

Cardiomyopathy for parents and carers

An introduction to cardiomyopathy in children



Cardiomyopathy^{UK}
the heart muscle charity

Acknowledgements

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“You are not alone”

Cardiomyopathy affects people of all ages, from the very young to older adults. Everyone’s experience varies, and depends on the type of cardiomyopathy they have. With the right treatment and support, most people manage their condition and lead normal lives.

This booklet is about cardiomyopathy in children and young people. It covers different types of cardiomyopathy and why they happen, the symptoms and treatments, and the impact of the condition. It covers topics that young people, parents and carers told us they would have liked to know about when they or their child was diagnosed. We also share the experiences of families who have a child with the condition.

You may have picked up this booklet because you have a child with cardiomyopathy, or you know someone who does. Or perhaps you have been told that your child may have the condition, and you are waiting for tests to see if they do.

If your child has been recently diagnosed, you may have many different feelings. You may want lots of information to help you understand their condition, or you may be feeling in shock or overwhelmed, and not want to know anything right now. You may be worried about what you might read, or have heard something that has caused you concern. All of these feelings are natural. Don’t feel that you have to read this booklet straight away – you can pick it up as and when you want to.

“At first it’s really difficult to get your head around, but life does get back to some sort of normality.”

However you are feeling, whether you are new to the condition or your child has been diagnosed for a while, you are not alone. We are here to support you each step of the way. For more about the many ways in which we can support you, see page 42.

What is cardiomyopathy?

Cardiomyopathy is a disease of the heart muscle. ('Cardio' means heart, 'myo' means muscle and 'pathy' means disease.)

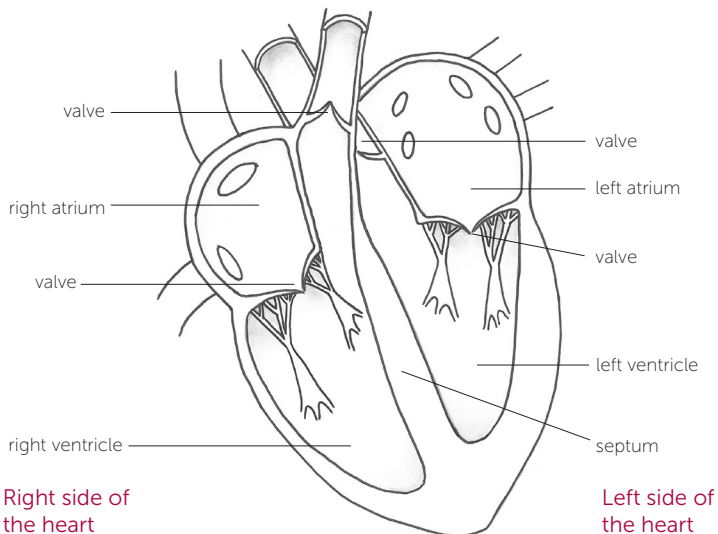
It isn't a single condition but a group of conditions with different causes, that each affects the heart muscle. It can affect the shape of the heart, the size and thickness of the muscle walls, and how messages are sent through the heart. This affects how the heart works, reducing its ability to pump blood around the body. How the heart is affected depends on the type of cardiomyopathy the person has.

To understand cardiomyopathy and how it affects the heart, it is helpful to know a little about the heart and how it works.

The heart: its structure and how it works

The heart is the centre of our circulatory system. It pumps blood around the body, carrying oxygen and energy sources to all cells and organs of the body to 'power' them so that they can work effectively.

The heart is a powerful muscular pump. It has four chambers: two on the right side and two on the left side. These pairs of chambers are separated by a wall called the septum.



- The two **atria** (top chambers) collect blood coming into the heart. The right receives blood coming from the body, and the left receives blood from the lungs. The walls of the atria are thin and elastic.
- The two **ventricles** (bottom chambers) receive blood from the atria above. They pump the blood out of the heart: the right side pumps blood to the lungs, and the left side pumps blood to the body. The walls of the ventricles are thick and strong and can force the blood out of the heart as they contract. The left ventricle has the thickest wall, as it has to pump blood all around the body. It is the ventricles of the heart that are often affected by cardiomyopathy.
- The heart also has four sets of **valves**, which help to ensure that blood flows in the right direction through the heart and that it doesn't leak or flow backwards.

The heart pumps blood around the body by relaxing and contracting the muscle walls of the chambers. For the heart to pump, it relies on electrical messages to be created and relayed around the heart, in a regular, rhythmical and ordered way. This ensures that the different chambers of the heart contract and relax in order, which makes blood flow in the right direction: from the heart to the lungs to pick up oxygen, and back to the heart to be pumped to the rest of the body.

When a condition such as cardiomyopathy affects how well the heart works to pump blood around the body, this affects how much blood is delivered to the cells and organs. And it also affects how 'waste' products such as carbon dioxide and fluid are removed from the body. This can cause a number of symptoms such as tiredness, shortness of breath, a build up of fluid on the lungs or around the ankles, and heart rhythm disturbances. (See page 13 for more about symptoms).

♥ *For more information see our factsheet 'About the heart'.*

Types of cardiomyopathy

The different types of cardiomyopathy are described by how they affect the heart muscle.

Dilated cardiomyopathy (DCM) – the muscle of the left ventricle becomes enlarged (dilated) and stretched. The muscle becomes bigger, thinner and weaker and less able to pump blood out of the heart.

Hypertrophic cardiomyopathy (HCM) – the muscle of the ventricle thickens (called ‘hypertrophy’), making the ventricle smaller. The thickening of the muscle is not related to any increased workload on the heart, but due to changes caused by the cardiomyopathy. If the thickening is in the septum (see page 5), it can affect the flow of blood out of the heart (called hypertrophic obstructive cardiomyopathy or ‘HOCM’).

Arrhythmic right ventricular cardiomyopathy (ARVC, also known as arrhythmic cardiomyopathy) – the heart muscle cells do not join together properly, and so they die and get replaced by scar tissue or fat. This makes the heart muscle stretched, thinner and weaker, making it less able to pump blood out of the heart.

