

# my life

The magazine from **Cardiomyopathy<sup>UK</sup>** the heart muscle charity

Issue 10 | Summer 2017

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emotional well-being

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**'I've made a good recovery and am now  
sharing my story with others'**

Abi (right) talks about her cardiomyopathy and raising awareness – Page 5

# Cardiomyopathy<sup>UK</sup>

the heart muscle charity

## Our services

We provide information and support to anyone affected by cardiomyopathy.

- **helpline nurses**

Our specialist cardiomyopathy support nurses answer medical questions and queries about living with cardiomyopathy. You can reach them through our helpline 0800 0181 024 (free from UK landline), livechat or email [supportnurse@cardiomyopathy.org](mailto:supportnurse@cardiomyopathy.org)

- **information packs**

We have a wide range of information leaflets and booklets about cardiomyopathy that are full of information for people living with the condition. We also have booklets and online training videos for doctors and nurses

- **support volunteers**

Our network of trained volunteers provide one-to-one support on the phone or by email. They are all affected in some way by cardiomyopathy

- **information days**

We hold information days around the UK each year. These days provide people affected by cardiomyopathy and their families with the chance to meet others who have the condition and hear leading experts talk about the disease, developments in care and latest research. Details of this year's information days are on pages 7 and 19.

- **support groups**

Our support groups around the UK provide people with cardiomyopathy the opportunity to meet others and share problems and experiences with them. Meetings are always positive and encouraging, and often have experts speaking on cardiomyopathy and living with the condition. There are details of forthcoming support group meetings on page 19

Our vision is for everyone affected by cardiomyopathy to lead long and fulfilling lives. Our goals are to:

- increase support
- improve diagnosis and care
- promote medical research.

If you would like more information on any of our services, please get in touch.



## Contact us

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Like us on Facebook

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Cardiomyopathy UK is a charitable incorporated organisation (CIO) with a registered charity no 1164263

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## Talking helps



Chair of trustees  
Alison Fielding  
chair@cardiomyopathy.org

Get talking is one of my mantras when it comes to cardiomyopathy. This is both to help people cope with the condition and to increase awareness and understanding.

We have some great volunteers who are raising awareness by talking to the media, in running support groups and being patient representatives.

However too many people have still not heard of cardiomyopathy or how it affects people. So please help us change this by

- Talking to your employers or community groups and asking them to consider making Cardiomyopathy UK the beneficiary of any charity events. Some organisations offer match funding for any money raised or will select a charity of the year. We can support you and your employers in putting events together and having fun.

- If you use social media, like Twitter or Facebook, follow us and help us share information by retweeting and commenting. Ask your friends to do so as well.

- If you know any celebrities who may be willing to help us as a celebrity ambassador, please get in touch. A personal connection is always better than a cold approach.

Have a lovely summer and keep cool.

## New cardiomyopathy support groups being set up around the country

Five new cardiomyopathy support groups have been set up around Britain this year.

The groups, which will provide more information about cardiomyopathy and living better with the disease, also offer affected families the chance to meet others with the condition and share experiences.

The groups are based in York, Milton Keynes, Ipswich, Fareham and Cumbria.

The York group, being run by volunteer Paul Minton (pictured right) and Cardiomyopathy UK's youth and peer support manager Jo Franks, is having its first meeting on Thursday, 25 May, 2pm at Friargate Quaker Meeting House in Friargate, York.

Heart failure nurse Caroline Jones, from York Teaching Hospital NHS Foundation Trust, will be speaking on cardiac rehabilitation, diet and exercise.

Paul, who was misdiagnosed before being told he had dilated cardiomyopathy seven years ago, said that he had got a lot of help from medical people and wanted to help others in return.

He said: "Having cardiomyopathy can be an incredibly lonely place. I thought setting up a support group would be something I could do and give me a purpose."

The Ipswich group has its first meeting on Wednesday, 7 June, 7pm at the Meeting Place, Limerick Close, Whitehouse, Ipswich. The speaker will be Cardiomyopathy UK support

nurse Robert Hall who will be talking about the different types of cardiomyopathy, treatments and genetics.



The Fareham, Portsmouth and Gosport group is having its first meeting on Tuesday, 23 May, 6.30pm at Community Action Fareham, West Street, Fareham. Our support nurse Robert Hall will be giving an overview of cardiomyopathy and answering questions.

The Buckinghamshire support group had its first meeting in February at Oxley Park Community Centre, Redgrave Drive, Oxley Park, Milton Keynes. The next meeting will be held there on Wednesday, 31 May, at 7pm. Cardiomyopathy UK's head of services Ali Thompson will be discussing benefits and welfare, and Dr Kelly Morris, from Northampton General Hospital NHS Trust, will be talking about cardiomyopathy research.

The Cumbria group's next meeting will be on Saturday, 10 June, 2pm, at the Keswick Quaker Meeting House, Elliott Park, Keswick, CA12 5NZ. Cathy Stark, who has cardiomyopathy, will be sharing her personal story.

New groups are being set up thanks to support from the Big Lottery Fund.

For more information about the groups, call Jo Franks on 01494 791224 or email [jo.franks@cardiomyopathy.org](mailto:jo.franks@cardiomyopathy.org)

## Share your story



Chief executive  
Joel Rose  
[joel.rose@cardiomyopathy.org](mailto:joel.rose@cardiomyopathy.org)

I am always amazed by the number of people who come forward and share their stories with the public or who take any and every opportunity to tell others about their experiences.

One volunteer once told me that they just kept "banging on about it" and hoped that they were not being a nuisance. They are not — they are saving lives.

We know how a casual conversation, a story in the press or a post online can be enough to prompt someone to go to the doctor for the first time or to get a second opinion after being misdiagnosed.

So in this issue we are celebrating some of the outstanding work our volunteers have been doing to raise awareness of cardiomyopathy and showing how you can spread the word.



## New cardiomyopathy factsheets available

Three new factsheets — on travel, heart failure and restrictive cardiomyopathy — have been added to our growing library.

We now have 11 factsheets as well as our detailed booklets on dilated, hypertrophic and arrhythmogenic right ventricular cardiomyopathy.

The other factsheets cover

- An introduction to how the heart works
- What is cardiomyopathy?
- Takotsubo cardiomyopathy
- Left ventricular noncompaction
- Exercise
- Cardiomyopathy and life insurance
- Cardiomyopathy and travel insurance

The factsheets can be found on our website and downloaded as a PDF or call the office for copies.



# Five steps to emotional well-being



**Graeme Gillespie** | consultant clinical psychologist,  
Northumbria Healthcare NHS Trust

Everyone facing the challenge of living with cardiomyopathy has to deal with the diagnosis, the uncertainty which follows, and the physical and emotional ups and downs of life.

Trying to understand and manage cardiomyopathy while also getting on with the rest of life's challenges can be hugely demanding.

The majority of people with cardiomyopathy who responded to Cardiomyopathy UK's online survey last year ([cardiomyopathy.org/psychology-needs](http://cardiomyopathy.org/psychology-needs)) reported that the disease affects their mental health and emotional well-being at least some of the time. So too did it affect their family, friends and carers. So what evidence is there about boosting our personal well-being?

The New Economics Foundation ([neweconomics.org](http://neweconomics.org)) was tasked with reviewing and summarising the key factors associated with people's well-being. It identified five factors, which it called the five ways to well-being, summarised in the coloured circles (right).

Life can throw many challenges and painful struggles our way. But the five ways do highlight the evidence that, of all the many things which affect our personal well-being, the things we do or the ways we think can have the greatest impact.

The link between well-being and being active is probably something everyone knows about. But being active can be tricky if our physical health is affected by cardiomyopathy. Working out the right level of activity, neither too little nor too much, can be difficult. Your cardiologist, specialist nurse or GP should be able to advise in general terms on the types of activity which are right for you.

But also look out for the way you talk to yourself about being active. Physical health problems which reduce exercise tolerance can cause huge frustration and these can be turned inwards into self-attacking thoughts. Are you beating yourself up about how little you're doing, how slow or weak you are or have become?

Are you dispirited by your previous relationship with activity or exercise? ('I used to be able to do....now I can only do....what's the point?') Or are you encouraging and kind to yourself? If anything in life is a struggle, it's always best to talk to yourself about it as you would to your own best friend rather than like a neighbour from hell.

A consistent finding in the field of positive psychology is that people feel better when they give something to others. It doesn't seem to matter too much what we give, but the emphasis seems to be on genuine acts of kindness or help, rather than on giving money or material goods. Giving

can help you connect more fully with people, as well as enhancing other people's well-being.

Taking notice refers to being truly aware of the present moment. Often our busy minds flit about from one thought to another and we become lost in rumination or worry. Our emotions can become like unhelpful mental guides, pulling us into thoughts about sad or difficult events from the past or anxieties about the future. That can lead to a vicious circle, dragging us into a downward spiral of sad or angry, irritable thoughts, and even stronger, more difficult emotions.

When this happens, it is hard for us to notice what is around us in the present. We can lose touch with our surroundings, our family and friends, and even our own actions. Life can pass us by.

