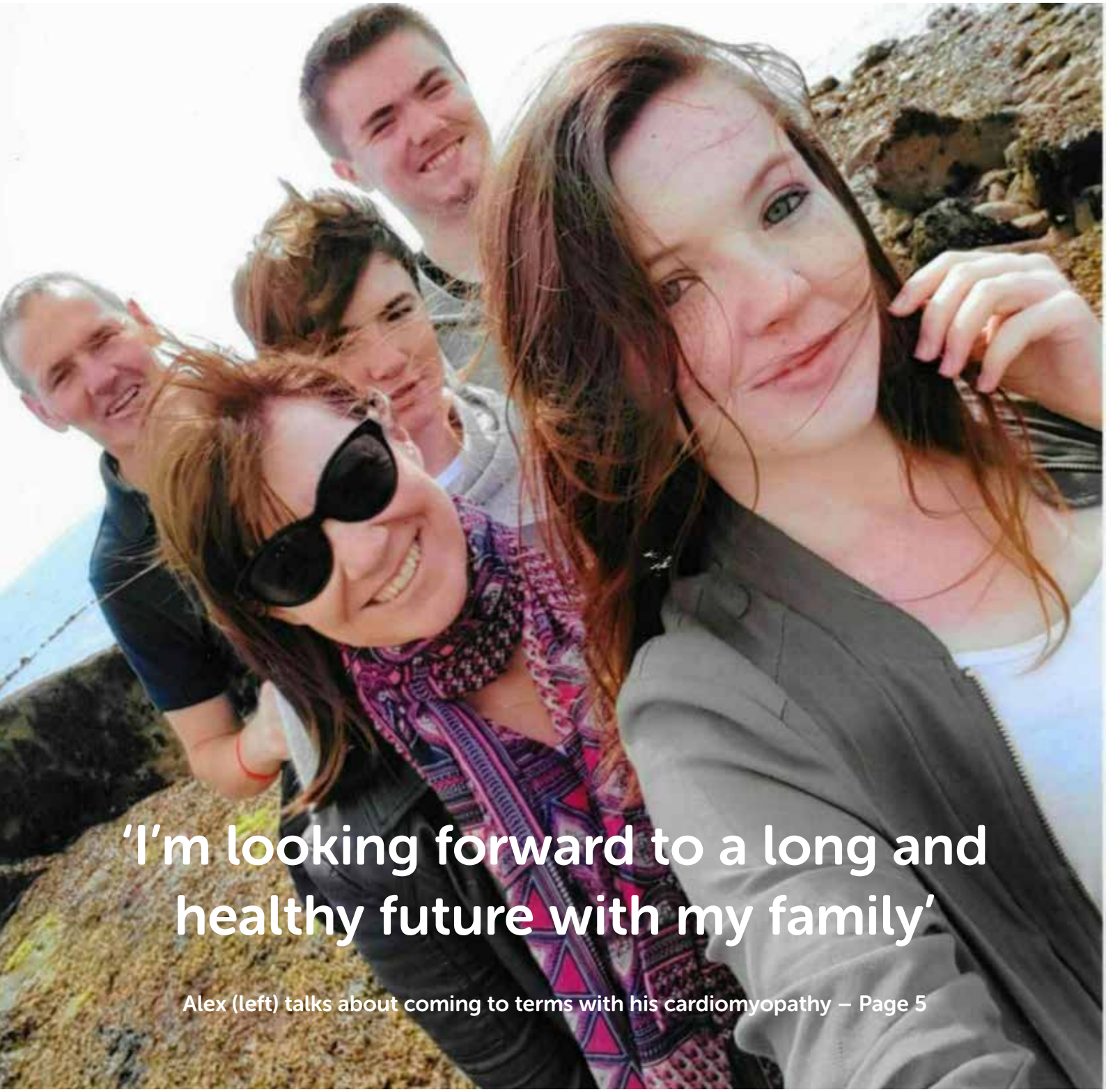
my life

The magazine from CardiomyopathyUK the heart muscle charity

Issue 11 | Autumn 2017



'I'm looking forward to a long and healthy future with my family'

Alex (left) talks about coming to terms with his cardiomyopathy – Page 5

CardiomyopathyUK
the heart muscle charity

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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

- information packs
  We have a wide range of 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.

- 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.

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Website **cardiomyopathy.org**
Helpline **0800 0181 024**
(free from a UK landline)
Email contact**@cardiomyopathy.org**

Like us on Facebook
facebook.com/cardiomyopathyuk

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Join our Facebook group
(closed privacy settings)
facebook.com/groups/cardiomyopathyuk

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

Contents

We are here for you

Chair of trustees
Alison Fielding
chair@cardiomyopathy.org

Being told that you are special is usually a good thing but when you are special because you have a rare disease, it can be very isolating. When neither you nor your doctor has heard of something it can also be frightening. I have sat in consultations whilst the doctor was reading Wikipedia in front of me! Cardiomyopathy UK is here to help anyone with a rare cardiomyopathy with information, support and someone to talk to who has the same condition. We are also happy for GPs and nurses to call our helpline as our team of specialist nurses can help them find appropriate information and resources or refer them to specialists in the field.

We would appreciate it if as many of you as possible would consider organising a 'September Stroll' to raise awareness and funds for the charity. I have decided to do one with my cousins that I haven't seen for years so that I can talk to them about their risks for cardiomyopathy before we gather with the wider family for an afternoon tea and catch up.

Rarer types

Chief executive
Joel Rose
joel.rose@cardiomyopathy.org

A few months ago, I attended a meeting for charities who support people with rare diseases. I chatted to a young man who was very excited to let me know that he was literally one in a million. His genetic condition was so unique that there were only a handful of people like him in the country. This got me thinking about how important it is that people are given the most accurate and specific diagnosis possible and treated in a way that is best for them as individuals rather than being lumped together under the banner of "heart disease".

We want to do more as a charity to highlight some of the less common forms of cardiomyopathy and make sure that we have the right support and information available for people who are affected by them. That is why we have recently updated our information resources and made sure that at our national conference we can run a wider range of information sessions so that there is something for everyone.