Restrictive cardiomyopathy (RCM) – the heart muscle becomes stiff and cannot relax properly, which makes it harder for the top chambers to fill with blood. The chambers then become enlarged and blood cannot flow properly.

Left ventricular non-compaction (LVNC) – the heart muscle doesn’t develop normally in an unborn baby. The muscle cells do not compact (tightly pack) together as normal, which causes small indentations in the muscle and it appears spongy. This affects how the heart works.

Takotsubo or ‘broken heart’ syndrome – this rare cardiomyopathy usually happens during a time of extreme stress (which gives it the name ‘broken heart’). The left ventricle becomes enlarged and weakened. It is often only temporary and gets better with time.

Although different types of cardiomyopathy affect the heart in different ways, the symptoms can be similar (see page 13).



"He is gorgeous, quirky and happy, and loves to perform on stage."

Marty's story, by mum Sarah

In 2010 a series of pregnancy scans revealed that our unborn baby had Cardiomyopathy. We were thrown into a world of fear and the unknown.

Initially all I could do was to cry, and sit and Google everything until I felt I could do neither any longer. The information I needed had to come from a trustworthy source. I nervously rang the Cardiomyopathy UK helpline and spoke in depth with one of their support nurses. She quickly became my lifeline. It was true that she couldn't predict what was going to happen or make all the sadness go away (as I was so desperately wishing) but she listened, she cared and she gave me understanding, information and support that was vital in those early days.

Despite a very poor prognosis for Marty's survival, he was born at 39 weeks weighing 8lbs 1oz. He was taken straight to the special care baby unit and for tests. We expected to see him connected up to machines and struggling, but he didn't even need a special crib. The hospital were so happy with his condition at birth that we were able to take him home.

Our world came crashing down once again when Marty was 11 weeks old. A scan showed that he had significant hypertrophic cardiomyopathy with non-compaction. He also had a hole in his heart and some valve issues. We had a telephone call from a nurse specialist at Great Ormond Street Children's Hospital, who asked us to take Marty down to London.

The world-renowned hospital is a daunting and frightening place for parents to enter. I stood outside and couldn't go in. I just thought this was something that you saw on the TV - it couldn't be happening to us. Of course we did go in and we were met with kindness, and the medical expertise we needed which was world-class. We still go for regular visits and check-ups, and Marty now takes them all in his stride quite happily.

Marty is a fabulous six year old now and leading a near normal life under ours and the hospital's watchful eye. He understands he has cardiomyopathy and has been involved in fundraising and awareness campaigns. We have come a very long way from our initial heart-breaking diagnosis and Marty is now described as having a mild uncategorised cardiomyopathy with non-compaction and some valve issues. The previous significant hypertrophy and a hole in his heart have now subsided as he has grown.

Who gets cardiomyopathy?

Cardiomyopathy can affect anyone, at any age. It is thought to affect around 160,000 people in the UK, which is around 1 in 500 people. Although many people are born with cardiomyopathy, the symptoms may not develop until adulthood, and some people can have the condition and never develop symptoms.

Why has *my child* got cardiomyopathy?

There are many different causes of cardiomyopathy, and it may not always be possible to say why someone has developed it.

Cardiomyopathy is often a genetic condition. This means that it is caused by a **mutation** (a change) in the person's **DNA** which affects how the heart develops and how it works. Some mutations happen spontaneously as a baby is developing in the womb, and some are passed on (inherited) from parent to child. As cardiomyopathy can be inherited, in some families several members will have the condition. For this reason, if someone's cardiomyopathy is thought to be genetic, it is recommended that their close family members such as parents, siblings and children (known as first-degree relatives) are tested for the condition too.

Other causes of cardiomyopathy include:

- viral infections which affect the heart;
- autoimmune diseases (which affect the immune system); and
- some medications (including those used to treat cancer) or toxins (such as alcohol or drug use).

Doctors will ask questions about the person's own and their family's medical history, as well as doing several tests, to try and work out why someone has cardiomyopathy. (For more about diagnosis see page 11.)

How is cardiomyopathy diagnosed?

Some people may go to their GP because they are experiencing symptoms that they are worried about. They may have been taken to hospital because they have unexplained symptoms such as chest pain or passing out. Perhaps someone in their family has a heart condition and they are concerned that they may have it too.

If it is suspected that your child may have cardiomyopathy, you will usually be referred to a specialist: a **paediatrician** or **paediatric cardiologist**. The specialist will ask questions about symptoms, look at their medical and family history, and ask for several tests to be done, to see if they have cardiomyopathy.

What the specialist will ask about

Symptoms – the specialist will ask about any symptoms your child has, such as shortness of breath, feeling dizzy or passing out, or chest pain. They will ask about when the symptoms happen, and whether anything makes symptoms worse (such as exercise). They might also do a physical examination (such as listening to the chest and heart).

Medical history – the specialist will ask about any conditions or illnesses that your child has had that could cause cardiomyopathy (or could explain any other cause of the symptoms).

Family history – the specialist will ask whether there is a history of cardiomyopathy in your family (as cardiomyopathy can run in families).

Usual tests for cardiomyopathy

ECG (electrocardiogram) – this looks at the electrical activity of the heart and whether **arrhythmias** (abnormal heart rhythms) are happening. An ECG might be done during exercise (if exercise usually brings on the symptoms), or a portable ‘holter monitor’ might record the heart rhythm over a couple of days.

Echo (echocardiogram) – this is a type of ultrasound scan, which uses sound waves to create echoes when they hit different parts of the body. These echoes are translated into 2- and 3- dimensional images. This test looks at the structure of the heart, and are used to see if the heart is enlarged or if there is any thickening of the heart muscle. The images are moving, so can also look at how the heart is working. A Doppler echo looks at the speed and flow of blood through the heart, which also helps to check how the heart is working.



An echo image of the heart.

An MRI machine.



