living with cardiomyopathy

Cardiomyopathy UK
the heart muscle charity
acknowledgements

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living with cardiomyopathy

Cardiomyopathy is a disease of the heart muscle. It affects people of all ages, including babies, and is usually inherited. Though not curable, it is treatable and most affected people are able to lead long and fulfilling lives.

When people are first diagnosed with cardiomyopathy, they can feel overwhelmed by fear and uncertainty. This is not unusual. But as they find out more about the condition and living with it, most come to terms with having it and can get on with their lives.

Cardiomyopathy UK publishes booklets on the main types of the disease – hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy – and their treatments. Information about other types of cardiomyopathy are on the charity’s website. This booklet provides information and advice about living with cardiomyopathy.
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diagnosis

Cardiomyopathy is diagnosed in various ways. It might be because of the symptoms you have or from a routine heart check. As the disease runs in families, you might be checked and diagnosed after a family member has been found to have the disease.

Being diagnosed with cardiomyopathy can be very worrying for you and your family. Having more information about the condition, how to live with it and the support available can all help you cope.

But make sure you get information from a reputable source, such as your care team or Cardiomyopathy UK.

Over time, most people are able to come to terms with the diagnosis and can deal with their worries.
life management tips

- Develop a good relationship with the nurses and doctors who are going to support you
- Allow yourself to feel upset and express your feelings
- Conquer feelings of guilt. Though usually inherited, the disease is caused by nature and very rarely by behaviour
- Allow yourself to grieve for the good health you have lost
- Spend quality time with your family. If extra support is needed, contact Cardiomyopathy UK. Sometimes counselling can help
- Join a local support group and talk to others who have learnt to cope
- Recognise what you can and can’t do. Set yourself realistic goals
- Learn to change and adapt so you can still enjoy many activities
- Take care of your body by having a healthy diet, taking moderate exercise and getting plenty of rest
- Get rid of stressful situations or learn how to handle them better
- Learn as much as possible about your condition and take an active role in your treatment
- Maintain a positive mental attitude
- Realise what life still has to offer
what to expect at hospital or specialist clinic

When you have been diagnosed with cardiomyopathy, you should be referred to a cardiologist with some expertise in the management and treatment of the condition. The cardiologist may work in a specialist inherited heart disease team or elsewhere. It is likely that specialist nurses, such as heart failure or arrhythmia nurse specialists, will be part of the care team.

The way your cardiomyopathy is managed and treated will vary depending on the type of cardiomyopathy you have and your particular symptoms.

When you are seeing a cardiologist for the first time you may have the following tests:

- electrocardiogram (ECG), a recording of the heart’s electrical activity
- echocardiogram (echo), an ultrasound scan that shows heart size and blood flow
- exercise test
- 24-48 hour Holter monitoring (you wear a device that provides a continuous ECG)

Other tests might include a stress echo taken during cycling on an exercise bike.

You might need to go back on a different day for more specialised tests such as an MRI (magnetic resonance imaging).
Blood might be taken for routine investigations, such as kidney and liver function. After the tests, you will be seen by a cardiologist who will examine you, give you the results and discuss your treatment. You should get a chance to talk to a specialist nurse. Other people you might see include a genetic counsellor (to talk about genetic testing) and staff who deal with heart devices such as pacemakers and internal defibrillators (ICDs).

Because the condition runs in families, many patients will need to talk to their care teams about heart checks for close family members (family screening). A nurse or doctor will talk to you about any family history of cardiomyopathy and draw up a family tree. Family members who might benefit from heart checks should be identified because early diagnosis is important.

Cardiomyopathy can appear in many ways in the same family. So care for family members varies too. Some patients will not need any treatment. For those who do, it will vary according to symptoms and the type of cardiomyopathy. Detailed information about treatments can be found in Cardiomyopathy UK’s booklets on the different types of cardiomyopathy.

**follow-up**

Because cardiomyopathy is complex, most patients should be reviewed at least once a year by a cardiologist. At each visit you are likely to have a physical examination and ECG. You might have some tests you have had before, including an echo,
exercise test, 24-hour Holter monitoring and blood test. Your family tree might be discussed again.

Other appointments may be split between the hospital and GP in some instances.

**how to make the most of your appointments**

Clinic appointments are the main point of contact between most patients and their care teams. So it is important that your appointments help you and your care team.

The doctors might be on a tight schedule and you might feel you should not ask too much. But it is important to get answers to your questions, including any queries you have about genetic testing or family screening.

You can make the most out of an appointment if you write things down. You might have a good memory but there will be a lot going on. Often patients simply forget to ask their most important questions.
before you go think about

- The reasons for your appointment and what you expect to get out of it

- Your symptoms, fears and worries. Be honest with yourself and your care team. Decisions on your care are influenced by what you think and feel

- Write down your questions and take them with you

- If your symptoms have changed since your last appointment, make notes or keep a brief diary of your symptoms to take with you

- Ask about any other information you have been given so you can get your care team’s opinion

- Don’t be afraid to ask if you don’t understand what your care team has said previously

- Make a record of all the medication you take. Take this record with you to all appointments

- Some more possible questions are given in the section ‘At the appointment’ (Page 13)

- If you have to cancel an appointment, give as much notice as you can

- You are likely to receive a lot of information. Many patients find it helpful to take a family member or close friend who can make notes. If this is not possible, you will probably want to take notes yourself
other patients have found these tips helpful

1. **Buy a special notebook for your appointments**
   Write down a numbered list of questions when you think of them. Tell the doctor how many questions you have and tick them off when you understand the answer. If you don’t understand the answer, ask the doctor to explain again. Don’t worry if your questions seem silly. They are not.

2. **Identify your symptoms**
   (such as breathlessness, palpitations, tiredness, ankle swelling) and when you get them. What do you think triggers them? What relieves them?
   Write all this down and tell your doctor. Recalling these facts quickly and accurately will help your doctor help you.

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**at the appointment**

- If any tests are carried out (or have been carried out before the appointment), ask what the tests were, when you are likely to get the results and how you will get them.

- Ask how to report changes in your symptoms or issues, such as side effects of drugs, between appointments. You might need to contact the specialist nurse, the doctor’s secretary or visit your GP.

- Check you understand and agree your treatment plan and any lifestyle changes.

- If you are given different medication, make sure you understand why and read the leaflet that comes with it.
Clinic appointments often run late, especially if you have to wait for tests. So be ready for a long visit and make relevant arrangements. Take a book and a snack. If there is a delay, ask if you have time to get a drink or something to eat.

The appointment is for you. When the appointment finishes, you need to feel you have got all the information you need. Unanswered questions can make it more difficult to accept your condition and adapt your life.
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dealing with your symptoms

Cardiomyopathy can cause a wide range of symptoms. They vary according to the person and the type of cardiomyopathy. Some people with the condition have no symptoms at all.

And, with all symptoms, if you are unsure or worried, contact your GP, specialist nurse or cardiologist. It is normal to have worries.

Always seek medical advice if you have sudden shortness of breath for no obvious reason, chest pain, collapse or near collapse or a fast heart beat that makes you feel unwell.

Many patients will have specialist heart nurses who can make sure patients are on the right drugs. If not, your GP or cardiologist will have this role.

Symptoms you might experience:

shortness of breath (dyspnoea)

Shortness of breath usually happens when you exert yourself and should stop when you rest. If symptoms get worse or you have them while resting, seek medical help.

In dilated cardiomyopathy, shortness of breath is often caused by fluid in the lungs (see below)

fluid retention

Sometimes cardiomyopathy causes excess fluid to build up in the body. As well as causing shortness of breath, it can lead to ankle and stomach swelling and sudden weight gain.
Fluid retention can usually be controlled with drugs such as diuretics (water tablets), which make the kidneys produce more urine, and ACE inhibitors, which improve the heart’s pumping action.