It is important to remember though that while we are a community of individuals, each with their own unique needs; when we come together we can do fantastic things. Our teams of volunteers, fundraisers and supporters are testament to this and I am always amazed by the commitment that they show. There would be no Cardiomyopathy UK without them.

New youth panel helps sets up services for children and young adults

New services aimed specifically at children and young people are being set up by Cardiomyopathy UK.

A special panel of young people affected by the condition has already helped to set up some services for 14-25 year olds. These comprise a Facebook page (14-25 Cardiomyopathy UK), a closed Facebook group and a Twitter account (@Cardio1425)

Ali Thompson, head of services at Cardiomyopathy UK, said: "We brought together a group of young people aged between 17 and 23, some living with the condition, some supporting another with the condition, to look at what children (aged 5-11), young people (12-17) and young adults (18-25) affected by cardiomyopathy need from us to feel better able to cope with their condition, to foster resilience and to create better informed communities.

"This group, known as the CYP&YA Panel, is responsible for working with the charity, healthcare providers, educational establishments and employers to ensure that young people with cardiomyopathy are fully supported and represented fairly.

"We have long recognised that there is a dearth of information and peer support services available nationally for children, young people and younger adults affected by cardiomyopathy.

"We decided that we wanted to change this and work with young people and younger adults to create services appropriate to their age and understanding that accurately reflect their needs."

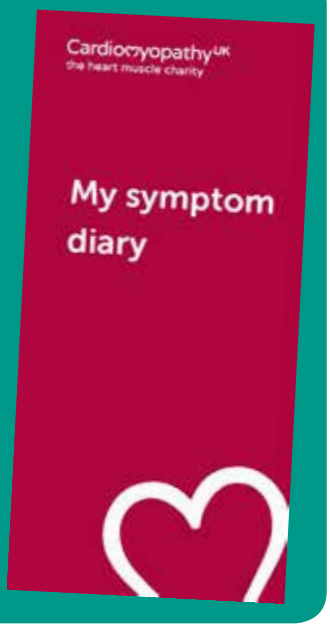
The closed Facebook group is for young people who want a confidential and safe space to ask questions from our children's support nurse, take advantage of peer support and to share their tips for living well with the condition. At the panel's last meeting in June, members began looking at literature and web content aimed at children, young people and young adults.

Ali added: "The panel wants to ensure that young people are able to get the type of resources and support they need at the time they need it."

Panel member Rosie said: "Young people deserve to be noticed, considered and have a voice too. If they can't be heard or don't have the confidence to stand up for themselves, they deserve someone to speak for them."

• Members of our new young people's panel are pictured above

Get your symptom diary



Cardiomyopathy UK has published a diary to help people with cardiomyopathy record their symptoms, heart readings and key medical information.

The 28-page diary enables you to record symptoms (such as breathlessness and palpitations), your readings (such as weight and heart rate), exercise, sleep and mood levels, drug treatments (including side effects) and also information about your care team and appointments.

It was written with suggestions from people living with cardiomyopathy and contains tips from them on living well with cardiomyopathy.

You can take your diary to appointments to show your medical team how you are doing.

To get your copy, call us or email services@cardiomyopathy.org

Coping with worry

Graeme Gillespie | consultant clinical psychologist, Northumbria Healthcare NHS Trust

In the first of a two part article, Graeme discusses what worry is and some ways of dealing with it. In part two (in the winter edition of My Life) he will outline a number of practical ideas for easing the more persistent worries we may find hard to shake off

We know from a recent survey of people living with cardiomyopathy (**cardiomyopathy.org/psychology-needs**) that it can be hard to be open about difficult thoughts and feelings.

Discussions with healthcare professionals can be dominated by a focus on physical symptoms and treatments, with various factors getting in the way of openness about emotional wellbeing.

Our emotions are very personal and sometimes it is hard to discuss them in a busy, time-pressured clinic appointment.

But avoiding the subject can be a barrier to getting help, which can keep difficulties festering. One type of difficulty, which we all experience at times, is worry.

Would you describe yourself as a worrier? Do the people closest to you often tell you to 'stop worrying'? It is not unusual for people living with cardiomyopathy to worry about it some of the time.

Ill health, such as cardiomyopathy, can kick-start worrying. What are these tablets doing to me? What if my symptoms get worse? What will it feel like if my ICD fires?

Partners and family members can also struggle with cardiomyopathy worries. Is he doing too much? What if she makes herself ill?

But what can you do if worry gets a hold of you, won't let go and is spoiling your life?

A useful first step is learning to understand what worry is and why it can affect us so much.

Worries are closely linked with anxiety, which is related to fear. And although it is a sensation we usually want to avoid, fear, just like pain, is there to protect us.

A quotation which sums up the effects of unhelpful worry is by the French essayist Michel de Montaigne, who said;

"My life has been full of terrible misfortunes....most of which never happened."

Anyone who has struggled with worries will know what that can feel like.

In many ways, fear and anxiety are our friends. Fear alerts us to something we see as dangerous which is actually present in our environment. Anxiety and worry come along when we think about something potentially threatening, dangerous or harmful.

Worries are thoughts about something threatening or catastrophic happening in the future, often starting with 'What if....?' questions. As we are evolved for survival, our instincts push us towards focusing on possible threats. Worry can certainly attract our attention and not easily let go.

So worry is just a type of thinking. Sometimes it can help us remember there is something important we must do or attend to. But often we may be worrying about something bad which hasn't happened or which we can't do anything about.
Our thinking only really helps us if it leads to helpful actions or emotions.

A good question to ask is how useful is this worry? Is this worry just an unhelpful thought that goes round my head like an unhelpful bee in the bonnet? Or is the worry telling me that I need to do something? Is it a thought I should keep paying attention to?

If you or a loved one is living with cardiomyopathy, how can you tell what sorts of worry are helpful or unhelpful?

It can be quite difficult to know whether or not we should be worrying. For example, is a racing heart a symptom I need to report, or just a sign of being anxious, which I can safely self-manage?

A sensible strategy is to check it out with someone you trust in your healthcare team. If you are worrying about a change in your symptoms, that could be helpful too because you can act on it. You could discuss the change with a trusted healthcare professional.

A worry about what to do if your internal defibrillator (ICD) fires could also lead you to ask for advice.