MRI (magnetic resonance imaging) scan – this is a type of scan which gives high quality images and is used to look at the structure of the heart and how blood flows through it. It can also be used to measure any areas of thickened muscle.

There may be other tests that are suggested (depending on the results of the tests above), and will be used to help diagnose the cardiomyopathy or look for other causes of the symptoms.

“Any question is not a silly question, but something that you are not sure of and you mustn’t be afraid to ask.”

What are the symptoms of cardiomyopathy?

The role of the heart is to pump blood around the body, carrying oxygen and nutrients to 'power' the cells and organs. Cardiomyopathy affects how effectively the heart works, and so when the heart isn't working as efficiently as it should, cells and organs don't get enough oxygen and nutrients. Symptoms of cardiomyopathy can be caused by:

- disruption in the electrical signalling in the heart;
- reduced or disrupted flow of blood around the heart;
- poor supply of oxygen and nutrients to the body; and
- poor removal of waste products from the body.

There are many symptoms of cardiomyopathy. Not everyone will have symptoms, but some will have symptoms (depending on how well their heart is working). Symptoms can include the following.

- Tiredness – due to reduced circulation and oxygen levels in the blood, which means that the cells and organs aren't receiving enough oxygen and nutrients to 'power' the body.
- Breathlessness – due to a build up of fluid (called **oedema**) in the lungs which makes it harder to breathe.
- Swelling in the abdomen and ankles – due to a build up of fluid.
- Palpitations (feeling your heart beating too fast, too hard or like it is 'fluttering') – caused by abnormal heart rhythms ('arrhythmias') where the heart is beating too fast or erratically. This can be caused by a problem with the electrical messages which control the heart's normal beating rhythm, causing the messages to be disrupted.
- Chest pain or a feeling of 'tightness' in the chest – although the cause is not always clear, it may be due to reduced blood flow out of the heart. It may happen when the heart is under increased pressure (such as during exercise), as the heart needs to work harder to supply the body with oxygen.
- Dizziness or fainting – caused by reduced oxygen levels or blood flow to the brain. This can cause light-headedness or dizziness and, in some cases, loss of consciousness or fainting.

Cardiomyopathy and heart failure

Heart failure is when the heart is not working effectively and it ‘fails’ to pump enough blood, at the right pressure, to meet the body’s needs. (It doesn’t mean that the heart is not working at all, just that it is not working *well enough*.) It describes a collection of symptoms caused by a heart that is struggling to work effectively. These symptoms include weight gain (due to fluid retention), a cough, shortness of breath, oedema, palpitations, dizziness and tiredness.

Heart failure is not always caused by cardiomyopathy (there are other causes) and not everyone with cardiomyopathy has heart failure.

How severe someone’s heart failure is may be measured by the New York Heart Association (NYHA) classification system, which measures how much the symptoms limit the person’s activity. You might come across these terms if your child has heart failure.

- Class I (unaffected): activities are unlimited, and ordinary activity doesn’t cause symptoms.
- Class II (mildly affected): activity is limited a little. Activities such as walking up several flights of stairs causes some symptoms such as tiredness, palpitations and breathlessness.
- Class III (moderately affected): activity is more limited than class II. Symptoms happen at activities such as walking on a flat surface.
- Class IV (severely affected): activity is very limited. Symptoms happen with all activity, and the person is breathless even when resting.

Treatments for heart failure support the heart to work better, such as:

- a healthy diet and reduced salt intake to help keep a healthy weight;
- exercise to help with overall fitness and help the heart to function (see page 25 for more about exercise);
- limiting alcohol and caffeine, and not smoking; and
- medication such as ACE inhibitors, beta-blockers and diuretics (see page 19 on treatment).

Other treatments depend on the cause of heart failure. For example, if there is a problem with a valve in the heart it might need to be repaired or replaced.

Are there any complications of cardiomyopathy?

Sometimes, because the heart is working less well than normal, there can be complications that develop from cardiomyopathy. Part of treating cardiomyopathy is to reduce the chance of complications, but there are also ways to treat any complications that happen.

Arrhythmias

Arrhythmias are abnormal heart rhythms that cause the heart to beat too fast, too slow or in an erratic way. Some arrhythmias are temporary and don't cause lasting problems. However, some are more dangerous and need to be treated urgently (as they can cause blood clots or a cardiac arrest). They can be treated with medication (anti-arrhythmic drugs) or devices that control the heart rhythm such as **pacemakers** or **ICDs** (see page 20).

Blood clots

Blood clots can form in the heart when blood doesn't circulate well. For example, in the arrhythmia called 'atrial fibrillation' the heart muscle doesn't contract properly, making blood flow around the atria turbulent which can cause blood clots to form. Blood clots travelling in the blood stream can cause strokes, so medications may be used to help the heart to contract in a normal rhythm (anti-arrhythmic drugs), and to thin the blood to reduce the risk of clots forming (anticoagulants).

Cardiac arrest

A **cardiac arrest** is when the heart suddenly stops pumping blood around the body. This can happen due to dangerous arrhythmias such as ventricular fibrillation (which makes the ventricles 'quiver' rather than contracting normally, and so blood doesn't flow out of the heart effectively). A cardiac arrest will cause the person to collapse and stop breathing, unless a defibrillator is used to shock the heart back into a normal rhythm. This is sometimes referred to as sudden cardiac death. People who are at risk of cardiac arrest may have an ICD (implanted defibrillator) which monitors the heart for any dangerous arrhythmias and shocks the heart if one is detected.



Rosie is recovering from her heart transplant.

Rosie's story, by mum Sara

Rosie was born on 28 November 2012. She was a perfectly healthy little girl for the first year and a half of her life, had a huge appetite and was full of energy.

A few months before her second birthday she started to suffer from repeated illnesses, totally went off her food and struggled to muster any energy to play with her brother and sister. She was eventually admitted to hospital for numerous tests. In July 2015 she was transferred to see a cardio specialist and that was the point at which our whole family's world was turned upside down.