Our well-being seems to improve when we become more aware of our external and internal world. Not only do we start to be more attentive but by noticing and being mindful of our own thoughts, we are better able to step back from them.

By recognising thoughts as just thoughts we can become less entangled with their content. And our thoughts are often inaccurate, biased or irrational. So try to take time to notice what is happening in the moment. Mindfulness meditation may sound a bit new age but has been proven to be beneficial to well-being. The website [freemindfulness.org](http://freemindfulness.org) has some downloadable meditation exercises which may help.

Learning something also seems to be good for our well-being. It doesn't seem to matter too much what we learn. It could be rediscovering something you used to be interested in. It can give us a sense of achievement, boosting our self-esteem.

Connecting reminds us that we are social animals and that time spent with partners, family, friends, and colleagues is vital to our well-being.

It seems that both the depth and breadth of our social relationships are important. Health problems like cardiomyopathy can lead to fatigue and low mood, which often have a knock-on effect on our relationships and tend to increase social avoidance and isolation. Spending time with friends and family, even in small doses, can help to reverse these effects.

In a previous article (My Life, January 2017) I described the way values can be a helpful guide to living a more fulfilled life. By linking goals in these five areas to the things that really matter to you, you can build a virtuous circle of positive actions and positive feelings. And you can even help your friends and family in the process.

Connect with people around you – family, friends, colleagues and neighbours. Invest time in them. Building connections will support and enrich you every day

Be active. Step outside. Go for a walk or run. Cycle, play a game or dance. Exercising makes you feel good. Discover a physical activity you enjoy and suits your level of mobility and fitness

Take notice. Catch sight of the beautiful. Be aware of the world around you and savour the moment, whether you are walking to work, eating lunch or talking to friends. Appreciate what matters to you

Keep learning. Try something new. Rediscover an old interest. Sign up for a course. Take on a different responsibility at work. Learn to play an instrument or how to cook your favourite food

Give. Do something nice for a friend or a stranger. Thank someone. Smile. Volunteer your time. Join a community group. Look out as well as in



# Raising awareness is rewarding



## Abi Findley's story

**After developing pregnancy-related cardiomyopathy, Abi wanted to raise awareness and became a volunteer for Cardiomyopathy UK, helping to get stories about the condition in the media**

My cardiomyopathy story started six years ago following the safe arrival of my daughter Grace, my second child.

I was 31 and already had a son, Freddie, who was 18 months old. His delivery had been awkward, but there was nothing to suggest any issues with my heart.

With Grace my pregnancy was fairly uneventful but towards the end I was putting on weight rather quickly. I didn't realise this was fluid gain because my heart was pumping poorly. I was also feeling breathless but put this down to pregnancy.

The delivery was quick and routine. I was discharged the same day. But two or three days later I quickly became very unwell. I was too weak and breathless to climb stairs and could hardly walk into the next room. I also had chest pains.

My GP initially put it down to anxiety and sent me for blood tests for anaemia. I was relieved a potential cause had been found. But I began to feel worse and started waking up in the night gasping for breath. I saw another GP who sent me to A&E. I had an enlarged heart. I had no idea what that meant but I was worried.

I was allowed home with an appointment to see a cardiologist two days later. Tests showed my heart's ejection fraction (EF — the volume of blood pumped out of the heart at each beat) was only 20 per cent, when normal is 55-60 per cent. I was told I had peripartum cardiomyopathy. The cardiologist said I had a 40 per cent chance of recovering completely, a 40 per cent chance of being

Pregnancy-related (or peripartum) cardiomyopathy develops in women in the last few months of pregnancy or soon after giving birth

on medication for life and a 20 per cent chance of needing a heart transplant. I was admitted to High Wycombe Hospital and it was a tough time. Grace stayed with me during the day but my family had to care for Freddie. My husband Matt came to see me when he could. I couldn't breastfeed as the drugs I needed would be passed on to Grace in my breast milk.

Because my heart was not pumping well, I had a lot of fluid retention. I was given an intravenous diuretic to get rid of the excess fluid and immediately started to feel better. But it took another couple of months for my symptoms to really improve and I found this very frustrating. When they did improve, I started exercising regularly. I started with swimming and fairly quickly moved to step classes, weight training and even spinning.

My EF took longer to improve but three years later it had reached 54 per cent. So my cardiologist took me off my beta-blockers (not my ACE inhibitors), discharged me but requested an echo a year later. This showed my EF had dropped to 40 per cent. I was floored. I was put back on beta-blockers and began seeing Professor Perry Elliott at St Barts Heart Centre in London.

Three years later my EF is still 40 per cent. I don't have heart failure symptoms, but I struggle with fatigue. I have a problem with how the electrical impulses travel through my heart, and the different chambers of my heart don't pump in a co-ordinated way. But my symptoms are currently too good for a heart device to be needed. I hope to stay this way for a long time.

I ran a 10km for Cardiomyopathy UK in 2015. I wasn't the fastest but I had the biggest smile crossing the finishing line. For the past 18 months I have also been a volunteer for Cardiomyopathy UK, helping with the charity's media work. This involves working with supporters willing to publicly share their cardiomyopathy stories to raise awareness of the condition and the charity. This has resulted in me and fellow supporter Claire Shepherd having our stories featured in national magazines. I've been in Chat and Claire has been in New!

I've had a great year helping at the charity. I would urge anyone with time available to consider volunteering. It's so rewarding.

• Abi is pictured (front page) with husband Matt and (above) with their children Freddie and Grace

# I enjoy being an NHS patient voice



## Richard Mindham's story

**After finding out more about his dilated cardiomyopathy, Richard decided to help improve the lives of others with the disease and became a patient voice on many health committees**

In my mid-to-late 40s I travelled a lot to the Middle East in my role as sales director of a software company. The long hours and constant travelling took its toll. I was always exhausted and unable to recover no matter how much I slept. I had experienced fatigue in varying degrees for over ten years, but not to this extent. So I stopped work to recover.

After four months my exhaustion was unchanged and my wife told me to get help. After initially being diagnosed with chronic fatigue syndrome, I discovered that I had dilated cardiomyopathy. This was over nine years ago and I was 50.

The cardiologist told me my condition was serious, and I'd need to make lifestyle changes. I shouldn't have caffeine or alcohol, nor attempt to lift anything — not even help my wife with the shopping. If I made these changes and took my prescribed drugs, there was a chance of improvement. If I failed to follow these strictures and was unlucky, I could be on the transplant list in three months.

This was a massive shock to me, not least as I thought heart failure affected older people who had not looked after themselves. I didn't feel old and had been diligent in keeping up my exercise. I loved skiing and mountain biking: it was part of my identity.

I needed to know more about the disease and found Cardiomyopathy UK. The charity was immensely helpful. I went to its information days and met others who were affected. They understood the challenges of living with the condition, not least the biochemical and psychological side-effects of treatment. Cardiomyopathy UK's Robert Hall and consultant cardiologists William McKenna and Perry Elliot all helped my understanding of the condition. The one big hole was exercise, and here the advice was sketchy.

I had never thought of myself as sporty but I had enjoyed pedalling around. I went skiing every year and I sailed a dinghy in the summer. I found that there was so much caution around exercise

that I became frustrated and eventually took events into my own hands. I cycled to all of my consultations (about four miles each way on the flat) and gradually began to cycle more.

Eventually my wife and I went skiing and, to my consultant's credit, he just raised an eyebrow when I asked him about being at altitude. He did not tell me to cancel the trip. We then pushed the boundaries further and went on a cycle trip to Morocco. We started at Africa's highest ski resort, crossed a high pass and cycled down the spine of the Atlas Mountains.

With hindsight, I was testing each step and making incremental increases in the effort I was expending. Nonetheless, this was a very uncertain time and most worrying for my wife who would have had to clear up the mess had I keeled over at any point. I think it took nearly five years for us both to understand the condition and to come to terms with it fully.

I wanted to give something back to Cardiomyopathy UK and to make the path easier for newly diagnosed patients. I have sat on numerous committees which seek to improve the lives of people with heart failure, including NICE's chronic heart failure guideline and quality standards committees. I have given presentations to MPs, cardiologists and heart failure nurses on what it's like to live with heart failure and I'm a patient voice advising Brompton & Harefield Hospitals' researchers on the patient perspective.

NICE's guidelines recognise the importance of cardiac rehabilitation for patients and its psychological and emotional components.

The National Heart Failure Audit that I sit on clearly shows the health benefit of being cared for by a multidisciplinary care team and, when admitted to hospital, being on a cardiology ward rather than a general ward. I continue to provide the patient voice on a number of committees, including a 50-hospital trial looking at whether intravenous iron can improve life for heart failure patients.

I now feel the luckiest of any person with cardiomyopathy I have met. I've never had breathlessness, water retention or been in hospital, and I'm almost unlimited in what I can do. I cycle regularly and go skiing, windsurfing and sailing when time and money permit.

Now, nearly ten years after my diagnosis, I'm in a great place. I am happily married, happy with my life and happy with my health.