**ankle swelling**

Many people with cardiomyopathy have mild ankle swelling. But if it worsens it could be a sign your heart is not working so well. Changes in your medication might be needed. You might also need to reduce your salt intake.

**chest pain**

Chest pains (and palpitations – see below) can be caused by anxiety. Relaxation techniques can help. But people with hypertrophic cardiomyopathy might get chest pain if their thickened heart muscle is restricting blood flow to the coronary arteries. Chest pain usually happens during exercise and stops at rest. Chest pain is more likely if you have apical hypertrophic cardiomyopathy (thickening at the apex of the heart).

If you have dilated cardiomyopathy you might have some chest pain because of high pressures on the heart wall limiting blood supply to the heart muscle. Medication is used to reduce the pressures.

**palpitations**

Palpitations are felt when the heart beats unusually, abnormally fast or more strongly than normal. You might also get palpitations when the heart beats irregularly or misses beats.
Most people with cardiomyopathy will have a 24 hour heart monitor when first diagnosed and subsequently to check for abnormal heart rhythms. If new symptoms occur, more monitoring might be needed. Some people find it useful to check their pulses to see if they are fast or slow, regular or irregular.

If palpitations come with other symptoms – such as feeling light-headed, chest pain, shortness of breath or collapse – then seek urgent medical help.

**light-headedness and collapse**

Light-headedness and collapse can be symptoms of heart rhythm problems, including slow heartbeats.

People with hypertrophic cardiomyopathy and obstructed blood flow from the heart might become light-headed or might collapse when exercising.

Hot environments – including saunas and hot tubs – can also cause a sudden drop in blood pressure which, in turn, can bring about light-headedness or collapse.

Medication to reduce blood pressure or slow the heart rate can also cause these symptoms.

Doctors need to establish whether your condition has worsened or whether the medication needs altering.

So, if you experience light-headedness, you should tell your cardiologist. If you collapse, faint or lose consciousness you should go to hospital.
Taking Your Medication

Today’s drugs for treating cardiomyopathy allow most patients to lead long and full lives. They can improve heart function, alleviate symptoms and prolong life. They are effective because they are powerful.

Some of the information in this section might seem obvious, but it is important. Many patients have found the following tips very helpful.

1. Making the Most of Your Medication

- Know what it’s for and how and when you should take it
- Take doses exactly as prescribed. Otherwise they might not do the job you need. They might not work and could cause side effects
- Be sure to get repeat prescriptions in time. It’s an obvious point but important
- If your medication does cause unwanted side effects, discuss them with your care team. Sometimes the dose can be adjusted, taken at a different time, or changed for another drug
- Tell your doctor about any other medications you are taking, including over-the-counter items, herbal medicines and so on
- It is also important only to take the medicines you have been prescribed. You could counteract one medicine by taking it with another
- Keep a record of all your medication. Take this record to all your appointments
remembering to take medicine

You would be surprised how easy it is to miss a dose. Many patients do. So...

- Take your medicine or medicines at the same time every day – with meals or other regular activities such as brushing your teeth
- If you can, use pill boxes with separate compartments to help you keep track
- Keep a calendar near your tablets and make a note every time you take your dose. You could put a sticker or reminder note on your medicine cabinet. Or buy a small magnetised white board with dry erase markers and list your pills on the board. Each day, mark the board when you take your medication. At the end of the day, just erase the markings and start again in the morning

3 safety reminders

- Store your medicine as instructed. Keep it away from heat, light and moisture – so not in the bathroom
- Don’t stop taking a prescribed medication if your symptoms go away
- Check with your doctor before you stop taking a medicine
- Let your doctor know about any side effects
- Ask your pharmacist’s advice before crushing or splitting tablets
- Don’t share your medication with anyone else. What’s right for you might not be right for him or her
Many drugs cause side effects. Getting the right balance between relieving symptoms, improving your heart and achieving minimum side effects can be difficult. But, usually, it can be done.

If you have a severe reaction, you should seek medical help immediately. But if you are having less extreme side effects, do not stop taking your medication without talking to your doctor. Most of the time, your doctor will have a better solution.

There might be alternatives that suit you better, or you might be able to reduce the dose to a level that suits you. Sometimes changing the time of day you take the medicine or splitting the dose can improve the side effects. So ask whether this is an option.

The two types of drugs most commonly used for treating cardiomyopathy are betablockers and ACE inhibitors.
**betablockers**

Betablockers (*atenolol, bisoprolol, cardevilol, metoprolol, propranolol*) slow down your heart and help to reduce the force of the heartbeat. Your heart will not work as hard, but it will pump more blood with each beat. Betablockers can also help to prevent fast heart rhythms.

Common side effects of betablockers are fatigue (usually when the drug has just been started or when the dose is increased), cold hands and feet, disturbed sleep, vivid dreams, mood swings, dizziness, erectile dysfunction and diarrhoea. In some cases betablockers may cause dizziness or collapse. If you get any of these, tell your doctor.

He or she might be able to reduce the dose, or switch to a different betablocker that might give fewer side effects.

*It can take a couple of months before you feel the benefit of betablockers. You might feel worse to start with. They should be started at a low dose and gradually increased. This helps to lessen side effects.*

Drinking alcohol with betablockers can lower your blood pressure and cause dizziness.

If you are unable to tolerate a betablocker, you might be given a calcium channel blocker (such as *verapamil* or *diltiazem*). These drugs can also reduce the heart’s workload. They might cause constipation and so sometimes you might need to take laxatives.
ACE inhibitors

ACE inhibitors (such as ramipril and enalapril) open up the blood vessels. This improves the flow of blood to your heart muscle. In the short term they can cause blood pressure to drop a little but, as they start to improve the heart’s pumping power, this lessens.

Very rarely, ACE inhibitors can cause swelling of the tongue and face. If this happens you should seek urgent medical help.

As with betablockers, it is important to start on a low dose which is gradually increased. Your blood pressure and kidney function should be checked with every dose increase.

The most common side effects of ACE inhibitors are a dry, tickly cough and itchy skin. If you experience these, speak to your doctor. You might be switched to a similar group of drugs called ARBs (angiotensin II receptor blockers) that do not cause these side effects.

As with betablockers, drinking alcohol with ACE inhibitors can cause your blood pressure to drop.

diuretics

Fluid build-up in the body that causes breathlessness and ankle and stomach swelling can be treated with diuretics (such as furosemide and bumetanide). They make you pass more urine, which can be inconvenient at times. You can alter
the time of day you take them (if, for instance, you are going somewhere without toilets).

You will get to know how long the medicine takes to work and how long the effects last. You can then adjust the time you take them to suit you.

Spironolactone, a diuretic that works in a slightly different way, can also cause swollen breasts in both women and men. If your breasts become painful, you can be switched to a similar drug.

Some of these medicines, such as ACE inhibitors and diuretics, can affect other organs. To check the effect of them you might need regular blood tests. If you are unsure whether or not you should be having blood tests, check with your GP, consultant or pharmacist. They can tell you what tests are needed and how frequently they should be done.

**amiodarone**

Amiodarone (a drug used to control heart rhythm problems) has a variety of side effects and particularly needs to be closely monitored. When starting this drug, make sure you know what tests need to be done, when they should be done and who is responsible for arranging them.

Other medication might be used to treat specific symptoms of cardiomyopathy.
coping with tiredness and fatigue

Some people with cardiomyopathy get tired easily. This can affect their ability to do everyday tasks and their quality of life. There might be physical or emotional reasons for the fatigue.

1 physical reasons

- If your heart is not pumping well, it affects the blood supply to your muscles. This can make you feel unduly fatigued, especially after exertion

- Medications such as betablockers, blood pressure treatments, tranquillisers and anti-histamines, might cause tiredness. Sleeping tablets can also leave you feeling like you have a hangover

- An underactive thyroid slows down your metabolism, leading to tiredness and putting on weight

- Anaemia, an iron deficiency in the blood, can make you tired because it means less oxygen reaches organs and tissues

- You may have sleep apnoea (a disrupted breathing pattern). There is a separate section in this chapter on sleep on Pages 28-30
### emotional causes

- People with chronic conditions such as cardiomyopathy can get emotional stress. Coming to terms with their diagnoses, living with the disease, and dealing with any changes in their condition can all cause anxiety. So can feeling you have no control over your condition.