Rosie was diagnosed with restrictive cardiomyopathy. We were told that the result of this condition is that the heart will eventually be too weak to function and will fail. She was given medication to assist her heart in pumping blood around her body and allowed to go home. Less than a week before Christmas Rosie had a cardiac arrest. I gave her CPR until paramedics and air ambulance teams arrived.

Following this, Rosie was put on the urgent heart transplant list.

At the start of 2016 Rosie was not growing in size or strength due to her heart not working hard enough. The decision was made to fit a Berlin Heart* as her own heart was just too weak. She stayed in intensive care for the next five months. Problems with blood clots and bleeds meant that Rosie was fitted with another mechanical heart called Levitronix. She stayed on this for over three months before going back on to a Berlin Heart.

After months of waiting, we received a call to say that a donor heart had been found for Rosie. Rosie's surgeon said it was "the perfect transplant surgery" with everything going according to plan. Rosie left the hospital at the end of September 2016. She is having rehabilitation because of strokes she had whilst waiting for a donor heart.

*A Berlin Heart is a device that supports the heart to pump blood.

How is cardiomyopathy treated?

Treatment for cardiomyopathy aims to reduce and manage any symptoms and reduce the chance of any complications (see page 15). Treatment depends on the type of cardiomyopathy someone has and, importantly, what symptoms they have. Someone with no symptoms, may not have any treatment. But people who are having symptoms, will have treatment tailored to them.



Your child might be offered one or more of the following, depending on their symptoms.

Medication

- **ACE inhibitors** (angiotensin-converting enzyme inhibitor) reduce the demand on the heart and make it easier for the heart to pump.
- **Angiotensin II receptor blockers** (ARBs) reduce the demand on the heart and make it easier for the heart to pump. They may be used instead of ACE inhibitors.
- **Anti-arrhythmic medication** control the heart's rhythm and correct arrhythmias (abnormal heart rhythms).
- **Anticoagulants** ('blood thinners') prevent blood clots forming, and are used for people with atrial fibrillation (an abnormal heart rhythm which causes uneven blood flow through the heart).
- **Beta-blockers** reduce the workload on the heart, and can help with chest pain, breathlessness and palpitations.
- **Calcium channel blockers** reduce the force of the heart's contraction. Some lower blood pressure by reducing the stiffness of the arteries, and others reduce chest pain and arrhythmias.
- **Diuretics** ('water tablets') reduce fluid build-up (oedema) by getting rid of water as urine. They also lower blood pressure.

Devices and surgery

- **Pacemakers** control the heart's rhythm by constant electrical stimulation of the heart. This ensures that the heart is beating normally (called 'sinus rhythm'). Some pacemakers, called biventricular pacemakers, used in cardiac resynchronisation therapy, send electrical signals to both sides of the heart to help both sides to beat together.
- **ICDs** (implantable cardioverter defibrillators) monitor the heart's rhythm and, if a dangerous arrhythmia occurs, shock the heart back into a normal rhythm. Some ICDs are also pacemakers.
- **Left ventricular assist device** (or LVAD) are artificial pumps which assist the heart to pump blood. LVADs are only used for people who have very severe heart function problems, while they are waiting for a heart transplant.
- **Surgery** might be used for people with hypertrophic cardiomyopathy where the thickened heart muscle obstructs blood flow out of the heart. This obstruction may be surgically reduced either by injecting medical alcohol into the area of thickening to chemically reduce it (called alcohol septal ablation) or using surgery to cut away some of the thickening (called surgical myectomy).
- In a small number of cases, a **heart transplant** might be needed. This would be if the heart is functioning so poorly that it cannot support the body's needs. They are more likely in children with restrictive cardiomyopathy than in other types of cardiomyopathy. However, heart transplants are rare, and most children will not need one.

Who looks after my child's condition?

Most children with cardiomyopathy are under the care of a specialist: a paediatrician, paediatric cardiologist, or a cardiologist (depending on their age). This might be at your local hospital or at a specialist hospital. The hospital may also have nurses that help support your child (such as heart failure nurses). The specialist will usually diagnose cardiomyopathy and start any treatment. They will usually see your child every six months or so, depending on how your child is doing.

Your child's GP will usually be responsible for 'day-to-day' care in between hospital visits, and will provide repeat prescriptions and support for their condition.

Depending on how cardiomyopathy affects your child, they may or may not need the additional support listed here.

Children's community nurses provide support to parents and children who have health needs. Their support might be with medical needs and equipment, or with development or care needs. The nurses might provide support at home, or at nursery or school.

Health visitors work with families with pre-school age children to support them at home with any health or development needs, depending on the individual's circumstances.

Dieticians (a health professional with expertise in diet and nutrition) can help with developing an eating plan for anyone who may need dietary changes to help manage their condition.

Social services and social workers provide help with additional support needs. For example, a 'needs assessment' looks at what support or services might be needed to support a child with any limitations caused by their medical condition. This is usually done by the 'children with disabilities team' from your local social services, and involves them visiting you at home. You can contact your local social services directly, or ask your GP, paediatrician or nurse to ask for an assessment on your behalf.

Psychological services offer support help with managing the psychological impact of being diagnosed and living with a long-term condition. This might include seeing a psychologist or counsellor. You can talk to your GP, paediatrician or nurse to ask about being referred to a service, or you can look for a service yourself privately. Some schools might be able to help with psychological support through an educational psychologist. You can talk to your child's school about this.

Palliative care is sometimes offered to people with long-term conditions, and focuses on supporting both medical needs (such as your treatment options) and psychological or emotional needs and choices to support quality of life. (Although 'palliative care' is often used to describe care offered to people who are terminally ill, it is not only available to those with a terminal condition.) You can talk to your GP or specialist about palliative care.

How can I help to keep my child well?

Cardiomyopathy is a variable condition, and children with the same condition can each have different experiences. Some have severe symptoms and some have none, and the way in which a child reacts to their condition will vary. And things can change over time as well.

“Take each day at a time.”

Understanding about the type of cardiomyopathy your child has, and their symptoms, can help you to understand what treatment and support they might need now, and in the future. Importantly, it also helps to work out what adjustments they might need and how they can be best supported so that they can carry on with normal activities (which can really help when they want to fit in with their peers).