• Richard is pictured above during a skiing holiday in Andorra





## Angela Herdman's story

After her daughter Carly died from pregnancy-related cardiomyopathy aged 26, Angela has been raising awareness of the condition and how to recognise it with her local health authority and further afield with Cardiomyopathy UK

From being a very little girl my daughter Carly always wanted to get married and become a mother.

She met her husband at work and after five years together they got married. During their honeymoon in Portugal she became pregnant and they were both thrilled.

During the later stages of pregnancy she became dizzy, began fainting at work and grew increasingly tired. She complained about palpitations and numbness in one of her legs.

She was over a week overdue but gave birth naturally (though with forceps). Baby George was born healthy and weighing 7lbs 11ozs.

After she had given birth she looked dreadful — her face was swollen, she had no colour, even in her lips, and her eyes appeared yellow — but her husband and I were assured by medical staff that she was fine.

Over the next few days at home she became progressively worse and was readmitted to hospital where a few days later she died. We only found out she had peripartum cardiomyopathy, a type brought on by pregnancy, in the hours brought on by pregnancy, in the hours before her death.

I've since looked up the signs of the disease (palpitations, chest pain, excessive fatigue, tiredness during physical activity, shortness of breath, swelling of feet and ankles) and she had them all. But I got the impression that those looking after her were mostly unaware of the condition and its symptoms. And I'm

told that midwives learn very little about peripartum cardiomyopathy during their training. I felt this needed to change.

I contacted Cardiomyopathy UK about Carly, and what happened to her was a major factor in the charity holding its first national medical conference on cardiomyopathy and pregnancy in June 2015. It included sessions on peripartum cardiomyopathy and how to recognise it. I was involved with planning for the day and promoting it. Through Cardiomyopathy UK, the British Journal of Midwifery used Carly's story, a medical article on pregnancy and cardiomyopathy, and details of the conference.

Around 150 medical people from around the UK attended, including midwives, obstetricians and cardiac nurses. Quite a big team came from the hospital where Carly died.

An obstetrician from that team asked if Cardiomyopathy UK would help put on a conference at its hospital so that even more of the local team could attend.

This was held last April and I gave a talk about our family's experience. Around 100 medical staff benefitted from that.

I was also involved in an enquiry into maternal and baby deaths at the hospital and gave permission for Carly's story to be used in training for medical staff, including midwives.

I hope all this will help save more mums and help stop more families from going through what we've been through.

• Angela is pictured above (right) with Carly on her wedding day

## Our cardiomyopathy information days

Every year we hold cardiomyopathy information days around the country to help people find out more about the disease and meet others who are affected.

The days include sessions on dilated cardiomyopathy, hypertrophic cardiomyopathy, other types of cardiomyopathy, managing your symptoms, treatment options and the impact of living with cardiomyopathy.

Also included are personal experiences of living with cardiomyopathy and how Cardiomyopathy UK can help you.

Our forthcoming information days, from 9.30am to 4.30pm, comprise:

- Novotel, Grey Friars Rd, Ipswich IP1 1UP — 22 April

- Edinburgh Training and Conference Centre, 16 St. Mary's Street, Edinburgh EH1 1SU — 13 May. Day being run in conjunction with the Familial Arrhythmia Network for Scotland (FANS)

- Kala Sangam Arts Centre, St Peter's House, 1 Forster Square, Bradford BD1 4EH — 3 June

- Southampton Solent Conference Centre, The Spark, East Park Terrace, Southampton SO14 0YN. Southampton — 24 June

Attendance at the event is £5 per person, including refreshments and a sandwich lunch.

More details are available on our website. See [cardiomyopathy.org/info-days](http://cardiomyopathy.org/info-days)



## Information booklets

If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets.

We have booklets on each of the main types of cardiomyopathy — produced with the support of the British Heart Foundation — and another on living with cardiomyopathy. The booklets are

downloadable from our website. For hard copies email [anne.foster@cardiomyopathy.org](mailto:anne.foster@cardiomyopathy.org)



# Importance of talking about cardiomyopathy



**Joel Rose** | chief executive, Cardiomyopathy UK

We all know that talking about cardiomyopathy can save lives whether it's a casual conversation with a friend, a social media post or story in the press.

That's because when we talk about cardiomyopathy we encourage more people to examine their family's heart history or seek help for their symptoms that might otherwise have gone undiagnosed, sometimes with tragic consequences.

It's not just about raising awareness among the public. The more we talk about cardiomyopathy the more the medical world takes note. It can prompt a GP to dust down some medical school notes or even visit our website to find out more.

You may have seen the recent widespread news coverage of singer George Michael's post-mortem. The coroner mentioned the presence of dilated cardiomyopathy and myocarditis and suddenly there was a rush of people visiting our website, following us on social media and calling the helpline. It just goes to show how much interest there is in cardiomyopathy.

One of our big challenges is to build on this interest and not only raise awareness of cardiomyopathy but also to convert that awareness into action. It's not enough just to know about cardiomyopathy. We have to make sure that people know what they can do about it and understand why it is important that they act. And that is not the only challenge. We also need to recognise that cardiomyopathy affects people of all ages and from

all communities. This means that we have to make sure that our message is heard by everyone whether they prefer Twitter or the Telegraph, come from London or the Highlands or are from what is sometimes called a "hard to reach community".

But we are ready to take on this challenge and are busy working on our plans for a national campaign. This campaign, which we hope to establish as an annual event, will focus on the signs of cardiomyopathy and in particular the need to see how a range of symptoms can indicate a problem especially where there is a history of heart problems in a family.

It is a shocking fact that in our last national survey more than 30 per cent of you told us that you had initially been misdiagnosed by your doctor. Often this was because they were not seeing, or did not know, the full picture. Too many people are wrongly being told that their palpitations are anxiety or their breathlessness is asthma. We want our campaign to address this issue.

The question is of course, how to run a national campaign in the most effective way? While we do not have the funds to pay for TV adverts or billboards, I do believe that we can have a ready and willing army of volunteers and that is a fantastic resource to have.

So over the next few months we will be telling you more about the plans for our campaign and how you can play a part. In the meantime please think about how you can spread the word right now. You could just save a life.



Supporters who have been raising awareness in the press recently include (far left) Abi Findley, who told her story to Chat magazine (also see page 5), (centre) Angela Herdman, who told her daughter Carly's story to the British Journal of Midwifery (also see page 7) and Colin McVittie who talked about his cardiomyopathy in the Kent Messenger newspaper to highlight the Kent Cardiomyopathy Support Group that he helps organise



# Apical hypertrophic cardiomyopathy



**Dr Thomas Gossios** | clinical fellow, and  
**Dr Costas O'Mahony** | consultant cardiologist, Barts Heart Centre, London

Hypertrophic cardiomyopathy (HCM) is a common inherited (genetic) type of heart muscle disease (cardiomyopathy).

In people with HCM the heart muscle is excessively thick but the severity and distribution of the thickening varies from person to person.

Apical hypertrophic cardiomyopathy is a type of HCM where the heart muscle thickening predominantly or exclusively affects the tip of the heart (the tip of the heart is technically known as the left ventricular apex, and hence the name).

Apical HCM is seen in about 10 per cent of HCM patients and although the genetic change is present at birth, muscle thickening most frequently develops later on in life.

Inheritance patterns in apical HCM are identical to other types of HCM and screening of first degree relatives is recommended.

As with other forms of HCM, patients often do not experience symptoms and are diagnosed either incidentally (for example during a medical examination for insurance purposes) or through screening if another member of the family is affected.

Patients are also diagnosed when they seek medical attention due to symptoms.

Chest pain or palpitations are frequently described and some patients may experience shortness of breath. Lightheadedness or blackouts can also occur.

Doctors often suspect apical HCM when an electrocardiogram (ECG — a heart rhythm trace) is abnormal but to confirm the diagnosis the heart muscle needs to be visualised. Imaging is required for a complete clinical assessment.

Apical HCM can be difficult to diagnose because the tip of the heart is frequently a blind spot with ultrasound scanning (echocardiography).

To overcome this problem, alternative imaging methods such as cardiac magnetic resonance (CMR) are used. Consequently delays in diagnosis are not uncommon and at the initial investigative stages other more common diseases are considered (for example heart attacks) and excluded.

Treatment of symptoms such as chest pain and shortness of breath aims to restore balance between oxygen demand and sup-

ply in the thickened heart muscle.

The mainstay of medical treatment is beta-blockers (such as bisoprolol) or calcium channel blockers (such as verapamil).

Sometimes the thick muscle may restrict the flow of blood in the heart causing obstruction (this is often called mid-ventricular obstruction) and some patients may gradually develop a pouch at the tip of the heart (apical aneurysm).