  *Some of these stresses can be managed, lessening tiredness*

### what you can do

- Some patients can help ease tiredness by making lifestyle changes *(See Pages 31-38)*

- Schedule important tasks to the times of the day when you feel most energetic

- Don’t be afraid to ask for help to finish tasks and delegate less important jobs

- Discuss how you are feeling with family members and friends. This can help to reduce tiredness caused by emotional stress

- If you remain unduly tired or become increasingly fatigued, talk to your GP, cardiologist or specialist nurse. Then the causes of your tiredness can be investigated, identified and possibly treated.

- Think about your tiredness in detail so that you can provide that detail to your care team. How often are you tired? Do you always feel tired or has the fatigue started recently? Does a specific activity make you more tired?
Most people have sleep problems at some point – and people with cardiomyopathy have many of the causes of insomnia.

Stress, anxiety and depression can all lead to sleep problems.

Waking early and not getting back to sleep is a common sign of depression and you might need antidepressant drugs.

If you have heart failure, severe shortness of breath can wake you up, especially if you are lying flat.

Patients with heart failure or high blood pressure are also more at risk of sleep apnoea, a condition that causes pauses in breathing and poor sleep quality.

Medications can also interfere with sleep. Betablockers, for example, frequently cause poor sleep or vivid dreams.

Your medication might need reviewing. Taking the drug earlier in the day or switching to an alternative might help. So speak to your GP or heart failure nurse.

Having a healthy lifestyle can also aid sleeping.

(See Pages 31-38)
sleep diary

Keeping a diary of your sleeping habits for two weeks can show which activities interfere with or help sleep.

Write down:

- the time you went to bed
- approximate time you went to sleep
- number of times you woke in the night
- time you woke up in the morning
- when you felt tired in the day or had any naps
- meal times, alcohol, exercise, stress

If you go to bed for ten hours and only sleep for six hours, go to bed later but get up at the same time.

If you manage to sleep for most of your time in bed, go to bed 15 minutes earlier to see if you can re-establish a longer night’s sleep.
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• Sleep experts recommend getting up at the same time each day even if you still feel tired

• Some people with cardiomyopathy find daytime naps beneficial. But if you are not sleeping well at night, try to avoid daytime naps

• Take at least 30 minutes of exercise a day, even if it’s a gentle stroll. In the four hours before bed do not exercise. This gives your body time to cool down

• Avoid tea, coffee, energy drinks, alcohol and nicotine. Although alcohol initially makes you feel drowsy, it will wake you up later. Avoid big or spicy meals before bedtime

• If you cannot sleep, get up and read for a short time, then try again

• If you are lying awake worrying, get up and write down your worries. Then try to forget about them until morning. Establish a night-time routine – have a bath and warm milky drink, for instance. Your body will then associate them with tiredness

• Create a good sleeping environment. Try blackout curtains or an eye mask and, if noise is a problem, ear plugs. If you get short of breath when lying down, use several pillows. Keep the bedroom for sleeping and sex – not for work or watching television

• If sleep problems persist see your GP. He or she might refer you to a clinical psychologist for cognitive behavioural therapy. If appropriate, a short-term course of sleeping tablets might be considered
having a healthier lifestyle

A healthy lifestyle will help your heart to work at its best whatever your age. So try to follow these guidelines as much as you can.

alcohol

Patients with cardiomyopathy need to be particularly careful about the amount they drink.

Alcohol depresses the heart’s pumping power and, in people who regularly drink too much, can trigger dilated cardiomyopathy.

Alcohol can also cause abnormal heart rhythms, high blood pressure and damage to the heart muscle.

So reduce your alcohol intake if you can. If you have dilated cardiomyopathy caused by alcohol, you should not drink it at all. If your dilated cardiomyopathy is unrelated to alcohol, complete avoidance is not necessary, but it is best to avoid drinking large amounts regularly.

Alcohol increases the effects of the blood thinning drug warfarin, for example. So it is best not to drink excessively if you take it.

smoking

Give up smoking if you can. Smoking damages your artery linings. It causes a build-up of fatty material and narrowed arteries. This reduces blood supply to the heart muscle and reduces the heart’s pumping power. Your blood is also more likely to clot causing strokes. Nicotine in cigarettes
stimulates the body to produce adrenaline. This makes the heart beat faster and raises blood pressure. So your heart has to work harder. The carbon monoxide in cigarette smoke reduces the amount of oxygen that the blood can carry to the heart and body.

**your weight**

Being overweight means your body has to work harder doing normal day-to-day activities. If you are underweight you might feel weak and be more susceptible to tiredness. Try to maintain an ideal weight.

**healthy eating**

Eating healthily can stop weight gain. Being a healthy weight will cause less strain on your heart and help it work better.

You can eat most foods but do get the right balance, with plenty of fruit and vegetables.

Eating too much salt increases the risk of high blood pressure which is best avoided in cardiomyopathy. So don’t eat more than the recommended amount of salt each day – 6g a day for adults (or 2.5g sodium). Many foods, such as crisps and ready meals, are high in salt. Even sweet foods such as cakes and biscuits have lots of salt. So read food labels.

Those taking diuretics need to take extra care. Patients on potassium-sparing diuretics, such as spironolactone, should avoid a diet rich in potassium as this can be harmful. Potassium rich
Foods include bananas, dried apricots, dark leafy greens and orange juice.

Salt substitutes contain potassium too. Do not use them while taking spironolactone unless you have been told to do so by your doctor.

But, on the other hand, ‘loop-diuretics’, such as furosemide, can cause potassium loss. Your GP will monitor this through blood checks and might prescribe a supplement if your potassium level is low.

**Eating at regular times and not skipping meals can make a big difference to your ability to deal with stress. This will allow your body to release a steady stream of energy throughout the day which will improve your concentration and mood.**
Living with cardiomyopathy

exercise

Take moderate exercise. As well as improving your overall fitness it can help your psychological well-being.

You are never too old or too unfit to start doing something. Being active can help your heart and help manage your weight.

But check with your GP or consultant what is possible and advisable. Ask if there is a cardiac rehabilitation programme that you could join or a special class at the local gym run by physiotherapists or trained health advisors.

Some people with cardiomyopathy feel short of breath while active but others do not. Most are advised not to take part in competitive sports or strenuous activity. Again, check with your GP or consultant.
Exercise warning signs

- Chest pain
- Dizziness
- Severe shortness of breath
- Sudden palpitations
- Lack of recovery in a reasonable time
- Worsening of the pre-existing symptoms with exercise

If you experience any of these when exercising, you should stop and seek medical attention or discuss the matter with your doctor.

exercise in hypertrophic cardiomyopathy (HCM)

If you have hypertrophic cardiomyopathy, intense physical activity involving bursts of exertion (such as sprinting or heavy lifting) is discouraged. Sports that demand fast and sudden exercise are also not suitable.

International guidelines suggest people with hypertrophic cardiomyopathy should not take part in most competitive events, irrespective of symptoms or disease severity.
But sports, such as golf, cycling, modest hiking, lap swimming, doubles tennis and bowling, are often permitted.

Precise advice on non-competitive exercise is difficult because of the legal implications as well as a lack of research. But any person with hypertrophic cardiomyopathy doing physical activity needs to be aware of the warning signs listed on Page 35.

Providing you do not experience any of the warning signs, regular exercise can be enjoyed by most people with hypertrophic cardiomyopathy. But you should listen to your body and adapt exercise to suit you.