If you are worried about changes in your medication, again you could ask to have the reasons explained.

If possible, try to let your healthcare worker know early on in a consultation that there is a worry you would like to ask them about. That way they know to make some space for it somewhere in the meeting.

In the next edition of My Life, we will look at some approaches for dealing with those unhelpful worries which just won't go away, even after you've tried discussing them with someone you trust.

We're appreciating each other more

Alex Robinson's story

Alex has found that being diagnosed with left ventricular non-compaction and dilated cardiomyopathy is not the death sentence he first feared that it was.

I was diagnosed with cardiomyopathy two years ago at the age of 42. I felt there was something wrong with my heart for some years as I had frequent palpitations and would be so dizzy I'd have to grab onto things to keep me upright.

I had seen a few doctors who had told me to avoid stress, drink less coffee and alcohol, buy a bike and exercise more, all of which didn't help.

Eventually my GP reluctantly agreed to me having a 48 hour Holter monitor to record my heart rhythm. A few weeks later I got a call at work telling me to pack a bag and go to A&E immediately. The monitor had shown episodes where my heart was racing up to 180 bpm (normal resting rate is 60-100bpm).

In left ventricular noncompaction cardiomyopathy, the walls of the left ventricle are noncompacted and spongy, affecting the heart's ability to pump For more details, see page 8/9

I was admitted to hospital for checks and discharged with a bag full of beta-blockers and ACE inhibitors and an appointment for an MRI. For someone who'd never taken an aspirin this was a shock.

After the MRI, my follow-up appointment with the cardiologist was forwarded by a month. He said I had a condition called cardiomyopathy. My heart was enlarged and there was a 50 per cent chance each of my three children would inherit the disease. It was such a stressful time as my daughter Dara was taking her A'levels and my son Oran was doing his GCSEs. I was struggling to accept my own diagnosis and battling with the guilt that I could have passed the condition on to them.

My wife Marie was very positive through the many early appointments but later she told me she would have panic attacks while alone as she feared she was about to lose her entire family.

We were referred to the inherited cardiomyopathy clinic at the Royal Brompton Hospital in London. There it was confirmed that I had left ventricular non-compaction (LVNC) and dilated cardiomyopathy (DCM). The clinical nurse specialist Bethan has been a great support and the whole team are so reassuring.

Because I continued to have dangerous heart rhythms despite my medication, I was given an internal defibrillator (ICD). I was very resistant to the idea of an ICD, mainly because I was worried about the impact on my work as a self-employed builder, life in general and the financial implications of taking time off to have the device fitted. I'm still frightened to exercise in case the ICD fires and I still haven't managed to get my driving licence back as the DVLA are not satisfied that my condition is under control.

Losing my licence has been difficult as we live in a village with poor transport links. Marie has to get up at 5.30am to take me to the station to catch a train to work. My condition is now stable and I have started cardiac rehab. I often forget my ICD is there and am extremely grateful it will keep me safe if I ever have a cardiac arrest.

As I'm adopted, genetic testing has not been straightforward but the team at Brompton are confident they have identified a genetic cause for my condition. My children will now undergo genetic testing. I hope they all get a negative result but I also hope to show them that having cardiomyopathy is not the death sentence I initially believed it was.

As a family we are closer than ever and have learnt to appreciate each other and the time we spend together. I couldn't have got through it without Marie. It is important to recognise the strain a diagnosis of cardiomyopathy has on partners whose lives also change forever. I am also immensely proud of my children. Being teenagers and facing all the difficulties that brings, as well as having to come to terms with my diagnosis and the possibility they have inherited the condition, is such a burden. I am so lucky they remain positive and happy and take it all in their stride.

I am looking forward to a long and healthy future with my family.

• Alex is pictured with his family (front) and (above left) with (from the left) Grady, Oran, Marie and Dara.

I'm enjoying my early retirement

Shirley Woodhouse's story

Worsening restrictive cardiomyopathy meant Shirley had to reluctantly give up work but now she is enjoying her retirement in Cornwall and looking forward to many more happy years there

At 31 I had a bad dose of flu which didn't clear up. I took several weeks off work but went back even though I felt dreadful. As long as I kept busy, I didn't seem too bad.

Then a worried friend pressed me to see my doctor. My GP found my heart was racing and out of rhythm and booked me an ECG.

In those days, very few people had heard of cardiomyopathy. The doctors were convinced I had mitral valve disease, probably caused by rheumatic fever which they said I must have had as a child, and I would eventually need a valve replacement. I was put on medication and had a cardioversion (a treatment to restore normal heart rhythm) which only worked for a while.

In restrictive cardiomyopathy, the muscle walls of the lower chambers of the heart become stiff. This restricts the movement of the heart.
For more details, see page 8/9

While visiting my parents in Singapore they urged me to see their private doctor. He agreed with the treatment but felt I should recover and not need a valve replacement.

Back home my cardiologists decided I might have restrictive cardiomyopathy, for which the only cure was a heart transplant. One doctor described the condition as a bit like a blow-out in a bicycle tyre, which could not be repaired only replaced. Another described it as being like a car seatbelt, restricting me when I overdid things.

Before this I was working in a stressful claims office. They offered me another role but I decided to leave. Feeling somewhat better after nine months, the NHS found me a job in a quiet office as a clinical coder (translating diagnoses and treatments into codes for statistical purposes). I worked three hours a day with an hour's lunchbreak and slept every afternoon. Gradually my health improved and I worked up to full-time. When I became ill again a few years later, I worked a four day week with Wednesdays off. For many years I continued in this job. I lived a normal life, moving to a larger house, taking in lodgers, being involved in church activities, gardening, going for long country walks and travelling abroad.

When my heart worsened at 49 my consultant suggested a cardiac catheterisation procedure to confirm my diagnosis. Although doctors wouldn't be able to do anything more to help and we knew there was a high risk of me having a stroke, I consented. I then had a stroke at home a few days later and spent a week in hospital, including my 50th birthday.

My parents looked after me at home and then I went to their home in Cornwall to recuperate. My left side was affected, but I could still walk and do most things slowly. I decided to move to Cornwall to be near my family.