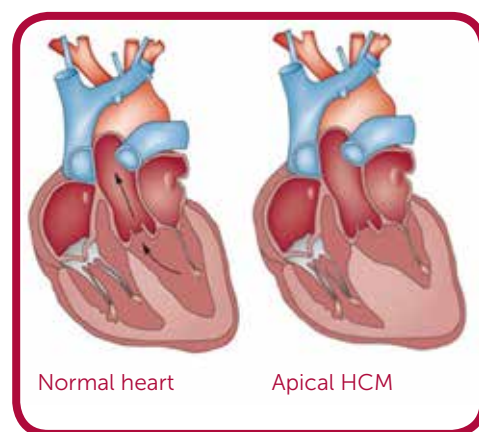
When symptoms caused by midventricular obstruction are refractory to the standard medication, implantation of a pacemaker may help in some cases. This is not an established treatment.

Invasive options such as alcohol septal ablation or surgery to remove part of the thickened heart muscle currently have limited, if any application in this setting.

Unfortunately symptoms may persist despite treatment. Independent of symptoms, patients are prone to the development of an irregular heart rhythm called atrial fibrillation (AF) which predisposes to stroke.

The risk of stroke in AF can be reduced by thinning the blood with warfarin or newer similar agents and it is imperative that patients undergo regular heart rhythm monitoring to detect AF. Tragically some patients die suddenly from a very fast and erratic heart rhythm called ventricular fibrillation but this is not common.

Sudden death can be prevented by the fitting of a defibrillator (ICD) which delivers a shock to the heart to interrupt ventricular fibrillation and restore normality. Every HCM patient should be periodically assessed for the risk of sudden death and ICD implantation discussed if the risk is high.



Normal heart

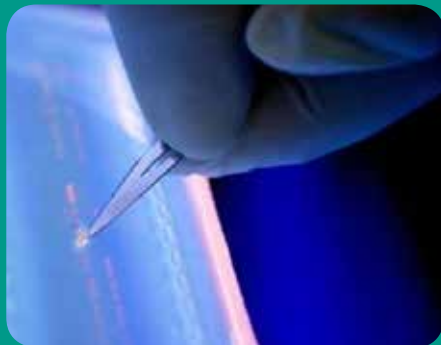
Apical HCM

**In apical hypertrophic cardiomyopathy, heart muscle thickening predominantly affects the tip of the heart**

**The mainstay of treatment is beta-blockers, such as bisoprolol, or calcium channel blockers, such as verapamil**

## New gene responsible for ARVC found

An international team of researchers say they have identified another gene responsible for arrhythmogenic right ventricular cardiomyopathy (ARVC).



The gene, called CDH2, is one of several found to cause ARVC which causes heart cells to be replaced by fatty and scar tissue. This in turn can lead to heart rhythm problems.

The study, published in *Circulation: Cardiovascular Genetics*, is the result of a 15-year collaboration between researchers in Canada, South Africa and Italy.

The study was led by Bongani Mayosi, professor of cardiology at the University of Cape Town, who began following a South African family who had had several young deaths from ARVC.

Excluding all genetic causes known at the time, Italian researchers sequenced parts of the genome in two affected members of the family, and found the mutation in CDH2.

CDH2 is responsible for the production of Cadherin 2 or N-Cadherin, a protein for gluing heart cells together.

Often symptoms of ARVC only become clear after many years. However, if someone is a known carrier of a mutation on the gene CDH2, other members of his family can be identified from genetic testing and preventive treatment started immediately.

### See more news

For news about cardiomyopathy, see [cardiomyopathy.org/news](http://cardiomyopathy.org/news)



## Recovered heart function study needs more volunteers

A study investigating whether it's safe for some people with dilated cardiomyopathy and recovered heart function to stop taking their heart drugs is looking for more volunteers to take part.

Already 28 volunteers, including one from Northern Ireland, have come forward for the study at the Royal Brompton Hospital in London but another 22 are needed by the end of July.

Eligibility includes still being on your recommended heart medications (such as beta-blockers, water pills and ACE inhibitors) and having heart function that has recovered to normal.

The research team wants to explore whether it is safe to stop heart medications in people who have recovered heart function. If the medicines can be stopped without the problem coming back, this suggests that the heart problem may have been cured.

"Volunteers will have their heart medicines gradually withdrawn in a structured, and closely supervised way", said clinical research fellow Dr Brian Halliday.

"We will use MRI heart scans, exercise tests and blood tests to assess heart function. If there are any early signs of a reduction in heart function, medication will be restarted immediately," he said.

Chief investigator Dr Sanjay Prasad, a consultant cardiologist, said: "When patients recover their heart function they

### To be eligible

- Your heart function must have been previously reduced. Left ventricular ejection fraction (LVEF) — a measure of the heart's pumping power — must have been less than 40 per cent and the heart enlarged
- Your heart function must have returned to normal: LVEF greater than 50 per cent with a normal sized heart
- You must still be on treatment for your (recovered) cardiomyopathy

often ask if they can stop taking their medications. Currently there is little research for doctors to base their answer on and no consensus about the best approach. We hope our study will answer this important question.

"We will go on to study factors that predict sustained heart function recovery including a person's genetic make-up and specialised measurements from the MRI scans."

If you would like to know more about the study, email [b.halliday@rbht.nhs.uk](mailto:b.halliday@rbht.nhs.uk) or call him on 0207 3528121 ext 2928.

## Children sought for study into heart drug specifically for them

A study is underway to develop a safe, effective formulation of the ACE inhibitor enalapril for children with dilated cardiomyopathy (DCM).

The study, being funded by the European Commission, is seeking children with the disease or other heart pumping problems to take part. They must be eligible to have an ACE inhibitor as well as their other treatments.

Enalapril, initially used to treat high blood pressure, has recently shown it also improves heart function in adults by helping the heart work more slowly and efficiently. It may also help children with heart failure, but the drug is currently not licensed for them.

Few medicines currently exist in formulations developed for children. Enalapril is only licensed for children with high blood pressure and weighing more than 20kg (the average weight of a six-year-old).

It is also used as an "off-label" drug in children with heart disease. But the tablets

have to be crushed and diluted in water before they can be given, an inaccurate and difficult method.

The plan is to get approval for a mini tablet no bigger than 3mm which is quick to dissolve and easy to swallow, reducing the risk of choking. The European Medicines Agency (EMA) has agreed that a safe formulation of enalapril should be made available to children.

The Children's Heart Federation (CHF), a UK charity, is taking part in the project, called the LENA study. The charity is representing parents and young patients and linking them to the researchers.

The study is still looking for volunteers, and forms have been created for two groups of children, 0-5 years and 6-12 years. Hospitals in the UK, Netherlands, Austria, Hungary and Serbia are recruiting children.

For further information about the study email [LENA@chfed.org.uk](mailto:LENA@chfed.org.uk) or see [lena-med.eu/](http://lena-med.eu/)



# Q&A

Cardiomyopathy support nurse Robert Hall, Cardiomyopathy UK, answers your questions about your rights to treatment and care



**Q:** I don't think I'm getting the right care for my heart failure. What are my rights here?

**A:** NICE guidelines for chronic heart failure were revised in 2016. These guidelines provide evidence-based recommendations for the diagnosis, treatment and management of heart failure conditions such as dilated cardiomyopathy. Since their introduction these guidelines have standardised therapy, particularly in relation to the use of drugs such as ACE inhibitors and beta-blockers. The independent clinical judgement of your cardiologist must also be taken into account. So if you are concerned you are not receiving the correct care this should be discussed with your cardiologist, with reference to these NICE guidelines. See [nice.org.uk/guidance/CG108](https://www.nice.org.uk/guidance/CG108)

**Q:** I have dilated cardiomyopathy and want to attend cardiac rehabilitation classes. What should I do?

**A:** NICE guidelines for chronic heart failure recommend that an exercise-based rehabilitation programme should be offered for patients with heart failure conditions. Eligible patients should be in a stable condition, that is not having evidence of pulmonary oedema and heart rhythm disturbance that could prevent exercise. Attendance of such groups is generally by referral from your cardiologist. Provision of these services varies across the country. In the first instance cardiac rehabilitation should be discussed with your cardiologist. If no suitable service is available in your area you can raise the matter with your hospital trust via its patient advice and liaison service (PALS). See [nice.org.uk/guidance/cg108/chapter/1-guidance#rehabilitation](https://www.nice.org.uk/guidance/cg108/chapter/1-guidance#rehabilitation)

**Q:** Can I insist on being referred to a specialist cardiomyopathy centre?

**A:** The European Society of Cardiology published guidelines on the diagnosis and management of hypertrophic cardiomyopathy in 2014. The guidelines provide recommendations for referral to specialist cardiomyopathy services, for example where there is uncertain diagnosis, severe symptoms, and risk of complications. The guidelines also recognise the complexity of the condition and the variation in models of delivery of care that exist. Describing the detailed systems of care was beyond the remit of the guidelines. However, the key point was made that, whatever model was used, all patients and families should be managed in accordance with the same internationally agreed standards. You are also entitled to request a referral to a specialist through your GP. The response to this request will be based on the GP's clinical judgement. See [nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/gp-referrals.aspx](https://www.nhs.uk/NHSEngland/AboutNHSservices/doctors/Pages/gp-referrals.aspx) and [bit.ly/2n94cOG](https://bit.ly/2n94cOG)