**exercise in dilated cardiomyopathy**

In dilated cardiomyopathy, the heart’s ability to pump and relax is reduced, limiting exercise capacity. But if you have only mild to moderate symptoms of heart failure, exercise will help to improve your well-being.

**what exercise should I do?**

Aerobic exercise has the most benefits for your heart. Over time, aerobic exercise can help decrease your heart rate and blood pressure and improve your breathing (since your heart won’t have to work as hard during normal, everyday life). Aerobic exercise includes walking, jogging, skipping, cycling (on a static indoor exercise bike or outdoors), cross-country skiing, skating, rowing, and low-impact aerobics or water aerobics.
To achieve maximum benefits you should gradually work up to an aerobic session lasting 20 to 30 minutes at least three times a week. Exercising every other day will help you keep in a routine. Every session needs to include warm-up, conditioning and cool down.

**what are the main benefits of exercise?**

- Strengthens your heart and cardiovascular system
- Reduces heart disease risk factors, such as high blood pressure and being overweight
- Improves your circulation and helps the body use oxygen better
- Improves your heart failure symptoms and builds energy so that you can do more activities without becoming tired or short of breath
- Improves muscle tone and strength
- Reduces body fat and helps you reach a healthy weight
- Reduces stress, tension, anxiety and depression
exercise in arrhythmogenic right ventricular cardiomyopathy

What exercise people with arrhythmogenic right ventricular cardiomyopathy can do depends very much on the individual and should be discussed with the patient’s doctors.
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 handling your feelings

People diagnosed with cardiomyopathy often feel lost, isolated, guilty and uncertain about their role in the family. But with help and support these feelings can usually be overcome.

Initially, you might be overwhelmed. Perhaps you have not heard of cardiomyopathy before. You might not be able to say it let alone understand it. You may feel alone, frightened and unsure of your next step. When you tell family members and friends, they are probably unfamiliar with the condition too – which adds to your loneliness.

What symptoms will you experience? What treatment will be needed? How will you cope with the treatment and how effective will it be?

You might have to change plans you have made for your life, and regret the change. The loss of control can affect your quality of life and even add to some of your symptoms, including fatigue.

All these issues can be very difficult to handle. But you do not have to cope alone. And there are coping strategies.

Any inherited disease means contacting family members, explaining the diagnosis and telling them that they too might need to be checked (screened). You might worry who else in the family has the disease or will develop it. Guilt is common.

But screening family members could really help them. It is important to remember that early diagnosis can be very beneficial. And knowing the disease is in the family can prompt relatives to seek help quickly if they experience any symptoms.
You might not be able to continue in your current job or you might have to work fewer hours. Your income might be affected. And you might not have the same energy to support children, parents and siblings as you did in the past. These changes in your role in the family can be difficult to handle and affect your self-esteem.

**developing coping strategies**

It’s important that you are not left feeling alone and unsupported. You should be given advice and support to help you come to terms with your diagnosis and help you get on with your life. Many patients now see multi-disciplinary teams who provide a range of good information, answer all questions and fully support patients through this stressful time.

*Cardiomyopathy UK* recognises that you and your family might need extra information and support outside what the hospital can provide through appointments. So the charity has a range of services (see Pages 83–85).
family and friends

Family and friends play a vital role in providing support. This can be demanding for some of them. You might feel people are being over-protective and you might not like it. But when you are trying to achieve some normality, your family and friends might feel excluded. So try to keep talking so everyone can say how they are feeling and resentment does not build up.

Others have been through this before, though. So sharing experiences with others through Cardiomyopathy UK, support groups and social network sites can be helpful.

patient empowerment

There are physical and psychological benefits to those who manage to regain some control of their lives.

For you to get that control, you need to be comfortable with the amount of information and support you are getting.

You need to be able to discuss your worries with your family. You are then likely to find it easier to discuss issues with your care team and help make decisions about your care.

You might want to take steps to help yourself by taking moderate exercise and eating more healthily, for example (see Page 31). It can be very difficult. But those who can do it find they benefit.

And with help, many people manage to take control of their lives – rather than feeling that cardiomyopathy is controlling them.
managing stress

Day-to-day frustrations like traffic jams, noisy neighbours and moving house can all cause stress. Other, longer term issues, such as unhappiness at work, financial worries – or a health issue such as cardiomyopathy – can exacerbate these stresses.

Too much stress, or stress which lasts too long, can lead to emotional, psychological and even physical problems. It can make us less efficient and poor at making decisions, and can lead to more ill health. Stress that continues without relief can lead to symptoms including headaches, upset stomach, elevated blood pressure, chest pain and problems with sleeping.

treating your stress

Talking to someone about your feelings might help you realise what is causing your stress. Speak to your GP. He or she might suggest you try some self-help techniques, such as exercise, or recommend counselling and cognitive behavioural therapy. If stress is making you angry, anger management can help.

Talking things through with a friend or work colleague is also useful. It can help you find solutions to your stress and put problems into perspective. Learning how to find solutions will help you feel more in control, lowering your stress. Talking to others in a similar situation can often be helpful too. Your care team might be able to find others for you to talk to you or put you in touch with a support group.
Cardiomyopathy UK has cardiomyopathy support nurses, support groups, a network of affected volunteers who speak to others, and a message board and Facebook group for people with cardiomyopathy. Speaking to others through these services can provide you with invaluable support, information and an opportunity to share problems and coping strategies. The people you talk to will all have some understanding of what you are going through.

People diagnosed with a life-long condition have an increased risk of suffering from anxiety and depression. It is normal to feel anxious, sad and fearful about the future when you are first diagnosed. But if you have these feelings over many months and they get in the way of your life, it could be a sign that you are suffering from anxiety or depression. See your GP who can recommend a variety of treatments that can help. These include drug treatments and cognitive behavioural therapy.

**relaxing**

If you are anxious or under stress, you will feel tense. Tension increases your muscle tone and the amount of work your body is doing, making you tired.

So try to relax more. There are many different ways to do this. For instance exercise, gardening, yoga, photography, cooking and reading can all distract you from your worries and help you relax. But if these are not successful, relaxation techniques can help.

Talking things through with a friend is useful. It can help you find solutions to your stress.
Try deep breathing. It can calm you down and help you step back from a stressful situation. It might not get rid of the cause of your stress but you might feel more able to deal with it.

**Try to reduce the amount of coffee, tea and cola that you drink.** These all contain caffeine, which can drive up stress levels. Instead have caffeine-free varieties or water. Avoid sugary soft drinks. Alcohol, smoking and comfort eating are all unhealthy coping mechanisms. They will not solve your problems. They will simply give you new ones.
living with a heart device

Most people with cardiomyopathy do not have nor need pacemakers or internal defibrillators (ICD). But those who do, react with different emotions.

Many people find their devices very reassuring. They have peace of mind knowing the devices are always there to help them.

But emotional problems do sometimes arise, particularly for those who have ICDs. These devices, given to people thought to be at risk of a dangerous heart rhythm, can shock the heart back into a normal rhythm.

Some patients easily accept ICDs, thankful they have automatic back-up. Others fear having the devices fitted and worry about them going off and shocking them. For some, depending on small pieces of technology is a continuous psychological struggle.

The more information you have about your device and how to live with it, the more likely you are to come to terms with having one.

If you can, give yourself a bit of time to think about having the device. If doctors want to fit it quickly, make sure you have good support after you leave hospital.

Ask your nurse to put you in touch with others who have ICDs and ask about your nearest ICD support group.

The more information you have about your device and how to live with it the more likely you are to come to terms with having one.
Cardiomyopathy UK can put you in touch with one of its cardiomyopathy support nurses or one of its many volunteers who have ICDs.

Patients with ICDs are sometimes afraid of having a shock while having sex. Discuss these issues with your doctor. An exercise test can often reassure patients that they can safely exercise to the levels needed for sex without the device firing.
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telling your family

If you have been diagnosed with cardiomyopathy, there are many benefits to telling your family and friends you have the condition.