To get over retirement and the feeling life had no purpose, I decided I was permanently on holiday. But I soon made friends and got involved in a church. I started volunteering at a charity shop where I mainly do filing. I also walk various dogs for a charity that helps elderly people look after their pets, and am now fostering an older dog for them.

The cardiologists check me each year. I was referred to London to consider a heart transplant but I wasn't keen. There are so few hearts available and I would rather one went to a younger person with a family.

Recently I have experienced more stroke-related problems with my left hand and foot. I get excellent care but no one can be sure how much things may improve. Stress certainly makes things worse and the Department of Work and Pensions deciding I was fit to work didn't help. Thankfully I now have two pensions coming in and savings which pay my bills.

I found there was a Cardiomyopathy UK support group in Cornwall which I joined and have found very supportive. Life is good and I'm looking forward to more happy years.

• Shirley is pictured out walking at St Mawes on the Fal Estuary

Learning to avoid stress

Caron Curragh's story

Caron devoloped takotsubo cardiomyopathy after two stressful incidents close together

I am an ex-ballet dancer who has kept fit by practising and teaching pilates. I don't smoke and have a healthy diet.

Four years ago, just after having a medical procedure on my back, a car drove into the back of me in a road accident. I had many sleepless nights as I was in a lot of pain and unable to teach.

Four weeks later my life changed even more dramatically. After having an unexpected, stressful incident with two members of the public, I felt a sudden, searing left-sided chest pain which radiated rapidly to my left shoulder blade and arm.

When my breathing pattern changed and I started to feel clammy and nauseous, I knew something was very amiss.

Takotsubo cardiomyopathy is a type of heart failure often brought on by stressful events. For many it is temporary but others face ongoing symptoms. For more details, see page 8/9

The paramedics arrived swiftly and after enduring an eight hour wait in A&E, I was admitted to a ward the following morning. My ECGs were all irregular and worrying blood tests led me to spending six hours in cardiac care. I was then transferred to a specialist hospital where tests confirmed my heart problem.

The cardiologist asked me if I wanted the good news or the bad news first. The good news was that I had clear arteries. The bad news was that I had acute heart failure due to takotsubo cardiomyopathy (TTC). Like many people, including some doctors, I hadn't heard of this condition. I believe the combination of two stressful events caused my heart failure.

I'm very keen to raise awareness of the condition with the general public and the medical community. TTC is still unrecognised or misdiagnosed and it can be life-threatening. Five months on I still had chest pain and other issues. Two nuclear scans (a radioactive tracer is put in a vein in the arm and absorbed by tissues and organs which are then photographed by a special camera) showed there was still an electrical storm going on in my heart. I was much relieved there was a reason for the way I was feeling.

Today I'm physically so much better. I still get daily heart rhythm problems and have had two unsuccessful procedures to help stabilise these arrhythmias. Anti-arrhythmic drugs don't help. So I self-monitor using a portable ECG recorder that works with a smartphone. I can always get a report through to my specialist if I have any concerns. My energy levels are good and my zest for life is back.

Because my TTC was stress induced I'm determined not to have a repeat episode. This led me to studying neuroscience and neurobiology, and now for an MSc in clinical psychotherapy and clinical hypnotherapy. Once qualified, I want to set up a practice to help people overcome stress and worry after being diagnosed with a heart problem. It will enrich my pilates work with people who are in chronic pain. Last year, I set up a facebook support group. It has approaching 400 members from around the world as well as doctors and nurses. I'm also helping to organise a takotsubo day at the Royal Brompton Hospital in London on Thursday, 24 August.

TTC encouraged me to re-evaluate my work/life balance and made me realise how precious time is. So now I have five teachers working for me and I choose the hours I want to work.

• Caron is pictured with her husband Brian

More cardiomyopathy factsheets

Six new factsheets, including ones on medical jewellery and driving, have been published by Cardiomyopathy UK for people with the disease.

The other factsheets cover support for carers, the Equality Act, and haemochromatosis, where a build-up of iron in the body can lead to cardiomyopathy.

There are two driving factsheets, one looking at group 1 drivers (of vehicles including cars and motorcycles) and one at group 2 (drivers of vehicles including large lorries and buses). Our other factsheets cover

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

The factsheets can be found at **cardiomyopathy.org/factsheets** and downloaded as a PDF or call the office for copies.

Information 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.

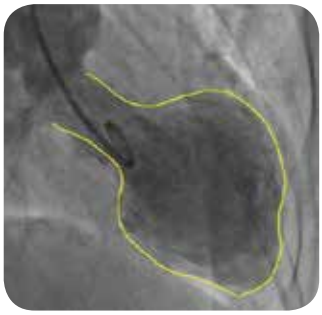
The booklets are downloadable from our website. For hard copies email services@ cardiomyopathy.org

Spotlight on rarer types

Robert Hall | cardiomyopathy support nurse, Cardiomyopathy UK

Robert gives a brief overview of some of the rarer types of cardiomyopathy

Takotsubo cardiomyopathy



Takotsubo heart and the octopus pot the disease is named after

Takotsubo cardiomyopathy most commonly affects women, rather than men, over the age of 50. The left ventricle of the heart can enlarge (see above scan) and reduce the effectiveness of the heart's pumping action.

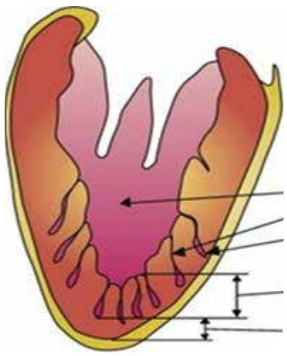
The condition was first described in Japan in 1990. Takotsubo is the name of a Japanese octopus trap, which is a similar shape to a heart with this condition (see above right).

The exact cause of the disease is unclear. The condition is thought to be linked to high levels of stress and emotion, resulting in it being occasionally referred to as 'broken heart syndrome'. It is also known to be linked to acute head injuries. But in almost one in three cases the cause is unknown.

Symptoms include chest pain, breathlessness and palpitations. Treatment is similar to that of any heart failure condition, principally with ACE inhibitors and beta blockers. The changes in the heart resolve in the majority of people after a few weeks but sometimes symptoms persist.