**Q:** I don't think my cardiologist is giving me the right treatment. What are my rights to a second opinion?

The important point, in the first instance, is to discuss your concerns and any things you don't understand about your care with your cardiologist. There isn't a legal right for a person to have a second opinion. However, if you are unhappy with your diagnosis or treatment, your GP or cardiologist will consider a request for a second opinion. The patient advice and liaison service (PALS) in your hospital can also provide useful support and guidance. See [nhs.uk/chq/Pages/910.aspx?CategoryID=68Q](https://www.nhs.uk/chq/Pages/910.aspx?CategoryID=68Q)

**Q:** I've read a lot about the benefits of the new drug Entresto. How can I get this drug?

There are two factors here. Firstly your cardiologist is responsible for managing your care and treatment and he or she will be making decisions based on their professional clinical judgement. Secondly, the availability of Entresto is covered by the clinical criteria set out by NICE in its review of its 2016 guidelines for chronic heart failure, with similar guidelines being published in Scotland. You can discuss Entresto with your cardiologist to see if it is a treatment option for you. See [nice.org.uk/Guidance/TA388](https://www.nice.org.uk/Guidance/TA388)

**Q:** I have cardiomyopathy and am taking numerous drugs. Am I entitled to help with prescription charges?

**A:** The answer depends on your level of income or if you are in receipt of certain state benefits. If you are unsure whether you qualify for free prescriptions (in England prescriptions are either free or not, you do not get a reduced rate) see the NHS HC11 booklet [nhsbsa.nhs.uk/Documents/HealthCosts/HC11\\_April\\_2015.pdf](https://www.nhs.uk/documents/healthcosts/hc11_april_2015.pdf) If you do qualify, you need to complete an application for an HC1 certificate. For more information contact our helpline and ask for Ali Thompson.

If you have a question you would like Cardiomyopathy UK to answer, email [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

## CMUK summer raffle

— be in it to win it!

Our annual summer raffle draw is now open, with amazing prizes to be won.

This year the top prize is £500 in cash, with two other cash prizes as well as smaller gifts to be won.



"As we receive no government funding, the summer raffle is a huge part of our fundraising, and every single ticket you buy will help us be there for more people affected by cardiomyopathy," said Cardiomypathy UK's community fundraising manager Bex Noble.

"Last year our generous raffle players helped us raise over £11,000 with sales and donations, and this year we're hoping to do even more. Whether you want to sell tickets or buy some yourself, every single £1 ticket sold makes a difference."

You can buy your tickets online at [cardiomypathy.org/raffle](http://cardiomypathy.org/raffle) or call our offices on 01494 791224 and we'll pop some in the post for you. Thank you for your support, and good luck!

## Good luck to our London Marathon runners

Wishing all 48 of our amazing London Marathon runners the best of luck for their 26.2 mile challenge on Sunday 23 April:

Adam Rathbone, Alexandra Buckland, Bethan Lewis, Carina Taylor, Chris Williams, Daniel Edwards, Darren Howson, Eileen Sawyer, Elena Hand, Emily Golding, Emma Venables, Emma Whitaker, Fahim Dawood, Freda Alvi, Gareth Beavis, Georgina Watkins, Helen Cruickshanks, Jessica Walker, Joanne Maitland, Joseph Otoo, Julie Glover, Karen Aloe, Kane Whitby, Kelly Doyle, Kevin McMillan, Kieran O'Ceallachain, Laura Doherty, Leon Whitby, Matthew Sanders, Michelle Wade, Neil Frost, Paul Haylock, Phil Gibbens, Rebecca Wetherall, Ricki Makin, Sam Alexander-Floyd, Sam Rigby, Sarah McDermott, Sophie Oldfield, Steve Gillan, Tanya Dalton, Tim Nosworthy, Tom Mason, Tony Sutton, Victoria Guthrie, Zoe Randle, Jack Saunders and Rachel Chard.



Win  
£500  
cash!

## Will banks of hearts for transplant be possible?

Scientists in America have successfully frozen and rewarmed pig heart tissue for the first time, raising hopes it may eventually enable banks of human hearts to be kept for transplant.

If the technique can be used for entire organs it could save the lives of thousands of people who die each year waiting for a heart transplant, the team says.

It is the first time large tissue samples have been frozen, thawed and warmed without them shattering, cracking or turning to a pulp.

The US team overcame these problems by infusing the pig heart tissue with magnetic nanoparticles, which could be excited in a magnetic field, generating a rapid and uniform burst of heat. The scientists now plan to use the technique on skin, muscle and blood vessels from human donors.

Kelvin Brockbank, chief executive officer of Tissue Testing Technologies in Charleston, South Carolina and a co-author of the study, said: "It is a huge landmark. We can see the road ahead for clinical use and getting tissues and organs banked and into patients."

Currently, donor hearts have to be transplanted quickly as their cells begin to die as soon as they are cut off from a blood supply. So many hearts donated for transplant go unused.



For more details, see [cardiomypathy.org/rewarm-heart](http://cardiomypathy.org/rewarm-heart)

## Robotic sleeve to pump the heart is developed

Scientists from around the world have developed a sleeve that fits around the heart and helps it pump.

The sleeve can squeeze the heart like the action of heart muscle and should be able to help people with heart failure.

Early trials, published in Science Translational Medicine, show the model can work in a laboratory and on pig hearts.

Engineers in America, Germany, Ireland and Leeds have been working on the project. The device, a robotic sleeve, is made from materials like heart tissue. The sleeve sits snugly around the heart, compressing it like

the movements of a normal heart. But unlike usual heart pumps, called left ventricular assist devices, this device has no contact with patients' blood and so is unlikely to increase the risk of blood clots forming.

The sleeve uses compressed air to power artificial silicone muscles. The researchers show that the artificial muscles could be selectively activated to twist, compress, or simultaneously perform both actions on one side or both sides of the heart.



For more details, see [cardiomypathy.org/heart-sleeve](http://cardiomypathy.org/heart-sleeve)

## Importance of flu and pneumonia jabs

Flu and pneumonia injections may help prevent life-threatening breathing infections in people with heart failure, says a comprehensive review.

Although clinical data from large trials is still limited, early evidence from various studies suggests that vaccinations can improve future health and quality of life in patients with heart failure, Dr Robert Mentz reported online in the Journal of the American College of Cardiology.

Dr Mentz, from the Duke University School of Medicine in Durham, North Carolina, also discussed possible benefits of giving heart failure patients over 65 higher doses as they may have a decreased immune response to a standard dose.

"Vaccination represents a low-cost intervention that may be able to prevent the significant disease, death, and cost associated with heart failure," said Dr Mentz. "A deeper understanding of current vaccination practices in the heart failure population is necessary to guide population-level interventions aimed at improving vaccination rates."

For the study, Dr Mentz and his team looked at studies on the use of pneumonia or flu vaccines among heart failure patients from January 1990 to July 2016.



For more details see [cardiomypathy.org/flu-jabs](http://cardiomypathy.org/flu-jabs)



## Human trials begin in experimental drug for DCM

Human trials have begun of an experimental drug designed specifically to treat heart contraction problems in dilated cardiomyopathy (DCM).

The drug's maker, American biopharmaceutical company MyoKardia, says it has begun giving the drug to a group of healthy volunteers.

The drug, called MYK-491, is designed to increase heart muscle contractility in people with DCM.

Reduced heart contractility is believed to be the cause of several types of the condition.

This phase 1 trial, a randomised, placebo-controlled study, will assess the safety, tolerability, and the early effects of oral doses of the drug and how it moves in the bodies of healthy people. Any changes in how the heart pumps will be measured.

"There are currently no approved therapies that address the underlying

biomechanical causes of DCM" said Dr Marc Semigran, chief medical officer of MyoKardia.

Dr Semigran said early research had demonstrated that MYK-491 may increase the heart's contractility with minimal adverse effects on the heart's diastolic function (when the heart is relaxing and filling with incoming blood) which can also be abnormal in people with DCM.

The company is also working on a drug to treat the underlying causes of hypertrophic cardiomyopathy (HCM). Early trials from this drug, MYK-461, has suggested the drug is well tolerated and has the ability to reduce excessive heart muscle contractility.

MyoKardia says it is generating a pipeline of therapies for HCM and DCM.



For more details, see [cardiomyopathy.org/DCM-drug-trial](https://cardiomyopathy.org/DCM-drug-trial)

## Skin cancer incidence soars after heart transplant

A person's risk of skin cancer appears to soar after getting a heart or lung transplant, a large study has suggested.

So doctors should refer people who have transplants for regular skin cancer screening by a dermatologist, suggests Dr Eric Engels from the National Cancer Institute in America. Patients should also ensure they use sun protection, including avoiding long periods in bright sunlight, wear protective clothing, and use sunscreen, he said.

Skin cancer occurred at a rate of 1,408 per 100,000 person-years after transplant, said the study published online in the Journal of the American Medical Association Dermatology.

