support nurses on 0800 018 1024. We can put you in contact with other people through our support groups, support volunteers and social media. Contact us for more about our services, or look online -

www.cardiomyopathy.org.

Send your feedback to contact@cardiomyopathy.org

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