For more details, including our factsheet on takotsubo cardiomyopathy (right), see cardiomyopathy.org/takotsubo-cardiomyopathy/intro To request a copy of our factsheet, email **services@cardiomyopathy.org**

Left ventricular non-compaction



Left ventricular non-compaction (LVNC) is a condition where small channels, known as trabeculations, are found in the heart muscle walls. It is thought this is due to a fault when the heart is forming as an embryo in the womb and the muscle tissue fails to compact sufficiently.

Debate still exists on whether this is a cardiomyopathy in its own right, or whether it's a natural variant or associated with another form of cardiomyopathy, such as dilated cardiomyopathy. There is currently no universally agreed diagnostic criteria.

Treatment will depend on the extent and vicinity of the trabeculations and their effect on the heart's function. For example, if the trabeculations significantly reduce the heart's pumping action, then heart failure therapy such as ACE inhibitors and beta blockers, may be prescribed.

Where the trabeculations interrupt the electrical conducting system of the heart, a pacemaker will be required.

The condition is known to be genetic, and screening of immediate family relatives is advised.

For more details, including our factsheet on LVNC (right), see **cardiomyopathy.org/left-ventricular-noncompaction/intro**

For a copy of our factsheet, email **services@cardiomyopathy.org**

# of cardiomyopathy

Peripartum cardiomyopathy

Peripartum cardiomyopathy is similar in presentation to dilated cardiomyopathy and can occur in women in the last month of pregnancy or the ensuing five months following the baby's birth.

While relatively rare there are geographic variations in the incidence of the condition, generally said to be between one in 1,000 to 4,500 live births.

The cause remains uncertain with genetics and an auto-immune response being implicated.

Symptoms of the condition include breathlessness, fluid retention, fatigue and palpitations. Awareness of the condition is essential as it is important not to assume these are merely the effects of pregnancy. Treatment is the standard heart failure therapy. Many women recover, though some will require ongoing treatment.

Plans for future pregnancies need to be discussed with a cardiologist so that the individual level of risk for the mother can be assessed. For more details, see **cardiomyopathy.org/peripartum-cardiomyopathy/intro**

Restrictive cardiomyopathy

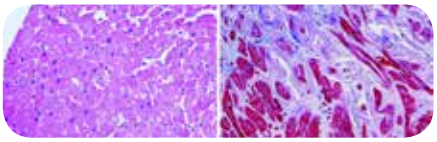
This is a condition where the heart becomes stiff, has difficulty filling with blood and the output from the heart is reduced. The condition is classified as idiopathic (cause is unknown) and due to scarring of the heart tissue, or related to other conditions such as sarcoidosis or haemachromotosis. Two other known causes, amyloidosis and Anderson Fabry disease, are discussed later in this article.

The condition represents approximately five per cent of all cardiomyopathies in Western populations. Symptoms include breathlessness, fluid retention, fatigue and palpitations. Treatment will include the standard heart failure therapy and possible treatment of the underlying cause.

For more details, including our factsheet on restrictive cardiomypathy, see **cardiomyopathy.org/restrictive-cardiomyopathy/intro** For a copy of our factsheet, email **services@cardiomyopathy.org**

• Cardiac amyloidosis

Cardiac amyloidosis is a cause of restrictive cardiomyopathy, more commonly affecting older people. It is a rare condition where abnormal protein cells, known as amyloid, are deposited in the walls of the heart and other organs.



Normal heart and heart with amyloid

This can result in the heart becoming stiff and its filling with blood becoming restricted.

On echocardiogram the changes to the heart may appear similar to those of hypertrophic cardiomyopathy, with thickened muscle, and electrical conduction abnormalities like heart block are common. The person may also have carpal tunnel syndrome and a family history of neuropathies.

Treatment is focussed on supporting the heart and, where possible, reducing the deposit of amyloid in the body's tissues.

• Anderson Fabry disease

This cause of restrictive cardiomyopathy is a metabolic disease (it disrupts the normal metabolism) where there is an insufficient supply of the enzyme alpha-galactose A. This substance breaks down fatty substances in the cells.

The lack of the enzyme causes a build-up of waste products in the cells which can progressively cause damage to some organs. These can include the skin and kidneys, as well as the heart.

The condition can be passed on through families and it is estimated that it affects approximately one in 40,000 people.

Treatment consists of supporting the heart and replacing the alpha-galactose A through enzyme replacement therapy.

How services have changed in 13 years

Departing My Life editor Sarah Dennis reports

Care for cardiomyopathy patients has improved drastically in my 13 years with Cardiomyopathy UK, but that's not to say all patients get the best care or that things are going to get even better in the future.

And many of the worries that diagnosed people and their families face are still the same as they were a decade or more ago and undiminished.

Back in early 2004 the situation for many cardiomyopathy patients was difficult:

- Medical knowledge of cardiomyopathy was not widespread
- Clinics dedicated to inherited heart conditions like cardiomyopathy were in their infancy and few and far between
- Very few people with any type of cardiomyopathy, even if there had been a death in the family, were told to get family members checked
- Many doctors did not believe dilated cardiomyopathy could run in families
- Drugs such as beta-blockers and ACE inhibitors were saving lives, but many people with cardiomyopathy were not on them
- Cardiac rehabilitation was very scarce and seldom available for people with cardiomyopathy
- When cardiomyopathy patients were given their diagnosis little, if any, information about the disease was given to them by the NHS and they were left frightened and anxious

Roll on to 2017 and there are specialist inherited heart disease clinics around the country, though not room for every patient to attend them.

Doctors generally know much more about the inherited nature of all the cardiomyopathies and the need for family heart checks. Information is more readily available to affected families too through reliable published material, websites and on social media.

NICE guidelines try to ensure all people with heart problems are on the right drugs, though new research still suggests many are not on high enough doses. Guidelines also recommend people with cardiomyopathy are offered cardiac rehabilitation, though some patients still have to fight to get it.

Research has moved on rapdily in genetics enabling families to be more certain about who is at risk of developing the disease.

New treatments like stem cell therapy and gene editing may offer hope of a cure.

But the health service is under greater pressure than ever before, and there are to be curbs on the amount the NHS will spend on new drugs.