Dr Sarah Arron, from the University of

California in San Francisco, said: "The skin cancer incidence rate in organ transplant recipients was nearly five times the rate of all cancers combined. Predictors of post-transplant skin cancer included previous skin cancer and a heart or lung transplant.

Dr Jayan Parameshwar, consultant cardiologist at Papworth Hospital in the UK, said: "Skin cancer is the most common malignancy after heart transplantation." He said that the suppression of the immune system needed after transplant increased the effect of sun damage to the skin.



For more details, see [cardiomyopathy.org/skin-cancer](https://cardiomyopathy.org/skin-cancer)

## Variety of heart pumps may help to tailor treatment

A new generation of heart pumps called left ventricular assist devices (LVADs) have shown some advantages over earlier models but also some shortfalls, says new trial evidence.

Two large trials have compared data from the traditional heart pump, the HeartMate2, with two new pumps, the HeartMate3 and the HeartWare that operate differently.

The studies showed risks varied in the different devices, including for stroke, device malfunction and two year survival rates.

Researcher Dr Joseph Rogers, from the Duke Clinical Research Institute in Durham, North Carolina, said that the prospect of having more heart pumps on the market might enable doctors

to better match an LVAD to a patient's specific characteristics, such as their risk of bleeding, stroke or infection.

He said: "It's always difficult to have one treatment option for patients. I think now, as we expand this field a bit and we get greater experience with different kinds of pumps in different patient populations, we may be able to do this in a much more intelligent, patient-centric way."

Heart pumps are used when patients are in severe heart failure and awaiting a heart transplant or sometimes as an on-going treatment. In the UK, they are only used in the NHS in people waiting for a transplant.



For more details, see [cardiomyopathy.org/tailored-pumps](https://cardiomyopathy.org/tailored-pumps)

## Drones could help save lives after cardiac arrest, say researchers

Researchers in Canada have been investigating using drones to dispatch resuscitation equipment to help people who have suffered a cardiac arrest.

The team said drones were emerging as a technology to help bystanders save the lives of people who have an out-of-hospital cardiac arrest when life-saving automated external defibrillators (AED) are not available.

They concluded that drones could beat paramedics by six to ten minutes in many cases.



The study, published in Circulation, was carried out by engineers from the University of Toronto and medical staff from the department of medicine at Queen's University in Toronto.

For more details, see [cardiomyopathy.org/drone-rescues](https://cardiomyopathy.org/drone-rescues)

## Lead extraction safe for young in specialist centres

Young people can safely have their heart device leads extracted if the work is done in specialist centres, say researchers.

The team was looking at how well their patients did when old leads for pace-makers and defibrillators were taken out. The leads, which go into the heart, can be difficult to remove, especially in younger people, because of fibrosis and calcification.

Doctors in Atlanta in America examined the outcomes for patients under 40 in one group and those aged 40 and over in another.

Patients in the older group had a higher overall average number of leads extracted per procedure. Most had had their leads in place for around ten years. The younger patients tended to have their leads extracted via the femoral vein rather than the implant vein. Researchers said this treatment needed to be done in expert centres.

Extraction was successful in over 94 per cent of cases. There were no major complications or post-surgery deaths in the younger group and only around a one per cent complication rate in the older group.

For more details, see [cardiomyopathy.org/lead-extraction](https://cardiomyopathy.org/lead-extraction)

## Drug to help disease causing DCM?

A proposed new drug to treat a disease that often leads to dilated cardiomyopathy (DCM) has been given special status by the European Commission.

The drug, currently called PBI-4050, has been granted orphan drug designation for the treatment of Alström Syndrome (AS), a very rare disease which causes fibrosis in organs including the heart, liver and kidneys. Around half of children with the disease develop severe DCM within the first few weeks of life.



DCM can also recur or develop for the first time in more than six in ten young people or adults with AS.

The drug's developer, Canadian based ProMetic Life Sciences, is doing early trials of the drug in the UK to see the effects on vital organs in patients with AS.

Dr John Moran, the company's chief medical officer, said: "PBI-4050 has successfully reversed fibrosis in the heart, lungs, kidneys, pancreas and liver in several preclinical studies. We are very excited at the idea that PBI-4050 may well offer a real long-term benefit for these patients".

The European Medicines Agency had decided that the intention to treat AS with PBI-4050 was justified based on early clinical data showing an improvement in liver fibrosis.

European orphan drug designation is granted to novel drugs that treat a rare disease or condition affecting fewer than 250,000 patients in the European Union. The designation provides the developer with various marketing and regulatory advantages.



For more details of the study, see [cardiomyopathy.org/rare-DCM-drug](https://cardiomyopathy.org/rare-DCM-drug)

## Move to prevent device hacking

A company that produces heart devices has taken action to safeguard its internal defibrillators and biventricular pacemakers from the threat of hacking.

The US Department of Homeland Security identified worries about the cyber security of the St Jude Medical heart devices using a remote-monitoring system called Merlin@home.

In response, St Jude Medical issued cyber security updates for its Merlin remote monitoring system. It said these would reduce the risk of an unauthorised user causing harm to the devices.

The US Food and Drug Administration said an unauthorised user could potentially cause rapid battery depletion and inappropriate pacing or shocks. But it is not thought that any malicious hacking has been committed and that no patients have knowingly been harmed, it said.

St Jude Medical said: "All medical devices using remote monitoring are exposed to the risk of a potential cyber security attack. In recognition of the changing cyber security landscape and the increased public attention on highly unlikely medical device cyber risks, we are informing the public about these ongoing actions so that patients can continue to be confident about the benefits of remote monitoring."

The company urged that device users should make sure their Merlin@home unit was plugged in and connected in order to receive the new software as well as future updates.



For more details, see [cardiomyopathy.org/hacking-safety](https://cardiomyopathy.org/hacking-safety)

## Why I'm leaving a gift in my will to Cardiomyopathy UK

Scott Drew (pictured below right with his dad and aunt) talks about helping future generations of people with cardiomyopathy



I am 43 and am at increased risk of dilated cardiomyopathy because of my family history.

I support Cardiomyopathy UK in various little ways. I have a collection tin in my shop, a standing order where I give a small amount each year to the charity and I buy its raffle tickets. But I still felt I needed to do more to give back to the charity that has supported my family and me so very much over the past 20 years.

My story with cardiomyopathy started in the mid 1990s when my 55-year-old aunt Joan Sturtridge was taken into hospital with a heart complaint that turned out to be dilated cardiomyopathy (DCM). None of us had heard about the disease and we didn't have Google then. The hospital advised her to mention the condition to the rest of her family and for her six siblings to get a GP referral for heart checks, including an ECG and echo. If any signs of DCM were found, their respective children should also be screened.

I remember my dad Stan Drew explaining the situation to our doctor and he confessed that he had never heard of the disease and would need to look in his medical books. Until then I had assumed that GPs knew everything. Little was known about the disease back then compared to now — mostly, I believe, thanks to Cardiomyopathy UK for raising awareness.

My dad was the only other sibling of six to be diagnosed with DCM. My brother and sister have check-ups every few years. I have had a few blips when things were not looking great but, as of late, things have improved and for the first time I have been moved on from annual screening to every three years.

My local hospital has been wonderful from day one, especially our consultant who has been seeing us for over 20 years. He is under the impression that in our particular family cardiomyopathy appears to present itself at around the age of 50.

A few years ago Cardiomyopathy UK used to charge a membership fee, but this was scrapped a while ago which made me think. Unlike some charities, Cardiomyopathy UK went the other way and decided people did not have to pay to join — it wanted its information to be free for everyone.

Because of this and for all the free help and support the charity has offered my family and some close friends with hypertrophic cardiomyopathy, I decided that I would leave a legacy to the charity when I changed my will. I feel this is a good way to leave money to a charity that has helped us so very much. However, I do hope that this will not be paying out until I make it to the age 101!

I can report that both my dad and my aunt are in their 70s and doing fine in the heart department — although they do have other unrelated medical issues. Who knows? Perhaps one day there will be a cure and cardiomyopathy might be wiped out completely.

Cardiomyopathy UK's trust fundraising manager Sheila Nardone said: "We are so grateful to those who leave a gift in their will to Cardiomyopathy UK, ensuring that we continue to make a difference for future generations."

• For more information about how to leave us a gift in your will, call Sheila on 01494 791224 and see [cardiomyopathy.org/legacy](https://cardiomyopathy.org/legacy)



# Helping your child move to adult care services



**Sarah Regan** | children's support nurse  
Cardiomyopathy UK

Moving from children's services to adult health care should be a gradual process of change to ensure children and their families are prepared and feel ready to make the move

As children with cardiomyopathy get older, their parents or carers will be thinking more about their future. The children will also be thinking about when they will move from children's services to adult services and how it will happen. They may also be experiencing other changes at a similar time, such as moving from secondary school to sixth form college or starting work.

In healthcare we use the term transition to describe the process of planning, preparing and moving from children's healthcare to adult healthcare where young people, rather than their parents or carers, will take more responsibility for their care.