It is not always easy raising the subject of cardiomyopathy because

- You might still be coming to terms with having a heart condition
- Your diagnosis might make family and friends worry about you
- As cardiomyopathy runs in families, you might be worried how the family will receive the news
- Knowing that some children in the family might have inherited the condition can be particularly difficult
- Some of the information can be difficult to explain, particularly if it is new to you

But there are many benefits to telling your family and friends you have cardiomyopathy

- It will help others understand the health problems you have
- Family and friends will understand any limitations you have – for instance with driving, running the home, looking after family members or taking part in social and sports activities
- Family and friends will be able to offer comfort and support if you need them
- You will be able to talk and share your concerns
- Any changes to your condition can be shared and managed
- Some family members might need heart checks (screening)
Living with cardiomyopathy

Talking about family screening

Because cardiomyopathy usually runs in families, other members of your family might need to be checked for the same condition. Telling others they need heart checks can increase your feelings of anxiety and worry family members about their own health. But it is important.

Hospitals cannot contact people who are not their patients. So you have the responsibility for discussing screening with other family members.

Initially, those who should have heart checks are your parents, brothers and sisters, and your children.

Your specialist will advise you which family members need screening

But remember:

- You can only advise adults. The decision about attending heart checks rests with them.
- Checks will help to identify other family members who might be at risk.
- Cardiomyopathy affects people differently even in the same family.
- You can ask your cardiologist or specialist about the best ways of telling family members.
- If your relatives ask questions you have trouble answering, suggest they contact Cardiomyopathy UK. It can help.
• Your clinic and Cardiomyopathy UK can provide information about cardiomyopathy and screening to send to your relatives

• Screening and referral to a cardiologist can be organised through GPs

telling children about your cardiomyopathy

The important thing is to talk to your child or children from the very beginning – whether the issue is your health or theirs.

If you were diagnosed with cardiomyopathy before your children were born, or when they were babies, they will grow up with cardiomyopathy as a normal part of life and not something to fear.

If a child is older when you are diagnosed, he or she will have picked up that something is wrong and notice that you and others are worried about something.

Cardiomyopathy UK has booklets for children which explain the condition in a simple way
don’t worry if you get upset

When you are first diagnosed and perhaps in emotional turmoil you might find it very hard to talk about your cardiomyopathy without getting upset. Even if you choose to have the conversation with your children when you feel your feelings are under control, you might still get upset.

Don’t worry. Your children will have sensed your feelings already. Explaining that you are a little anxious or sad (while reassuring them that you are being monitored, getting medicine and not in danger) will help them to know you are not keeping secrets and so there is no reason to be afraid.

avoid secrets

Secrets make children feel unsafe. They are likely to take the little bits of information they do know and imagine a much worse story, particularly if they feel you are keeping something from them.

If you are able to have a conversation with your children about your health, they will feel more able to ask questions about it as they get older and not see it as a taboo subject. This is really important as children’s understanding of health changes significantly as they get older and if they can ask you questions you will be able to set them straight. For example, a younger child might assume that cardiomyopathy is a punishment or that it is contagious. So it is very important that your children feel able to check these things with you.
questions

If your children ask a question you don’t have an answer to, it’s all right to say you don’t know. Sometimes there isn’t an answer. Sometimes there might be one but you don’t have it. You can always ask your nurse specialist or cardiologist the next time you get the opportunity.

If children ask you whether you are going to die, you can explain that that is very unlikely because you are having regular check-ups and are taking medicine. Reassure them that there is no immediate danger.

Ultimately there isn’t a right or wrong way to talk to your children about your health. You have to do what suits your family style and beliefs. But in general, be open and honest as this helps everyone to adjust and cope.
When you are diagnosed with cardiomyopathy, it also has a big impact on your partner. Often he or she will not get any support to help cope with the situation.

Just as you need to learn to live with the condition, your partner might also have to make changes to his or her lifestyle.

Partners often have many concerns. These include:

**fear of the future**

Although life expectancy is good for the majority of patients with cardiomyopathy, knowing a loved one has the condition can make the future seem uncertain. Not knowing exactly how the disease will progress and, in particular, concerns about sudden death (although this is rare) will often play on a partner’s mind.

Worries can be eased if your partner attends hospital appointments too. Then he or she can learn first hand information about the condition and how you are doing.

**depression and anxiety**

Partners might suffer greater levels of depression and anxiety than you. This can be due to their worries about the future and the increase in demands on them, as carers, for physical and emotional support.

Partners might also decide to suffer in silence because they don’t want to add to your worries. This can intensify their feelings and make them feel very alone.

You and your partner can talk to others in a similar situation through Cardiomyopathy UK’s support groups and volunteers’ network.
a change in your relationship

You might no longer see yourself and your partner as equals, but rather you and your carer. If this is how you feel, try to talk to each other at a normal adult level. It can be easy for a partner to slip into using childlike exchanges but this will lead to a greater feeling of separation between you. Talking to each other and expressing your feelings about the impact of the diagnosis on you both, although very difficult to do, will bring you closer together.

concerns about patient distress

Many patients with cardiomyopathy have very few symptoms (if any), or their symptoms are well controlled with medication. However, where this is not the case, it can be distressing for your partner to see you in pain or struggling to breathe. Once again, talking to other people in the same situation can help.

fatigue

If your partner is taking on more family roles and caring for you, it can make him or her physically very tired and resentful. Emotional stress can make this feeling worse. Tempers can easily fray, and the burden can feel too great. Partners might need to rest when they can and sometimes take time for themselves. And when people offer to help, do accept.

effects on social life

Having cardiomyopathy might restrict what you can do. It may mean that both you and your partner miss out on social activities you previously enjoyed. Your partner might turn down invitations from friends and colleagues as he or she feels a duty to be there for you. This can make you both feel isolated. Although you might not go out as often as before, do not feel you have to turn down every invitation. Going out occasionally and your partner doing something for himself or herself will do everyone good and make you both feel better about the occasions when you really can’t go.

Support for partners is also available from Cardiomyopathy UK.
**sex**

Most people with cardiomyopathy can have a normal sex life. A general rule is that if you can walk 300 yards or climb two flights of stairs without difficulty, then having sex should not be a problem.

But some people who are newly diagnosed with cardiomyopathy and not yet on top of their symptoms might notice a change in their sex drive.

Problems can include lack of libido and erectile dysfunction. Many people with cardiomyopathy never discuss these issues with their doctors. But if they don’t, they can go unresolved and cause relationship problems.

**lack of libido**

Sexual desire is a complex phenomenon involving psychological, physical and other factors. It can wane because of depression, anxiety, worries about whether having sex is safe for the partner with cardiomyopathy, medication side effects, lack of fitness and, if you have an internal defibrillator (ICD) fears that it may fire.

These issues can often be solved. So do talk to your partner and your health team.

For example, drugs can often be changed and couples can be reassured that an ICD is very unlikely to go off during sex and, if it did, it would not affect the partner. Having an exercise test can often reassure you that having sex will be safe.
erectile dysfunction

Erectile dysfunction (ED) can be caused by many things. These include severe heart failure impairing the blood supply needed for an erection, and sometimes medications such as diuretics, betablockers and anti-arrhythmic drugs. Only a small number of people taking betablockers get ED. Changing to another betablocker or, when possible, using a lower dose can help.

People with heart conditions should not take impotence treatments such as Viagra before checking with their doctors. People with hypertrophic cardiomyopathy with obstruction should particularly avoid this type of medication. If you suffer from ED do talk to your care team.

discussing problems with your partner

When sexual problems happen, many couples find it difficult to discuss them.

Many men find it difficult to talk about a sexual problem because they feel embarrassed and distressed. It is particularly so if they suffer from erectile dysfunction. Men often fear that talking about a sexual problem will make things worse. They try to put it out of their minds and hope that everything will soon be fine. But this can lead them to avoiding any intimate contact with their partners. Women sometimes avoid talking about a problem because they don’t want to cause further embarrassment. But the longer the situation is left, the more difficult it becomes.