Coming to terms with a diagnosis, and learning how to live with cardiomyopathy, can be difficult, and can take time. Sometimes you have to find out how to adjust to this new life, and how to balance ‘normality’ with things such as doctors appointments and managing symptoms. While it can be helpful to focus on ‘getting on with life’ sometimes this means making some adjustments. There are no rules about how to do this, as every child, and every family, is different.

*“You just want to wrap her up and protect her.
However, she needs to live a life.”*

Below are some questions that parents have told us are important.

How do I monitor my child’s condition?

Monitoring often refers to keeping a record of your child’s condition, symptoms and treatment. This can be helpful in identifying any changes to their condition, for example, if they have started a new medication and you can see that it is working. This can be useful for the specialist to review their condition and its treatment.

It might also be helpful to monitor other things that affect, or are affected by, your child’s condition. This might include their sleeping pattern and their mood (how they are feeling).

How you monitor your child's condition might depend on their age, and whether they want to monitor their own condition. It can be a good way of encouraging young people to get involved in managing their own condition. This can be important in teenagers who will start to be transferred from their paediatrician to an adult cardiologist (called 'transition' to adult services) at around 16 to 17 years of age.

♡ *Contact us for a copy of our free symptom diary.*

How do I manage medication?

Most children who have symptoms from their cardiomyopathy will be taking medication. There are many different types of medication, which all do different things (see page 18 on treatment).

When should they take their medication? Most medications will be taken once or twice a day, and this will usually be written on the pharmacy sticker on the packet, or within the patient information leaflet in the packet. For medication to work best, it is helpful to take it at about the same time each day, which helps to keep the levels in the body consistent. Sometimes it helps to link taking medication with another regular task, such as brushing their teeth, as a reminder.

I'm worried about side effects. All medications have the potential to cause side effects, but not everyone gets them. You can ask your GP or paediatrician what side effects to look out for with any medication, and the details will also be in the patient information leaflet in the packet. Although the list of side effects can be long and off-putting, it is worth remembering that they are only *possible* side effects and are not guaranteed. If your child has side effects from one medication there are usually others that can be tried instead.

What do I do if my child vomits or gets diarrhoea? The patient information leaflet in the packet of medication should tell you what to do if your child is ill after taking medication. This will usually be to take the dose again if it was soon after taking it, or to wait until the next dose is due. Your pharmacist can also give you advice on this.

If you have any questions about medication, you can talk to your specialist, GP, nurse or pharmacist.

What activities can my child do?

Many parents are concerned about whether their child's condition will affect what activities they can do, and how to keep them safe while still encouraging them to get involved in the normal activities.

Parents are often concerned that physical activity will be difficult, or will cause too much strain on their child's heart. Generally, exercise is encouraged in all children, unless there is a particular reason why it is not suitable. It can improve overall health and fitness, and has a positive effect on emotional wellbeing. Aerobic exercise such as walking and swimming (which relies on oxygen getting to the muscles) can be beneficial for the heart. However, in someone with cardiomyopathy, exercise can place an additional burden on the heart, which may already be struggling to meet the body's normal demands.

Guidelines on exercise are complex, and depend on the type of cardiomyopathy someone has, and their symptoms. Also, it is hard to give recommendations as each child is different. Generally, it is advised to join in 'recreational' (fun) exercise but to avoid sports that are intense or competitive, or that need sudden bursts of exertion (such as sprinting). It is also important to be aware of any symptoms that start during exercise, such as feeling chest pain, dizziness, breathlessness or palpitations.

♥ *For more information, see our factsheet 'Cardiomyopathy and exercise'.*

It is a good idea to discuss exercise and activities with your child's specialist, as they will be able to help you and your child make decisions about what activities are suitable based on your child's experience of cardiomyopathy.

Aaliyah's story, by mum Sabrina

In July 2015 my daughter Aaliyah was diagnosed with viral DCM (Dilated Cardiomyopathy). We'd spent six weeks trying to get to the bottom of her failing health, back and forth to GPs and the walk-in centre. We were told she just 'had a bug', that 'it's probably anxiety' and 'lots of girls her age have eating disorders'. But actually my little girl was in multiple organ failure and critically ill due to a virus damaging her heart and causing DCM. We were lucky. Aaliyah got treatment and medical attention in time to save her life and avoid any need for surgical procedures. But those first days in intensive care were like living my worst nightmare.

Nearly two years later our life has been changed irreversibly. Aaliyah's heart is stable and her health has improved massively. She's nearly taller than me (which I am less happy about). I gave up teaching to become Aaliyah's carer and we have had to learn how to manage a life-limiting condition in a relatively short time frame.

It's been a challenging journey. Supporting a teenager through the grief of losing her health and her control over her own life at such a key stage of her development, has made me long for my old day job. A positive mental attitude is great in theory but when faced with a moody teenager and the ongoing battles with various organisations to ensure she gets the support she needs (from school to doctors and the local authority)... it's not always possible!

The struggles of parenting teenagers are well known, but add a disability like DCM and it's impossible for either of us to know what's teenage attitude and what's the DCM. The emotional and psychological fall-out of having to deal with the immense changes have been the hardest part of the process for the entire family.

We have had support through a local children's hospice who have been a lifeline, providing a listening ear, respite care and a network of other teens and parents who understand our experiences. As a parent our worst fears are focused on our children and their wellbeing but as terrifying as it was to watch helpless while my baby was in the ICU (intensive care unit), my pride in the determined and resilient young woman she is becoming through this experience, is far greater.



"I am proud that she is becoming a determined and resilient young woman."

Can cardiomyopathy affect my child's wellbeing?

Living with cardiomyopathy can be challenging, whatever age you are. People respond differently to a diagnosis, and feelings can change over time. There might be times when someone feels well, and is positive and able to manage their condition so that it has minimal impact on their life. At other times, they may feel very unwell, or feel upset and unable to cope. All these feelings are understandable, and can be part of living with a long-term condition.