Transition should be a gradual process of change, which gives everyone time to ensure that young people and their families are prepared and feel ready to make the move to adult services. The move from paediatric care with its particular ways of doing things into the adult healthcare system can be a challenge for teenagers and their families and the experience can be daunting.

## What does transition involve?

Transition is the gradual shift of responsibility for care from parents or carers to the child. The process can be introduced at any age but should start at around 12 to 14 years but will also depend on individual circumstances. The majority of young people will move directly from children's to adult services when they are aged between 16 and 18 years.

## How can I start preparing my child for transition?

Parents can begin to evaluate their children's readiness for transition by asking themselves the following questions

- does my child know the name of his or her condition?
- can my child describe it to someone in three simple sentences?
- does my child know the names of the drugs he or she takes and the times they should be taken?

Parents can begin to encourage their children to take an interest in their condition and talk independently to their medical team and perhaps see them alone.

If children are able to practice this with the doctors and nurses they know well in the children's services, the better able they will be to gain confidence and feel more independent when they see doctors and nurses in adult services.

It is recognised that it is a really difficult time for parents and carers too. It can take time for them to get used to handing over some of the responsibility.

In adult services the responsibility is usually given to the patient rather than the family. So it is vital that your teenager has the skills necessary to feel comfortable in the adult healthcare service.

The children's healthcare team should also be encouraging young people's independence and are responsible for ensuring that both the teenagers and parents or carers receive all the preparation needed to feel ready to move.



## Information for families

There should be a written transition plan which outlines the timing of key phases of the transition process, and the expected time for the eventual transfer. You should also be given information about the adult service or services, contact details for the staff there, how the service is organised and how the adult services differ from children's services.

It can be very helpful to arrange an informal visit to adult services to meet the new team and start to get to know them. Travelling to a new hospital and finding out where the appointments are held in advance, can make the first official appointment feel less daunting.

It can also be useful to speak to other families who have recently experienced transition. Your child's care team or Cardiomyopathy UK may be able to put you in touch with other families who have been through the process.

Some children's services run adolescent clinics, joint transition clinics and transition days which offer really useful preparation. Teenagers may also be given a 'healthcare passport' that they bring to all their hospital appointments. It is individualised to each young person and contains information about their condition, medicines, transition, educational material and details of different support groups and agencies.

The hardest thing for some families is to break contact with the children's services and particularly once the move to adult services has happened. The topic of transition may also bring up aspects of growing up with a medical condition that you may not have discussed before, for example in relation to career choices, benefits and relationships.

Not preparing young people adequately for transition can lead to problems later on. These can include young people failing to go to hospital appointments and not adhering to their treatment, including not taking their medicine or forgetting to order more.

It is also vital that they know how and when to seek medical help when unwell to prevent any deterioration in their condition.

## Helping your teenager through transition

- Encourage them to know about the medicines they take – the names of them, why they need to take them, how much to take and how often
- Let them see their doctor or nurse on their own for part of the appointment, for example by going in for their tests (ECG and echo) by themselves
- Help them be able to ask and answer questions about their health and treatments and be able to describe their symptoms. Help them think before clinic visits of questions they want to ask their medical team
- Encourage them to keep track of their hospital appointments and know how to book or change an appointment.

If you have any queries, contact [sarah.regan@cardiomyopathy.org](mailto:sarah.regan@cardiomyopathy.org)

# How your support makes a difference



Late last year we featured in My Life details of how we had helped people with cardiomyopathy.

We've been measuring our work to ensure we use our funds wisely and effectively and have now released the details in our 2016 Impact Statement.

None of what we do would be possible without the support of our incredible donors, volunteers and fundraisers up and down the country.

So here are a few facts about how your funds make a difference to the work we can do:

- A donation of £5 can help us send an information pack so someone can feel more informed and less scared about their condition.

All of our information resources are regularly updated and written by experts in the condition.

This means that people can get the right information about how to live with their condition. We are very proud of the fact that last year we provided information online and in print to 105,000 people.

- A donation of £25 can give a helpline caller all the time they need to speak to one of our nurses.

Each of our four nurses are cardiomyopathy experts, and we have a nurse available every weekday 8:30am – 4:30pm.

Between them our nurses have over 60 years' experience in caring for people with heart disease.

From emotional support to clinical advice, help is on hand from our nurses.



Everything we achieve is thanks to our fantastic supporters. We simply couldn't do it without you. Thank you all. If you would like to read our impact statement, it is available on our website at [cardiomyopathy.org/impact2016](http://cardiomyopathy.org/impact2016) or you can request a copy in the post by calling the office on 01494 791224.

## I'm running 5km every day despite my cardiomyopathy



Chris Morley (pictured centre with friends Sam and Sarah) invites people to join him on a 5km run in London on Saturday, 13 May

If you never knew, or no one talks or tells you about cardiomyopathy, then how is anyone ever going to look out for signs and symptoms and diagnose you correctly?

I had always felt something wasn't quite right. Even as a teenager I had chest pains, especially if laying still for a while. However, not knowing my family history and not telling anyone about my symptoms, the feelings just became the norm for me.

I have always been keen on running, doing 20-30 miles a week and even marathons and ultra marathons. The massive strain on my heart doesn't bear thinking about. Despite feeling like I'd been kicked in the chest by a donkey after every run, I thought this was completely normal. I ended up in A&E in agony following an ultra challenge training run, but was sent home with "pectoral muscle strain". I felt stupid and was determined not to waste my time or theirs again.

I kept pushing myself to the limit until I ended up in hospital with a heart rate of 28 and dropping rapidly. After being given as much atropine as they could with no affect, the wonderful nurses and doctors began defibrillating me to get my heart back into a normal rhythm. I spent several weeks in hospital in terrible pain, until finally a cardiologist diagnosed me with apical hypertrophic cardiomyopathy. I now have a pacemaker and a modified lifestyle. But I won't let cardiomyopathy and heart related problems define me or restrict my life. I will forever look for the challenges and push myself to achieve things, but the goal posts have moved slightly and things have had to be moderated slightly.

My cardiologists have told me "nothing too far or too fast". So I came up with the idea of running 5km every day for 365 days. This technically fits into their advice but is a challenge. However I want to do more than just run around my local park every day.



They say that 1 in 500 people in the UK is affected by cardiomyopathy, which means there are hundreds more living with strange chest pains, feeling flutters in their hearts and having a family history of heart problems. I am passionate about getting the knowledge out there. Knowledge is power. If people know what cardiomyopathy is and feel confident to ask their doctors questions, then hopefully others will get the right diagnosis and treatment.

If I can raise much needed funds for Cardiomyopathy UK in the process, then fantastic. I know there are many out there, whose symptoms and cardiomyopathy are much worse than mine and struggle with everyday life. To those people I say — keep going, please take strength in the fact that many people, me included, think you're amazing.

On Saturday, 13 May come and meet me at the London Eye at 10.30am for a group 5km loop to help support and raise more awareness. If you want to get involved, either jogging or walking a 5km with me, or just liking or sharing the information on my Facebook page, then I am grateful.

For more details, see Chris's facebook page [facebook.com/5k365Cardiomyopathy/](https://www.facebook.com/5k365Cardiomyopathy/)



# #teamcardio highlights

Thank you so much to all our fantastic #teamcardio fundraisers – none of our work would be possible without you!

Interested in being part of #teamcardio?  
Get in touch with our fundraisers,  
Sarah or Bex, at  
[fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org)  
or visit our website  
[cardiomyopathy.org/support-us](http://cardiomyopathy.org/support-us)

## Jumping for joy



Susanna Baker and friends, in festive costumes, hurdled a 10km horse cross country course at Foxberry in December. A big thank you for taking on such a unique challenge and raising £75 in the process

## Best foot forward



Scott Thornton from Glasgow took to the streets of the city in October and completed the Glasgow 10km.

He finished in a time of one hour and 11 minutes and raised £500 for Cardiomyopathy UK.

Thank you Scott

## Hitting a high note



Supporters Peter and Marion Davies again secured permission for their choir to sing by Trafalgar Square's Christmas tree in December. They all sang their hearts out and raised £260 for us

## Striding santas



Andrea Tucker and members of her family got in the Christmas spirit by taking part in the Victoria Park Santa Dash in London. They raised a fantastic £2,700 in memory of Oliver Tucker

## A fiery fundraiser



In November our corporate partners Mayer Brown organised a firewalk for us in central London. Twenty intrepid fundraisers literally walked over hot coals for us, and raised an incredible £2,500

## Brilliant birdies



Eighty golfers took part in a golf day in memory of James Stephenson, a keen supporter of Cardiomyopathy UK. Organised by James' father Kevin, family and friends, the day raised £2,450





## Challenge yourself

### Ultra challenges

Walk, jog or run – it's up to you. This series of five ultra-challenges offers every participant and team a unique view of the UK countryside. With routes from 25, 50 or 100km, there is a distance to suit everyone. So what are you waiting for?