And for those affected by cardiomyopathy many of the personal issues they face have not changed at all over the years. These include the shock of getting a diagnosis of cardiomyopathy, the uncertainty about the future, worry about how the family will manage financially, and the guilt many feel about the possibility of passing the disease on to their children. So charities supporting families are just as important as they have ever been.

So though I'm leaving to retire - and will not be campaigning or reporting on these issues in the future, my colleagues have much to do to ensure people with cardiomyopathy get the best care and support available.

Tracey's award for setting up support group

Heart failure specialist nurse Tracey Bradshaw (pictured right) has won a special award for setting up a cardiomyopathy support group.

Tracey, who works for Ashford and St Peter's NHS Hospitals NHS Foundation Trust, was rewarded in the trust's staff achievement awards for our new Surrey Cardiomyopathy Support Group.

Tracey set up the group after a patient's wife asked about what local support was available.

Tracey said: "My enquiries showed there was nothing in Surrey. So I set up a group in my own time supported by Cardiomyopathy UK."

The group meets quarterly on a Saturday in Chertsey, giving people the opportunity to meet others with the same condition, provide information and to share experiences.

Speakers come from a variety of backgrounds to offer support and advice on various topics.

The next meeting is on Saturday, 15 July **at St Peter's Hospital**. For more details, see page 19.

Meeting others is so helpful

Sue Bailey (pictured right) talks about why she has set up a support group

I was diagnosed with dilated cardiomyopathy (DCM) just over a year ago after collapsing at my local swimming pool. I had been feeling increasingly exhausted and ill. Everything was a struggle and there seemed to be little joy left in my life no matter how much I slept.

While it was a relief to have an accurate diagnosis I had never heard of cardiomyopathy. I struggled for many months to come to terms with it and cope with the medication and the change in direction my life was taking.

Having always been rather in awe of the medical profession, I had to learn to question and seek a network of support that would help me make the best of things.

My husband googled DCM and found Cardiomyopathy UK, and the charity has been an absolute lifeline. Its information is really enlightening and every time I contact the team they are tremendously kind and practical.

I attended the national conference in London and got so much out of talking to and hearing from other people with the condition. It confirmed for me that talking to others is so helpful; it really assisted my mental well-being.

I also met the charity's support group manager Jo Franks who wanted to restart a Hampshire support group and I tentatively volunteered. Jo could not have been more helpful. She offered advice at every stage of setting up the Fareham, Portsmouth and Gosport group.

She has helped me with venues, speakers and organisational issues. Paul Griffin, the retired Hampshire support group leader, has also given me helpful input. Our first meeting was in May and the charity's cardiomyopathy support nurse Robert Hall was our speaker.

Our second meeting is in September and Jo has put me in touch with a retired doctor who has cardiomyopathy and is interested in speaking.

Setting up the group has been interesting and stimulating. I hope that anyone with half a mind to start one will take the plunge. Jo will offer you all the practical help you need.

To find out more about the group, contact Jo Franks (details below).

Would you like to set up a support group?

If you've been inspired by reading Tracey's and Sue's experiences and would like to help set up a support group or help with an established one do get in touch.

Full support and training will be provided so you are fully equipped to co-lead a support group with a small team of volunteers.

Our target locations are Dorset, Ipswich, Fareham – Hampshire (to assist Sue - see above), Brighton, Bristol, Bradford, Nottingham, Spalding, Cornwall and North Wales. Other locations will also be considered where two suitable volunteers apply.

Get in touch with Jo Franks, support group manager, at **jo.franks@cardiomyopathy.org** or tel 01494 791224.

Q&A

Cardiomyopathy UK's head of services Ali Thompson answers your questions on benefits

Q: I work full time and have a mortgage. Can I still apply for PIP?

A: Personal Independence Payment, or PIP, is not a means tested benefit. It is for people who need extra help because of a disability, illness or mental health condition. You can apply for PIP if you are aged 16-64, need help with everyday tasks or getting around and have needed this help for three months and expect to need it for another nine months. You must live in England, Wales or Scotland and have lived there for at least two years. You can qualify for PIP regardless of being employed or not and the amount of savings you have. PIP does not depend on previous or current National Insurance contributions either. So providing you meet the eligibility criteria, you can apply for PIP if you work full time and have a mortgage.

Q: I have been told that I should exaggerate how bad I feel to the PIP assessor. Is this right?

A: No. PIP, like other government benefits, is only for those who truly need extra support. It is important that you are honest with the assessor. Explain how your condition affects you on a daily basis and describe any fluctuations in your condition and how it makes you feel. Assessors are trained to ascertain if someone is exaggerating a claim and therefore are likely to dismiss a claim if they believe the person is giving a worst case scenario which might not be accurate. It is better to be yourself.

Q: I have had my PIP claim turned down. What should I do now?

A: If you think that your claim has been turned down unfairly you should ask the DWP to look at the claim again. This is called a mandatory reconsideration and must be made within one month of you receiving your PIP decision letter. It is better to ask for a mandatory reconsideration in writing; over the phone requests should only be made if your letter will not arrive at the DWP in enough time before you exceed the one month deadline. If you have any further evidence including from your GP, cardiologist or social worker, that might add weight to your claim, you should send this with your letter. Letters to the DWP are best sent recorded delivery.

Q: My ESA has not been paid. What should I do?

A: Having a benefit stopped by the DWP is called sanctioning and you can only be sanctioned if you have been placed in the Employment and Support Allowance (ESA) work related activities group. Those in the ESA support group cannot be sanctioned. You should have received a sanction notification letter from the DWP which will tell you why you have been sanctioned. If you do not agree with the DWP's reason for sanctioning, you should contact them as soon as possible via the ESA helpline 0800 055 6688 and apply for a mandatory reconsideration stating why you feel the sanction is unfair.

Q: I want to apply for a Blue Badge. How do I do this?

A: If you are disabled or have a health condition that affects your mobility, you can apply for a disability parking permit called a Blue Badge. It allows disabled drivers and their passengers to park nearer to where they are going. You can also apply for a badge if you care for a child with a health condition. If you are awarded certain benefits you will automatically be entitled to a Blue Badge. You can apply for a Blue Badge via your local council. See **gov.uk/blue-badge-scheme-information-council** or **gov.uk/apply-blue-badge**

Q: What help can Cardiomyopathy UK give me related to benefits and other non-clinical issues?