Some people experience stress, depression and anxiety. While many people feel this way at some time and it can be a normal reaction to a diagnosis, when these feelings are persistent and start to get in the way of life, it may be helpful to look for sources of support. Support can take many forms. For some, having the opportunity to talk through how they are feeling can be really helpful, either with family, a friend, or a teacher or counsellor at school. More formal counselling (having appointments with a trained professional) might help, or medication might help to manage these feelings. You can talk to your child's doctor about this.

Depending on their age, you might find that there are times when your child is happy to talk about their condition, and times when they seem worried or withdrawn. Some children may find it difficult to express themselves, and how they are feeling physically or emotionally. Sometimes this can show in their behaviour, and they may be withdrawn or irritable. And this can be hard on you too. Talking to your child about their feelings is often a good place to start.

What should nursery/school know?

You child's nursery or school might already know about your child's condition; perhaps you have spoken to them about it, or they have picked up on symptoms your child is having. So that they can support your child and look after any medical needs, it can be helpful to talk to the nursery or school about your child's condition, focusing on how it affects them and what help they may need.

What to tell nursery or school will depend on your child and what symptoms, if any, they are having. The teachers and support staff might not have experience of supporting a child with cardiomyopathy before, and they may not know much about the condition. It might be helpful to give them some information to explain more. For example:

- the type of cardiomyopathy your child has;
- how it affects the heart;
- what symptoms your child has and how they need to recover;
- what medication they are on and any side effects to look out for;
- whether they have a pacemaker or ICD (see page 20);
- what help they might need so that they can join in activities; and
- when to call for help.

You might also like to give them a copy of this booklet.

What help might my child need?

This will depend on your child and their condition. Some children will need very little support, and others will need more. It might be helpful to talk to teachers and support staff about what symptoms your child has, how this might affect them in the classroom, and how they can be helped. The following are some examples.

- If your child feels tired during activities they may need time and somewhere to sit down.
- If your child is breathless or has swelling in their ankles they might need to lie down to help reduce this.
- They might be worried about their condition and need reassurance.

If you have a community or a heart failure nurse, you could ask if they can talk to the school. Some may even be able to visit the school to explain more.

Time off for appointments

You may need to take your child out of school during the day for medical appointments. Talking to staff in advance can help so that they know when your child will be away from school and can make arrangements so that they don't miss out on school work.

Risk assessments: what activities can my child do?

Before a nursery or school decides what activities your child can't do, it is helpful to look at how they can be supported to do activities. To do this, it can be helpful to do a risk assessment. This involves looking at what the activity is, and why it might be a risk to your child. Assessments need to be specific and individualised: based on how your child's condition *actually* affects them, and not on how people think their condition *might* affect them. They are not about looking at risks to restrict what your child can do, they are about looking for ways in which activities can be managed, changed or safety-measures put in place so that your child can be included. This is sometimes referred to as reasonable adjustments so that children can be included.

Extra help from school

Children with health conditions may have extra support needs at school. While this is not necessarily the case for all children with cardiomyopathy, if you are concerned about how your child is getting on at school, you can ask the school about an Education, Health and Care plan (or EHC plan). This involves having a needs assessment to identify what help a child needs to support them with their education. An assessment is done by your local authority, and either you or the school can request this.

♥ *For more information visit www.cafamily.org.uk or www.gov.uk and search for 'EHC'.*

CPR and defibrillators

It is important that nursery and school staff have first aid training in case any child should need it. But this can be even more important when there is a child with cardiomyopathy, as there is a risk that they could have a potentially life-threatening arrhythmia. Arrhythmias can cause loss of consciousness, and can cause cardiac arrest if they are not treated as an emergency. Giving cardiopulmonary resuscitation (**CPR**) is important until an ambulance arrives.

Some schools will have automated external defibrillators (or 'AEDs'). These are portable machines that detect abnormal heart rhythms or a lack of heart beat, and can give an electric shock (defibrillation) to get the heart back into a normal rhythm. The machine gives instructions about how to use it correctly, and it can be helpful for staff to know where the machines are, and how to use them.

Some children who are at risk of dangerous arrhythmias may have ICDs (internal cardioverter defibrillators) implanted (see page 20). If this is the case, it is important that the school know about this, and what to do if the child's ICD goes off.

Services and support

Not everyone with cardiomyopathy needs extra help and support, depending on how their condition affects them. However, there is various support available, as and when you need it.

Health and social care assessments

If your child has health and support needs, you can ask your local authority for a health and social care assessment (sometimes called a 'needs assessment'). This involves someone such as a social worker discussing with you, either at home, by phone or online, your child's medical and physical needs and what might be helpful for them. Help might include special equipment, access to day care, and help with daily tasks. It will identify whether this help can be provided by your local authority.

♥ *For more information visit www.gov.uk or www.citizensadvice.org.uk and search for 'health and social care assessment'.*

Welfare benefits

Not everyone with cardiomyopathy is entitled to welfare benefits, as it depends on how the condition affects individuals. However, some benefits are given to help with any additional costs due to having a disability or medical condition. This includes Disability Living Allowance (or 'DLA') for children and Personal Independence Payment ('PIP').

♥ *Contact us for more information on welfare benefits, or visit www.gov.uk or www.citizensadvice.org.uk and search for 'benefits'.*

Help with hospital travel costs

If your child receives benefits, or you are on a low income, you may be able to get help with the cost of travelling to and from hospital appointments.

♥ *For more details visit www.nhs.uk and search 'help with travel costs'.*

Support for families

The Family Fund is a charity that provides financial support to families with disabled or seriously ill children. This includes grants for equipment, as well as signposting to other sources of support.

♥ *Find out more at www.familyfund.org.uk*

Support for carers

A carer is “anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support” (Carers Trust). Although some parents meet this definition of ‘carer’, not every parent feels that they are a ‘carer’. Many feel that the care and support they give their child is just an extension of their normal parental responsibility. But for some people, the term of ‘carer’ can open up avenues of support that they were not aware of. The following are just some of the things a carer is entitled to.