**Location** – Five UK locations  
**When** – Throughout the year  
**Distance** – 25, 50 or 100km

To register or get more information, please visit:  
[cardiomyopathy.org/walks](http://cardiomyopathy.org/walks)



## Family strolling

### September stroll

Our flagship walking event is back this year and we would love you to be part of it. Organise your very own September stroll this autumn, get back to nature and explore your local countryside with family and friends as part of #teamcardio.

**Location** – Your choice  
**When** – Throughout September  
**Distance** – Your choice

To register or get more information, please visit:  
[cardiomyopathy.org/sep-stroll](http://cardiomyopathy.org/sep-stroll)



## 10km – 29 May

### Vitality 10,000

Join #teamcardio this year for London's greatest 10km. The Vitality London 10,000 offers all of the sights and sounds of its big brother, the London Marathon, but over a shorter 10km course.

**Location** – St James's Park, London  
**When** – 29 May  
**Distance** – 10km

To register or get more information, please visit:  
[cardiomyopathy.org/london-10000](http://cardiomyopathy.org/london-10000)



## London abseil – 17 June

### Abseil day

Experience the most spectacular views of London from 80m up by taking on a free-fall abseil off the famous ArcelorMittal Orbit sculpture. Take in the sights of the capital from the Queen Elizabeth Olympic Park for Cardiomyopathy UK.

**Location** – Queen Elizabeth Olympic Park, London  
**When** – Saturday 17 June

To register or get more information, please visit:  
[cardiomyopathy.org/obstacle/abseil-day-june-2017](http://cardiomyopathy.org/obstacle/abseil-day-june-2017)

### Superhero Run ★ ★

14 May



Whether you're a Cat Woman or Batman, come and join ★ #teamcardio for the Superhero Run this spring in Regent's Park, London.

You can choose between a 5km and 10km race and, with prizes for the best costume, creativity is encouraged. ★

To register or get more information, please visit:  
[cardiomyopathy.org/superhero](http://cardiomyopathy.org/superhero)

### Peru trek

April – October each year



This ten day challenge to Macchu Picchu, the 15th Century Inca citadel high in the Andes Mountains, offers a glimpse into the Peruvian way of life as well as taking you to the famous, breathtaking ruins nestled between the peaks.

To register or get more information, please visit:  
[cardiomyopathy.org/machu-picchu](http://cardiomyopathy.org/machu-picchu)

## GET INVOLVED

To take part in any of these events just email [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org) or call 01494 791224. We provide a free fundraising pack with a t-shirt or running vest – and can help you smash your target!





# Dates for your diary

## April

*Saturday 8 April 9.30am*

### Kent Support Group

Mercure Maidstone Great Danes Hotel, Hollingbourne, Maidstone, ME17 1RE  
GP Dr Paul Roome, who is affected by cardiomyopathy, will be talking about exercise and building a good working relationship with your GP.  
For details email Colin McVittie, cardio myopathykent@gmail.com

*Saturday 8 April 2pm-4pm*

### North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle  
Julie Goodfellow, cardiac genetics nurse, will be discussing patients' experiences of cardiac care services in the North East  
For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

*Sunday 9 April noon-3pm.*

### West Scotland Support Group

Boardroom, Glasgow Royal Infirmary, Castle Street, Glasgow, G2 3NY  
Informal meeting, including discussion on the development of the group  
For more details contact Jo Franks on 01494 791224 or email jo.franks@cardiomyopathy.org

*Saturday 22 April 9.30am-4.30pm*

### Cardiomyopathy information day

Novotel, Grey Friars Rd, Ipswich IP1 1UP  
For details, see the panel below

*Tuesday 25 April 2pm*

### Cornwall Support Group

Inn for All Seasons, Treleigh, Redruth TR16 4AP  
Sam Dimmock, specialist cardiac nurse, and Dawn Foss, specialist cardiac physiotherapist, will talk about community cardiac services in Cornwall  
For more details contact Eric on 01736 351439

*Saturday 29 April 2pm-4pm*

### Surrey Support Group

Post Graduate Education Centre, St Peter's Hospital, Guildford Road, Chertsey, Surrey, KT16 0PZ  
Speakers are specialist heart nurse Liz Murphy on exercise and cardiac rehabilitation and pharmacist Carolyn Adamson on heart medications.  
Email tracey.bradshaw@asph.nhs.uk

*Saturday 29 April 3pm*

### North London Support Group

Finchley Memorial Hospital, Granville Road, London, N12 0JE  
For details contact Jane Barnett on 0208 343 1940 or jane@email58.co.uk

## May

*Saturday 13 May 9.30am-4.30pm*

### Cardiomyopathy information day

Edinburgh Training and Conference Centre, 16 St Mary's Street, Edinburgh EH1 1SU. For details see panel below

*Tuesday 23 May 6.30pm-8.30pm*

### Fareham, Portsmouth and Gosport Support Group

Community Action Fareham, 163 West Street, Fareham, Hants, PO16 0EF  
Main speaker is Cardiomyopathy UK support nurse Robert Hall  
For details contact Sue Bailey on 01329 285733 or sabailey53@btinternet.com

*Thursday 25 May 2pm-4pm*

### York Support Group

Friargate Quaker Meeting House, Friargate, York, YO1 9RL  
Heart failure nurse Caroline Jones, York Teaching Hospital NHS Foundation Trust, will be speaking on cardiac rehabilitation, diet and exercise  
For details contact Jo Franks on 01494 791224 or jo.franks@cardiomyopathy.org

*Wednesday 31 May 7pm-9pm*

### Milton Keynes Support Group

Oxley Park Community Centre, Redgrave Drive, Oxley Park, Milton Keynes, MK4 4TA  
Cardiomyopathy UK's head of services Ali Thompson will be discussing benefits and welfare, and Dr Kelly Morris, Northampton General Hospital NHS Trust, research into cardiomyopathy  
For details contact Jo Franks on 01494 791224 or email jo.franks@cardiomyopathy.org

## June

*Saturday 3 June 9.30am-4.30pm*

### Cardiomyopathy information day

Kala Sangam Arts Centre, St Peter's House, 1 Forster Square, Bradford BD1 4EH

For more details see panel below

*Wednesday 7 June 7pm-9pm*

### Ipswich Support Group

The Meeting Place, Limerick Close, Whitehouse, Ipswich, Suffolk IP1 5LR  
Main speaker is Cardiomyopathy UK support nurse Robert Hall on cardiomyopathy and genetics  
For more details contact Jo Franks on 01494 791224 or email jo.franks@cardiomyopathy.org

*Thursday 8 June 7pm*

### Cheshire and Merseyside Support Group

Outpatient Department, Liverpool Heart and Chest Hospital, Thomas Drive, Liverpool L14 3PE  
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

*Saturday 10 June 2pm*

### Cumbria Support Group

Keswick Quaker Meeting House, Elliott Park, Keswick, CA12 5NZ  
Main speaker Cathy Stark will talk about living with cardiomyopathy  
For more details contact Jo Franks on 01494 791224 or email jo.franks@cardiomyopathy.org

*Tuesday 20 June 2pm*

### Cornwall Support Group

Inn for All Seasons, Treleigh, TR16 4AP  
Clinical psychologist Dr Liz Barnes will be talking about the stroke and brain injury rehab centre Wired Cornwall  
For details contact Eric on 01736 351439

*Saturday 24 June 9.30am-4.30pm*

### Cardiomyopathy information day

Southampton Solent Conference Centre, The Spark, East Park Terrace, Southampton SO14 0YN.  
For more details see panel below

*Saturday 24 June 2pm-4pm*

### Dorset Support Group

Best Western Hotel Rembrandt, 12-18 Dorchester Road, Weymouth, DT4 7JU  
British Red Cross representatives will be teaching resuscitation  
For more details contact Jo Franks, 01494791224 or jo.franks@cardiomyopathy.org

### • Support group meetings in July

*Thursday 13 July 7pm*, South London Support Group

*Saturday 15 July 2pm-4pm*, Surrey Support Group and North East England Support Group

*Saturday 22 July 2pm-4pm*, Cheshire and Merseyside Support Group (Ellesmere Port)

For more details see [cardiomyopathy.org/expert-advice/home](http://cardiomyopathy.org/expert-advice/home)

## Enquiries

If you have questions about

- our information days and support groups
- how to register for one of our events
- how we help people affected by cardiomyopathy

please phone us on **01494 791224**, email [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org) or visit our website at [cardiomyopathy.org](http://cardiomyopathy.org)



# Our i♥pact



2016 was a big year for us: we expanded our services and reached even more people who needed us.

Our new impact report is now available, with information about what we achieved over the last year.

The types of issues we dealt with on the helpline in 2016



**58%**  
Medical



**18%**  
Welfare, benefits  
and rights



**9%**  
Emotional



**7%**  
Accessing  
treatment



**8%**  
Children and  
young people



**98%**  
of people  
found service  
'very helpful'

Our information days  
around the UK

**300+**  
attendees

Glasgow

Newcastle

Belfast

Bristol

Manchester



Read our full impact report at  
[www.cardiomyopathy.org/impact2016](http://www.cardiomyopathy.org/impact2016)