If you are having problems, acknowledge the situation and decide to work together to find an answer. Couples who discuss their sexual needs and concerns seem to cope better.
1 how to start the discussion

• You need to set aside a time when you will not be disturbed and think carefully about what you are going to say

• Use language that you’re both comfortable with. Avoid using technical terms and use whatever words feel natural to you

• Use ‘I’ or ‘we’ rather than ‘you’. And start with a positive statement. This helps people to listen. People love praise and knowing that they did something well

• Sit close to one another. Don’t worry too much about maintaining eye contact but holding hands or making physical contact in a natural way might help

• Explain your feelings and ask for help in coping with the emotions you might be experiencing. Explain that you are worried

• Encourage your partner to do the same as he or she is just as likely to be as concerned as you are. In this way, you can act as a team to solve the problem, rather than both feeling unable to tackle the issue

• Most of all, don’t panic or allocate blame. No one will talk openly if he or she is being blamed for the sexual problem

2 restarting your relationship

If intimacy has been lost you might feel romance has died. Think about what made your relationship good in the past and what can revive it.

• Increase your day-to-day closeness by holding hands, kissing and hugging when you meet each other. It is about letting your partner know you care and want to be close
Take time to find out what you enjoy. It might take some time to regain confidence. But be patient with yourself and your partner.

- If you used to enjoy a meal or visit to the theatre or cinema, do these again. Being together and not with others is important.
- Look at photos of you both in earlier times so you have a sense of how far you’ve come together.
- If you haven’t had sex for some time, it might be awkward taking those first few steps.
- If you’ve stopped touching one another, especially in an affectionate way, your chances of making love decline. So take things slowly and don’t rush.

**create a better environment for sex**

- Choose a time when you are both rested and free from stress. The best time might be early in the morning after a restful night’s sleep or during the day after a nap.
- Make sure the room temperature is not too hot or too cold.
- Try a position that is the most comfortable and least stressful for you.
- Wait three hours after eating a full meal so it can digest. Eating a heavy meal diverts the blood to the digestive system making more demands on your heart.
- Avoid sex after a hot bath.
family planning

People with cardiomyopathy need to think carefully about family planning. The possibility of passing the condition on to a child will need to be considered as well as the potential risks of pregnancy to a woman with cardiomyopathy.

However for those who have decided pregnancy is not what they currently want, then safe, effective contraception is available.

Women with cardiomyopathy should have their particular pregnancy risk and the risks associated with various contraceptive methods assessed by a cardiologist. Then the safest and most effective contraceptive method for the woman should be recommended.

For further support or information about the contraceptive options available contact Cardiomyopathy UK’s support nurses or see the website www.cardiomyopathy.org.

pregnancy

Many affected women can have their babies safely if they receive high quality specialist care

In the past many women with cardiomyopathy were told it was not safe for them to have babies. But we now know that many affected women can have their babies safely if they receive high quality specialist care.

So seek a pre-pregnancy review by an expert who understands pregnancy and your heart condition. Make sure you know and understand the risks before you try for a baby.
There are specialist centres around the UK who see women with cardiomyopathy before they become pregnant to assess the risks to mother and baby. The centres then provide care, using multi-disciplinary teams, to help prevent or reduce complications.

Some couples affected by inherited heart conditions, such as cardiomyopathy, can get IVF treatment (in-vitro fertilisation) that will ensure their babies are not affected by their disease.

If the affected partner knows the gene mutation causing his or her disease, the couple may be suitable for the treatment called preimplantation genetic diagnosis (PGD). PGD involves checking the genes of the embryos created through IVF.

For more information about specialist centres, talk to your care team or contact Cardiomyopathy UK.
and only implanting unaffected embryos in the womb.

The Human Fertilisation and Embryology Authority has already granted licences for PGD in some types of cardiomyopathy.

For more details contact Cardiomyopathy UK’s helpline 0800 0181 024.
carrying on with life
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Most people diagnosed with cardiomyopathy can continue working. Others have periods of ill health or treatment that prevent them going to work for a while, but resuming your job afterwards can be part of getting back your quality of life.

So don’t make rushed decisions and don’t necessarily do what well-meaning friends, relatives or colleagues say. You have to decide for yourself, informed by what your care team say about your specific circumstances. It might be useful to talk to others who have had similar decisions to make – and Cardiomyopathy UK can help you here.

If you have just been diagnosed, or if you are very unwell, you might feel you will never be able to go back to work. But once you are on the right treatments and the maximum doses, you are likely to feel much better and be able to do much more. As time passes, and you get back into a more normal routine, anxiety about returning to work will reduce.

Many patients go back to the jobs they did before. But continuing health problems mean some cannot. Some change to more suitable jobs – perhaps less physically demanding. Some take early retirement.
Consult your GP or cardiologist about your fitness to work

You might need to consider:

- The type of cardiomyopathy you have and whether your condition is stable
- Your treatment and how long it will take you to recover
- Is your work particularly stressful? For instance, are there demanding deadlines?
- Some jobs, such as being in the armed forces or an airline pilot, are ruled out
- Jobs involving heavy lifting, strenuous activity or operating heavy equipment might be a problem
- Shift work might cause extra stress or tiredness. So can a long commute
- Handling electrical, specialist equipment or magnets might have implications for people with an internal defibrillator (ICD)
- Do you need a driving licence for your job? For more details about driving restrictions, see Pages 79-80
- Are there specific regulations or health checks which could be an issue?

Talk to your GP or cardiologist about your career options and when you can start working again.
• Talk to your employer about your specific circumstances.

• The Equality Act 2010 protects people in England, Wales and Scotland with a disability at work. ‘Disability’ includes a physical impairment that has a substantial and long-term adverse effect on ability to perform normal day-to-day activities.

• Talk openly with your manager. If your employer has an occupational health department or human resources experts, make sure they are involved. You should get a fair and supportive medical assessment and accurate advice.

• Recommendations from occupational health advisors can include reducing driving, changing shift patterns, ensuring time off for medical appointments and changing heavy manual work to something lighter.

• Recommendations like these can enable people with cardiomyopathy to stay in work and help employers benefit from their contributions.

• If you feel you are being discriminated against at work, talk to your manager or human resources representative. Ask about referral to the occupational health department if there is one. A doctor might also be able to advise the employer.

• If you cannot resolve the issue, you might wish to seek legal advice, possibly via your trade union. The Citizens Advice Bureau and Cardiomyopathy UK might also be able to offer advice.
what about applying for jobs?

Companies cannot ask prospective employees about their health before deciding whether to offer work, unless they can prove they’re doing so to check whether the employees can carry out essential tasks (such as heavy lifting for a removals company). They can also ask about health issues to monitor diversity.

They also cannot ask how much time employees have taken off work in their previous jobs. But they can ask relevant questions – such as access requirements – when arranging job interviews.
finances

sick pay

You can get Statutory Sick Pay (SSP) if you are too ill to work. It is paid by your employer for up to 28 weeks. You need to qualify for SSP and must have been off work sick for four or more days in a row (including non-working days). You cannot get less than the statutory amount. You can get more if your company has a sick pay scheme (or ‘occupational scheme’). Check your employment contract.

benefits

Some people with cardiomyopathy can claim benefits because of how the illness affects them. Your local council might have a benefits advice team with up-to-date information on benefits, appeals and entitlements. Any council which charges people for care in their homes is obliged to have a team of people available to offer this support. Cardiomyopathy UK has details on its website and can offer advice.

If you have an informal carer, such as a partner, friend or relative, he or she can apply for a carer’s allowance. An informal carer is someone who is not paid but provides care for someone with substantial needs. The carer must be 16 or over and spend at least 35 hours a week caring for you.
life insurance

Getting life cover for anyone with pre-existing cardiomyopathy is never easy. Failed applications can lead to you being refused cover by another insurer who might have insured you but for the previous rejections.