Carers assessment – this is an assessment done by social services which looks at ways in which you can be supported to look after your child. It focuses on your needs (rather than your child’s), including your own health and wellbeing, as well as practical help and employment. You can ask your local authority for an assessment.

Respite care – you can ask your local authority for information about short breaks away from caring responsibilities (called ‘respite care’). This includes providing support for your child so that you can have some ‘time out’, whether it is a few hours at home or a few days away.

Carers allowance – if you provide care for someone for at least 35 hours a week, and they receive welfare benefits, you may be entitled to carers allowance.

♥ *For more about help for carers, see the organisations on page 40.*

In our survey we found that, when their child was diagnosed, 65% of respondents would have liked practical support but were not offered it, and 67% would have liked emotional support but were not offered it.

My cardiomyopathy, by Steffi

As a young adult, I enjoy life and appreciate every little opportunity I encounter, especially exploring the world and seeking new horizons. My outlook on life came about after I was diagnosed with hypertrophic obstructive cardiomyopathy when I was only 18 years of age.

It was Saturday 30th August 2014, and I went to my local hospital for an echocardiogram and this is when they discovered my condition. I had an ICD implanted later on that week. It was a lot to take in within the space of a week, for both myself and my family.

Once I came out of hospital a week after the operation, I was mentally drained, embarrassed of my appearance and in lots of pain. This caused me to push some people away as a coping mechanism. I felt that being in hospital I was safe and protected, and being at home I was scared and over-thought many things. However, I had to put myself in the mind-set that "I am going to get through this" and that is it happening either way. This made me look at the diagnosis more positively: I used it as an excuse to live my life to the full. I was supposed to go to University that year, but my plans had to change due to exams.

The next couple of years I felt it helped to speak to my friends, my family and people at the hospital, and no question was a silly question. When I was diagnosed I didn't have many places to turn to, but my cardiac nurses were incredible and they encouraged my development as a young person with a heart condition.

Self-belief was a massive part of my recovery as I was my own best motivator to carry on with life. I am now 21 years old and it's nearly 3 years since my surgery. Although I have a lot of challenging roads ahead of me, I am not alone and am able to rely on a network of people.

Now my life is back on track as an apprentice. I travel, I work full-time, I volunteer and I still have time for adventures. I am thrilled to have shared my experience and encourage others to share theirs.



"I enjoy life and appreciate every little opportunity I encounter."

The impact on you

If your child has been recently diagnosed you may have many different feelings. Some people feel shocked or scared, especially if they are not aware of a history of cardiomyopathy in the family. Some are worried; they may not have heard of the condition before and don't know what the diagnosis means. Others feel relieved, knowing what the condition is and that it can be treated. People respond to a diagnosis in different ways: there is no 'right' or 'wrong' way.

"We have continuous questions, this will never change as they are driven by everyday life."

You may have a lot of questions. You may not want to ask because you are worried about the answers. Or you may feel overwhelmed or not know *what* questions to ask. It can feel scary and very lonely.

"I still struggle daily with my son's diagnosis, I worry about him constantly."

If your child has had the condition for a while, you may still find it challenging. And you might have good days and bad days.

"Someone to wave a wand and take it away."

Looking after yourself

Naturally, when a child is diagnosed with cardiomyopathy, everyone's focus is on them: understanding their condition, their symptoms, their treatment and supporting them. But a diagnosis can affect everyone in the family: siblings, parents and the wider family.

It may sound ridiculous to say 'look after yourself' when it is your child who has the condition. Looking after your child, managing the practical aspects of a condition, and dealing with symptoms, all become part of your new life, adjusting to the condition. Alongside that, you may be dealing with the reaction and emotions of others around you.

But this doesn't take anything away from how you are feeling, and the impact it is having on you. It can be easy to focus all of your attention on your child, but it is also important to focus on your needs too. This isn't always easy to do.

It can be hard asking for help, or to share your emotions. You may feel that you have to 'be brave', or that you should be coping better. We can be hard on ourselves, but taking some time out to look after your needs can also make you feel 'refuelled' and able to take on life again.

Coming to terms with a diagnosis can also affect family relationships. You may find yourself spending less time with your partner or with close family. You may feel that other people don't understand, or are not able to care for your child in the way that you do. Or you may find that your family are incredibly supportive and helpful, and can make sure that you get time to look after yourself, and your other relationships.

"Knowledge is power! The more you understand the better equipped you will be to deal with the ups and downs to come. And be patient – it can be an overwhelming diagnosis for a family but take each day as it comes and be kind to yourself."

Giving yourself permission to take time out without feeling guilty, to spend time alone or with friends, to focus on your needs, is important to help you feel 'normal' again, and to recover from any pressures you are feeling.

"Just be there for us."

Terms explained

Arrhythmias – abnormal heart rhythms caused by a problem with the electrical messages that control how the heart beats. They cause the heart to beat too fast (tachycardias), too slow (bradycardias) or erratically (atrial or ventricular fibrillation). They can affect blood flow from the heart, and increase the risk of blood clots forming, which could cause a stroke. They are usually treated with medication, or devices that monitor the heart and correct dangerous arrhythmias.

Atria – the top two chambers of the heart which receive blood from the body and the lungs. The atria contract to force blood into the ventricles below.

Blood clot – these are thickened ‘clumps’ of blood which happens when platelets and cells in the blood stick together. Blood clots form to stop bleeding, for example at a wound site. However, they can also develop where they are not needed, and can cause blockages such as in the blood vessels.

Cardiac arrest – when the heart suddenly stops pumping. This happens due to dangerous arrhythmias. It causes the person to collapse and stop breathing. This is different from a heart attack which is caused by a blockage in the heart’s own supply of blood which starves the heart of oxygen and causes areas of muscle to die.

Cardiologist – a doctor who specialises in conditions of the heart in adults. Normally people will see a cardiologist from age 16 or 17.

CPR (cardiopulmonary resuscitation) – this is a technique used to help save someone’s life if they stop breathing or their heart stops beating, by giving ‘rescue breaths’ and chest compressions to keep blood circulating around the body until paramedics arrive.