A: We can help you to determine what if any state benefits you might be entitled to and tell you how to apply for these. We can support you over the phone and via email to appeal against a decision not to award you a benefit. With regards employment and housing, we can give general information and advice on a range of issues including tenancy rights, threats of eviction, disclosing your condition to your employer and your rights related to the Equality Act. As we are not Office of the Immigration Services Commissioner (OISC) registered we are legally not permitted to provide immigration advice.

For more information on benefits contact our helpline 0800 0181 024 and ask for Ali Thompson, or email her at **alison.thompson@cardiomyopathy.org**

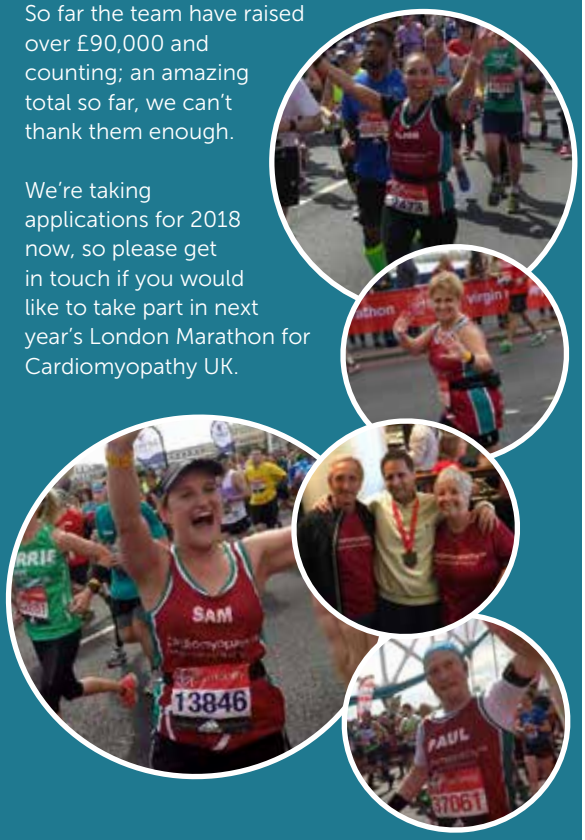
If you have a question you would like Cardiomyopathy UK to answer, email contact@cardiomyopathy.org

London Marathon 2017

Sunday 24 April saw this year's London Marathon make it's way through the streets of the capital. We were there to cheer on every single one of our 45 #teamcardio runners as they completed the famous 26.2 mile course.

So far the team have raised over £90,000 and counting; an amazing total so far, we can't thank them enough.

We're taking applications for 2018 now, so please get in touch if you would like to take part in next year's London Marathon for Cardiomyopathy UK.



wwcardiomyopathy.org/vlm2018

New resource for parents

We have recently launched an new information booklet 'Cardiomyopathy for parents and carers'.

The booklet is designed for parents and carers, but may also be useful for friends and school.

It includes information about the condition in children and young people, covering the different types of the condition and the typical symptoms.

It looks at how it is diagnosed and treatment options, as well as lifestyle issues and the impact of the condition. It also has a list of useful contacts and websites for further help and support.

We are very grateful to the individuals featured in the booklet who kindly allowed us to share their experiences.

Both resources are available from our website at www.cardiomyopathy.org. To order a printed copy go online or call the office on 01494 791 224.

Wearable defibrillator suitable for children

A new study has shown wearable heart defibrillators are safe and effective in treating children at risk of a dangerous heart rhythm

Wearable defibrillators, worn outside the body like a vest, can be used as a non-invasive alternative to an internal defibrillator (ICD) in treating people at risk of a dangerous heart rhythm.

Results of the study were presented at the Heart Rhythm Society's annual scientific sessions in America.

The vest can be used when someone is waiting for an ICD, needs an ICD replaced, is waiting for a heart transplant, or does not need a permanent ICD as their condition may improve.

In the study 455 children wore the vest for a median of 33 days. A total of 180 of the children (40 per cent) had cardiomyopathy. Most were given the vest while an ICD was repaired or replaced.

Eight received at least one shock treatment while two had one inappropriate shock each. In the six patients who had an appropriate shock, there were seven episodes of dangerous heart rhythms with a total of 13 shocks given. All episodes were successfully dealt with and all the children survived. The vests were discontinued mostly after ICD fitting, heart improvement and transplant. Seven deaths occurred and each time the child was not wearing the vest.

For more details, see cardiomyopathy.org/child-vest

Moderate exercise helps those with HCM

A new study has confirmed the benefits of moderate exercise for people with hypertrophic cardiomyopathy (HCM).

Researchers looked at brisk walking as a way of improving heart fitness in people with HCM. They found that the people in the study had no adverse events, though the study was not designed to establish long-term safety.

In the American trial researchers, including Dr Sara Saberi from the University of Michigan, looked at the well-being of 136 people aged between 18 and 80 with HCM who followed a four month structured but unsupervised moderate intensity training programme. They were asked to briskly walk for a minimum of 30 minutes between four and seven days a week. All received a pedometer and heart rate monitor.

The patients, who had a mean age of 50, had a small but significant increase in exercise capacity compared with others who kept to their normal habits.

The exercise did not trigger dangerous heart rhythms, cause a sudden cardiac arrest or make their internal defibrillators go off appropriately

For more details, see cardiomyopathy.org/HCM-exercise

Many heart-related pregnancy deaths avoidable

More than a fifth of pregnancy-related deaths are due to heart problems, and almost three in ten of those are potentially preventable, says a new study from America.

The researchers looked at maternal deaths in Illinois from 2002 to 2011. A total of 636 women died while pregnant or within a year of giving birth, producing an overall death rate of 37.1 per 100,000. Of those 140 (22 per cent) were heart related.

The most common cause was cardiomyopathy (28 per cent), followed by stroke (23 per cent), high blood pressure (13 per cent) and heart rhythm problems (almost 11 per cent). Fewer than one in ten had coronary artery disease.

Of the 39 women who died of cardiomyopathy, almost a third developed the condition during pregnancy (peripartum cardiomyopathy).