So getting life cover is a minefield if you do not know where to start. But if you want to try to arrange cover do contact Cardiomyopathy UK who can put you in touch with independent financial advisers who have a track record of getting life insurance for people with cardiomyopathy. They cannot guarantee success for everyone, but by using their knowledge and experience they have had some success.

mortgages

Mortgages are usually available for people with cardiomyopathy. So even if you are unable to get life cover, you can usually still get a mortgage using your home as collateral against the loan.
pensions

The effect of cardiomyopathy on your retirement plans depends on the type of pension scheme you have.

1 defined benefit pensions

A defined benefit pension scheme is one run by your employer that promises to pay you a pension based on your pay and how long you have been in the scheme. If you have to retire because of ill health, you may be able to apply for an ill-health pension, which would start to be paid immediately, even if you have not reached the normal retirement age. Make sure that you tell the scheme doctor about your cardiomyopathy.

2 defined contribution pensions

The other type of pension scheme is called defined contribution. In this you, and possibly your employer, build up a pension fund to provide you with retirement benefits.

You can cash in your fund when you retire. You can take a quarter of the fund free of tax, but the remainder will be taxed as part of your income for the year that you cash it in. For this reason you might save tax if you spread cashing-in your pension fund over a few years.

When you have your pension fund you will have to invest it so that it can support you throughout your retirement. This means putting your money into savings accounts and investment funds that will provide you with an income. You will also need to supplement this income by gradually withdrawing capital.

For more information see Cardiomyopathy UK’s website.
holidays

choosing a holiday destination

Most people with cardiomyopathy can enjoy holidays like everyone else. But some things do need to be considered.

before booking

Before choosing a destination, do think about:

- Will the climate or pollution levels affect you? If you have hypertrophic cardiomyopathy with obstruction, being hotter than you are used to can provoke dizziness and fainting.
- Places high above sea level have reduced oxygen levels and lower atmospheric pressure. This might make some people with cardiomyopathy feel unwell.
- Trekking or climbing might make you feel unwell.
- What medical care will be available if you need it? The Foreign Office can tell you. If the care is poor or you would have difficulty reaching it, is it an appropriate holiday destination?
- If you have a pacemaker or an ICD, check that there is a pacing clinic nearby. If no pacing/ICD clinic exists, it is not advisable to travel there. The websites for the manufacturers of pacemakers and ICDs contain a directory of clinics worldwide that can check their devices. The manufacturers include Medtronic, Boston Scientific and St Jude Medical.
- You are more at risk of diarrhoea and vomiting in countries with poor sanitation and hygiene. These illnesses can cause dehydration and affect your electrolyte balance, neither of which is good for your heart.
- Most people with cardiomyopathy do not have any problems on aeroplanes. However, if you have shortness of breath and fluid retention, require regular or continuous...
oxygen, or have unstable symptoms, discuss with your doctor whether you are fit to fly.

If you have a particular destination in mind but are unsure if it is the right choice for you, ask your cardiologist, GP or nurse specialist.

before travelling

- If you have any concerns, check with your consultant, nurse or GP
- If you are normally breathless at rest, you might need oxygen on the plane. Ask your care team. Oxygen can be provided on aircraft but it must be pre-booked. Discuss this with your airline or travel agent
- Ask your GP if he or she recommends taking an aspirin before flying. Flight socks are also a good idea if your ankles are prone to swelling
- Ensure that you have the correct vaccinations for the country you are visiting. There is no specific guidance restricting people with cardiomyopathy from having travel vaccinations

- If you get tired easily, avoid long, tiring journeys
- If you are travelling to Europe, make sure you get a European Health Insurance Card (EHIC). The card is valid in all European Economic Area (EEA) countries, including Switzerland. It is free (beware unofficial sites that charge for an EHIC). Your EHIC gets you state healthcare at a reduced cost or sometimes for free. It will cover you for treatment that is needed to allow you to continue your stay. It also covers you for treatment of pre-existing medical conditions and for routine maternity care, as long as you are not going abroad to give birth. Go to www.nhs.uk/NHSEngland/Healthcareabroad/ EHIC/Pages/about-the-ehic.aspx
• Regardless of your destination and the extent to which cardiomyopathy affects you, you must have travel insurance as well as an EHIC. You must disclose all the details of your cardiomyopathy and any other health problems you have (see travel insurance on Page 78)

• If you are on prescription medication, ensure you have enough for the trip, including possible delays. Keep medication in your hand luggage with a duplicate pack in your luggage. Keep a list of medicines and the reason you are taking them on a list in your hand luggage. If you are changing time zones, remember to get the timings right for all your medicines

• Take copies of your medical history, including any ECG readings and the most recent letter from your cardiologist to your GP. If you have any problems while you are away the doctors will find this information helpful

• If you have a pacemaker or ICD, carry some form of device ID (which you can get from your ICD/pacemaker clinic)

**on your trip**

• To keep stress to a minimum, it is best to arrive early at the airport and avoid handling heavy luggage

• If your flight is more than two hours, walk in the aisle at regular intervals to reduce the risk of blood clots in the legs. If you cannot get up, move your feet – raising your toes with your heels on the ground – for several minutes every half hour

• Don’t get dehydrated on the aeroplane or in the sun. Drink plenty of fluids and avoid alcohol
• Don’t sit in the sun for too long, especially when the sun is strongest. Use high-factor sun block and apply more at least every two hours. Be extra careful if you take amiodarone – your skin might burn very quickly.

• If you get tired easily, avoid long trips that give you little time to rest.

Apply high-factor sun block at least every two hours

Internal defibrillators (ICDs) and pacemakers

The metal in internal defibrillators (ICDs) and pacemakers occasionally triggers alarms in some airport security systems. If you walk straight through the frame without lingering, there should be no effect on your pacemaker.

If you have concerns about going through airport security, discuss this with your clinic before you travel. It is always best to carry your data card and explain you have a pacemaker fitted. If you show your card, you can usually bypass the system.

If you have a manual search, staff might use a handheld scanner. The scanner might come close to your pacemaker but this rarely causes problems.
**travel insurance**

Most people with cardiomyopathy can get travel insurance, although it can be expensive for America, Canada and the Caribbean.

It can prove more difficult to get insurance if you are waiting for tests or for a medical procedure. *Cardiomyopathy UK* can put you in touch with companies that can help, but shop around too. Always beware of on-going medical warranty. This phrase allows an insurer to amend the policy terms and conditions if your health status changes.

For instance, if you take out a policy in March for an August trip and in June you have to see a doctor about a change in your health, then you must tell your insurer. You might have to pay more or have the terms of the policy altered.

Your partner needs to beware of the “free” insurance provided with his or her credit or debit card. This policy might not cover what your partner wants to do if you are ill. If you have to travel home early, your partner might not be covered to do so. If you have a hospital stay which prolongs your time abroad, your partner might not be covered to stay on with you.

**Make sure your insurer is fully prepared to offer full, unqualified cover for your medical condition.**
Most people with cardiomyopathy can drive private cars and motor cycles (Group 1 entitlement), but some are not allowed to drive vehicles such as lorries and buses (Group 2).

If you are diagnosed with hypertrophic or dilated cardiomyopathy (and no other disqualifying condition) you are allowed to drive a car or motorcycle, but are disqualified from driving Group 2 vehicles if you have any symptoms.

If you are diagnosed with arrhythmogenic right ventricular cardiomyopathy (ARVC), you can drive Group 1 vehicles if you have no symptoms. But all driving must stop if an arrhythmia (heart rhythm problem) has caused, or is likely to cause, incapacity. You can only get your Group 1 licence back when the arrhythmia is controlled and there is no other disqualifying condition. Driving of Group 2 vehicles might be permitted if you have no symptoms and following a specialist
electrophysiology assessment, provided there is no other disqualifying condition.