DNA – genetic material that determines how we develop and our characteristics.

Gene – part of DNA which codes for a particular characteristic, such as height or hair colour.

ICD (implantable cardioverter defibrillator – a device that monitors the heart rhythm and gives a shock to the heart if it detects dangerous arrhythmias. They are implanted under the skin on the left upper chest wall, and connected to the heart via wires into the ventricles.

Mutation – a change in part of the DNA that affects how a **gene** is expressed. This can cause the development of a disease or condition.

Oedema – in cardiomyopathy, oedema is a build up of fluid around the lungs, ankles and abdomen. This happens when the amount of blood flowing through the heart is reduced, because the heart is working less well. The kidneys then react to this reduced blood flow (as if it was caused by significant blood loss) by reducing the production of urine and holding on to fluid. This fluid then, in turn, increases the volume of the blood. This increased volume of blood puts additional pressure on the heart to pump, and so the blood ‘backs up’ in the blood vessels. Fluid then ‘leaks’ out of the blood vessels into the surrounding tissue.

Pacemaker – a device that sends electrical impulses to the heart to stimulate the contraction and relaxation of the heart muscle, and set a normal heart rhythm. They are used for people whose heart is unable to set its own pace, or where the heart rhythm is disrupted.

Paediatric cardiologist – a doctor who specialises in conditions of the hearts in children.

Paediatrician – a doctor who specialises in conditions that affect children (up to around 16 – 17 years of age).

Valves – structures in the heart and veins (blood vessels that carry blood from the lungs and the body) which help to ensure that blood flows in the right direction and doesn’t flow backwards.

Ventricle – the bottom two chambers of the heart which receive blood from the atria. The ventricles have thick muscular walls to pump blood to the lungs and around the body.

Useful contacts and websites

Carers Trust

www.carers.org

info@carers.org

0300 772 9600

Support and information for carers, including carer's breaks, getting an assessment and benefits and money issues.

Carers UK

www.carersuk.org

info@carersuk.org

0808 808 7777

Support, advice and information for carers, including entitlements. Provides carers groups and volunteers.

Citizens Advice

www.citizensadvice.org.uk

Adviceline 03444 111 444

Information on health, benefits and sources of national and local support available.

Contact a family

www.cafamily.org.uk

info@cafamily.org.uk

Freephone 0808 808 3555, 9.30am – 5pm, Monday – Friday

Offers information and advice on a variety of topics including needs assessments, education, and welfare benefits.

Heart Failure Matters

www.heartfailurematters.org

Has a series of simple videos to explain the causes and symptoms of heart failure.

GOV.UK

www.gov.uk

The website of the UK government. Has information on education, finances and benefits, and help available.

NHS choices

www.nhs.uk

Information on medical conditions and services available through the NHS.

Turn2us

www.turn2us.org.uk

National charity offering information on benefits, grants and support.

How we can help you

We have many services to inform and support you, and to put you in touch with other people.

- Helpline and Live Chat – staffed by specialist nurses, our helpline and Live Chat can answer your medical questions about cardiomyopathy. Call 0800 018 1024 (Monday to Friday, 8.30 am to 4.30pm) or go online whenever you see the ‘chat to us online now’ message on our website. You can also email supportnurse@cardiomyopathy.org
- Website and information services – if you would like information on cardiomyopathy you can go online to our website or call us for booklets and factsheets. www.cardiomyopathy.org or call 01494 791 224.
- Information days and conferences – learn more about cardiomyopathy and share your experiences with others at our information events. Look online or call us to find out what events we have. www.cardiomyopathy.org or call 01494 791 224.
- Peer support volunteers – talk on the phone to people who have gone through a diagnosis of cardiomyopathy in their child, to share your experiences. Call 01494 791 224 and ask to speak to a peer support volunteer.

*“To speak to another mum going through this.”
[‘What would have helped you?]*

- Support groups – meet other people, hear from expert speakers and share experiences with people in your area. www.cardiomyopathy.org/support-groups or call 01494 791 224 to see if we have a group in your area.

*“Have someone to talk to who understood the condition.”
[When asked ‘what would have helped you?]*

In our survey, 65% of respondents said that they would like to talk to other parents, carers or families, about the condition.

How we help children and young people

We have specific services for children, young people and young adults (CYP&YA). This includes peer support through a closed Facebook group, and on Twitter (for people aged 14 – 25 years).

These services are developed with the guidance and involvement of our panel of young adults. The services are also moderated to ensure the safety of all of our users, and our panel members are online to give support.

You may like to pass the following information on to the young person in your life.



14-25 Cardiomyopathy UK
and closed group



@cardio1425



Live Chat www.cardiomyopathy.org



Helpline: 0800 018 1024

Know yourself...

- ♥ know who you are
- ♥ know your limits
- ♥ know when to ask for help
- ♥ know who to ask
- ♥ *know your condition*

Know yourself: self-manage your condition
Cardiomyopathy UK's children, young people & young adult advisory panel



Supporting other young people like us...

This introduction to cardiomyopathy in children is written for parents and carers. It is also for families and teachers. It includes information on the condition and how it is managed, and includes common topics that parents have questions about.

Cardiomyopathy UK is grateful to all of the parents, carers, families and children who have helped to shape this booklet and allowed us to use their experiences to help others.

Contact us

Helpline: **0800 018 1024**

Email: **contact@cardiomyopathy.org**

Office telephone number **01494 791 224**

Address: **Unit 10, Chiltern Court**

Asheridge Road, Chesham, Bucks HP5 2PX

You can find us at **www.cardiomyopathy.org**



Facebook



Twitter



Support in realtime via Live Chat

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

Every effort is made to ensure that this information is accurate. This information is not intended as a substitute for advice from your own doctors. It is intended for a UK audience. Cardiomyopathy UK does not accept responsibility for action taken after reading this information. Please note that information may change after printing.

Cardiomyopathy^{UK}
the heart muscle charity

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