Other conditions that can affect your eligibility to drive include angina, arrhythmias and having a pacemaker or internal defibrillator (ICD).

A person fitted with an ICD because he or she has had a collapse is not allowed to drive for six months after the device is fitted. A person given an ICD because he or she is at risk of a dangerous rhythm is not allowed to drive for one month. If the ICD gives an appropriate shock or a particular type of pacing, driving is not allowed for the next six months.

*For full details and the latest information go to www.gov.uk*
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**getting good information**

When you are first diagnosed with cardiomyopathy, you might be given lots of information by your cardiologist, nurse or GP but remember little of it.

When you get home you might realise you know very little about the disease, its treatments and implications.

In the search for more information, some people go immediately to the internet. An enormous amount of health information is available online. But it is not all accurate, up-to-date or reliable information.

Some of the data online does not take into account today’s improved treatments. A lot of the information relates to older people with coronary artery disease – so it gives a misleading picture.

Ask your nurse where to get accurate and reliable information. Some hospitals have their own information or give out information from charities such as the British Heart Foundation and Cardiomyopathy UK.

In partnership with the British Heart Foundation, Cardiomyopathy UK produces free booklets on each of the main types of cardiomyopathy – dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy.

Cardiomyopathy UK also produces CD-ROMs on dilated and hypertrophic cardiomyopathy.
For parents of affected children, there is a booklet on cardiomyopathy in children and young people, and a children’s guide to cardiomyopathy (for children aged up to about eight). All these booklets are available free from Cardiomyopathy UK.

The charity’s website (www.cardiomyopathy.org) has articles on restrictive cardiomyopathy, left ventricular non-compaction cardiomyopathy and tako-tsubo cardiomyopathy (or broken heart syndrome). The website has information about treatments, latest research and patient stories.

**getting support**

If you call Cardiomyopathy UK’s helpline (0800 0181 024) you can speak to one of its cardiomyopathy support nurses

Cardiomyopathy UK has cardiomyopathy support nurses, support groups and a network of affected volunteers who provide support to others by telephone and email.

The British Heart Foundation has support groups for heart patients all over the UK.

Many hospitals have support groups for those with ICDs and pacemakers
how Cardiomyopathy UK can help you

If you have a question, want to discuss your diagnosis and situation, or need some support you can:

- Contact our helpline on 0800 0181 024 (free from a UK landline). We can put you in touch with a cardiomyopathy support nurse. Our helpline is open on weekdays from 8.30am to 4.30pm. Out of hours you can leave a message and we will call you back the next working day. You can email our cardiomyopathy support nurses at supportnurse@cardiomyopathy.org
- Attend one of the regular cardiomyopathy information days we hold around the UK each year
- Go to one of our support groups

- You can speak to volunteers on our network of affected people who provide one-to-one support to others by telephone and by email. They can help you to understand the condition better and get on with your life
- You can contact others with cardiomyopathy through our message board and facebook page and group
- You can join Cardiomyopathy UK and get our magazine My Life which contains information on developments in care, latest research, patient stories and details about our activities
Can I take over-the-counter cold remedies?
Generally people with cardiomyopathy can take these drugs, but always check with the pharmacist. If you take warfarin, be careful to check the cold remedy does not include aspirin. Aspirin can increase the action of warfarin.

Is it safe for me to have a flu jab?
Yes, it is safe for people with cardiomyopathy to have the flu jab.

Can people with cardiomyopathy get free prescriptions?
Free prescriptions are not available to people in England because they have cardiomyopathy. Prepayment certificates can reduce the cost. For further details see www.nhs.uk/NHSEngland/Healthcosts/Pages/Prescriptioncosts.aspx

Is it safe to go on theme park rides if you have an internal defibrillator (ICD)?
In some circumstances, this might not be advisable. Always discuss activities like this with your doctor.

How important is it for people with cardiomyopathy to keep their weight in check?
Being overweight will increase the likelihood of symptoms.

Is it safe for people with cardiomyopathy to use jacuzzis, saunas and steam rooms?
In general yes. But you need to be careful if you have low blood pressure, are taking drugs that open up blood vessels (vasodilators) or have hypertrophic cardiomyopathy with obstruction. When in doubt, ask your doctor.

What happens if I need a general anaesthetic?
Most people with cardiomyopathy can tolerate a general anaesthetic. But special precautions might be necessary for people with poor heart function or uncontrolled heart rhythm problems. In some cases, essential operations should be supervised by an anaesthetist with a particular interest in heart conditions.
What should I do about taking my heart tablets if I get diarrhoea and sickness?

In general it is wise to continue most prescribed medications when you have diarrhoea and vomiting. An exception can be diuretics (water tablets) as these can increase dehydration caused by diarrhoea and vomiting. If diarrhoea and vomiting persists for more than 48 hours, seek medical advice.

Am I entitled to a Blue Badge?

Blue Badges allow people with disabilities to park in areas restricted to other motorists, and to park free in some car parks. Traditionally people with severe cardiomyopathy have been eligible for Blue Badges. These are provided by local councils. Ask you cardiologist if you might qualify.

What should I do if I am unhappy with my care?

First talk to a member of the team taking care of you. If the problem involves a particular individual, you might want to talk to another member of the team. Perhaps someone close to you could talk to the team on your behalf. You can also talk to your local Patient Advice and Liaison Service. They can advise you about what to do and how to make a complaint if you want to. Hospitals have complaints procedures. Information about how to comment on your care should be prominently displayed in outpatient clinics and in wards. You can also talk to your GP about your experience and discuss what to do.

If you have any other questions related to cardiomyopathy, call Cardiomyopathy UK’s helpline on 0800 0181 024 or email supportnurse@cardiomyopathy.org
How Cardiomyopathy UK has helped us to live with cardiomyopathy

“I was so much more relaxed about my diagnosis after I found Cardiomyopathy UK and spoke to its support nurses and other people with cardiomyopathy.”  Mick

“Thanks to a lot of support from my hospital, family, friends and Cardiomyopathy UK, I am able to get on with my life.”  Jenny, diagnosed with cardiomyopathy at six weeks old

“I was in a shock wondering how I was going to tell my family about my diagnosis when a medical student handed me a slip of paper with a website address. This was my introduction to the wonderful support machine called Cardiomyopathy UK.”  Lynn

“We received amazing support from Cardiomyopathy UK’s support nurses and volunteers. And it’s been a privilege to hear some of the world’s experts in cardiomyopathy speak at the information days.”  Kate, whose husband Simon is affected
How you can help others affected by cardiomyopathy

If you would like to help others with cardiomyopathy, do consider supporting Cardiomyopathy UK.

As well as providing information and support to affected families, the charity:

- raises awareness of cardiomyopathy among the general public and medical professions
- helps to educate doctors and nurses about the disease to improve patient care and save lives
- campaigns for improved services for affected families
- sits on medical groups including NICE (National Institute for Health and Care Excellence) and the new Clinical Reference Groups to help improve care

There are many ways you can help:

- Making donations
- Fundraising
- Volunteering
- Raising awareness
- Helping with campaigns

We rely entirely on donations to fund our work supporting people affected by cardiomyopathy. For details about supporting us, go to our website.

If you can help in any way, please call the charity on 01494 791224 or email info@cardiomyopathy.org
Get in touch

Cardiomyopathy helpline
0800 0181 024 (free from a landline)

Visit our website at
www.cardiomyopathy.org

Email us at
info@cardiomyopathy.org

facebook.com/cardioympathyuk
@cardiomyopathy

Cardiomyopathy UK
the heart muscle charity

Cardiomyopathy UK is the operating name of The Cardiomyopathy Association, a registered charity no. 803262. Registered Office: Unit 10 Chiltern Court, Asheridge Road, Chesham, Bucks HP5 2PX