Women with cardiomyopathy who died were more likely to be younger. The death rate in the under 20s was three times that of women aged 20 to 29 years.

Cardiomyopathy UK support nurse Robert Hall said: "This study illustrates the crucial need for awareness of the possibility of cardiomyopathy in pregnancy."

For more details see cardiomyopathy.org/pregnancy-survival

Heart pumps can lead to good recovery, says small study

New research in the UK has suggested people with advanced heart failure that are given a temporary heart pump can get better.

The small study showed that some people given a left ventricular assist device (LVAD) could be successfully weaned off it if they followed a particular medical protocol designed to accelerate heart healing. Their heart function returned to normal or near normal.

The researchers from Newcastle, who published their study in the Journal of the American College of Cardiology, said the study was a further sign that offering patients LVADs for recovery could be a mainstream if not totally understood approach. At present LVADs are only permitted on the NHS for people waiting for a heart transplant.

In the observational study, led by Dr Djordje Jakovljevic from Newcastle University, of 18 patients with LVADs (16 who had the devices taken out), 24 heart-transplant candidates and 97 healthy people, the patients whose devices had been taken out achieved heart and physical powers comparable to the healthy people, with about four in ten reaching normal range for peak heart power output and about two-thirds achieving a normal range of oxygen consumption during exercise.

Taken together these findings confirm the benefits of LVAD therapy and direct future investigations to enhance heart muscle recovery and allow the device to be removed, the group wrote.

People given an LVAD might also have a different reason for their heart failure, different history of disease, be of different age, and other factors that may influence the outcomes and recovery, he said.

For more details, see **cardiomyopathy.org/pump-benefits**

Specialist hospital more important than close hospital

People who have an out-of-hospital cardiac arrest fare better when taken directly to a hospital with specialist heart care, even if a less capable hospital is closer, according to more than a decade of data from Denmark.

The researchers, Dr Tinne Tranberg, from Aarhus University Hospital, and colleagues have published the results of their large, historical follow-up study online in the European Heart Journal.

Emergency response teams typically bring cardiac arrest survivors to the closest hospital but almost a third die on their way. Most hospitals, however, are not specialised in the treatment of survivors of cardiac arrest and lack 24-hour coronary angiography and intensive care units.

The researchers used the Danish Cardiac Arrest Registry to identify 41,186 unselected patients who experienced an out-of-hospital cardiac arrest and in whom resuscitation was attempted between 2001 and 2013.

Notably, the distance to the nearest specialist centre was not associated with survival.

"These results support a centralised strategy for immediate post-resuscitation care in these patients," Dr Tranberg and colleagues concluded.

For more details, see **cardiomyopathy.org/special-hospitals**

More comfortable way to treat atrial fibrillation

People who intermittently have the heart rhythm disorder atrial fibrillation (AF) may soon be able to benefit from a less painful treatment.

The standard treatment, called a cardioversion, involves a high energy shock to the heart, designed to return it to having a normal rhythm.

But Dr Fu Siong Ng, from Imperial College, London, told the annual Heart Rhythm Society scientific sessions in America that research he is involved in shows that cardioversion can still work using a series of very low energy pulses.

He said that normal rhythm was restored using low-energy multistage electrotherapy (MSE) in nine of 16 consecutive AF patients.

MSE is thought to work by upsetting the drivers of atrial fibrillation, reducing its foothold, and stopping irregular heart wave tendencies.

Dr Ng said: "You deliver a lot less energy over a longer time, which is a totally different mechanism of stopping fibrillation."

The researchers said that MSE had been shown to work in dogs and its safety and feasibility had previously been shown in 20 people in an upublished study .

In the new study, the patients had a mean age of 61 years and just over three quarters were men. They had been diagnosed with AF for an average of four years.

For more details, see **cardiomyopathy.org/AF treatment**

Information and support needed at many key times

Cardiomyopathy patients need information and support at key times on their journey from diagnosis to learning to live with the condition, new patient-led research has shown.

As well as at diagnosis, patients particularly need information and support on discharge from hospital, when issues around family screening for cardiomyopathy arise, when their condition (such as symptoms) change in any way and when having a heart device, such as a pacemaker or internal defibrillator (ICD), fitted, said the small study carried out with support of Cardiomyopathy UK's North East England Cardiomyopathy Support Group.

Last year cardiac genetics nurse Julie Goodfellow, from the Freeman Hospital, Newcastle carried out the study with support group organiser Cathy Stark (pictured above with some members of the group), Ian Mackersie and Vera Mackersie.

They interviewed 21 people (16 people with cardiomyopathy and 5 carers) about their experiences of the healthcare system and looked at the impact of the condition on the physical and emotional health of those with the condition and their families.

Many said they experienced a paucity of information and support at critical times, and psychological support was often lacking. Their experiences of the health care system, including consultant cardiologists, GPs and specialist nurses, were mixed. They said specialist cardiomyopathy nurses were needed to answer their questions and help guide them.

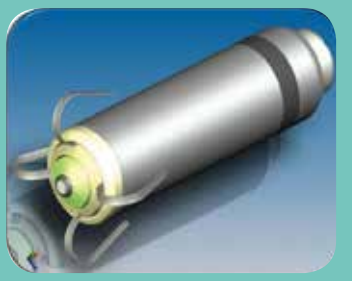
Patients and carers also had concerns about practical issues such as exercise, work and social activities.

Overall, the respondents were deeply affected by a diagnosis of cardiomyopathy, and had both positive and negative experiences in the health care system. They felt it did not fully understand cardiomyopathy or the impact it has on the lives of patients and carers.

The findings have been published in a report called Cardiomyopathy Patients' Experiences of Cardiac Care Services.

For the full report, see **cardiomyopathy.org/patients-experiences**

Few fitting problems with tiny pacemaker



The first study into the use of a tiny leadless pacemaker "in a real world setting" has shown a high implant success rate and a low risk of major complications in the first 30 days.

The data has come from a worldwide post registry study from a team including Dr Paul Roberts from Southampton General Hospital and reported in the Heart Rhythm Journal.

The Micra leadless pacemaker, which is placed directly into the heart, is the newest and smallest of Medtronic's pacemakers. It was approved in the US last year.

Much smaller than a conventional pacemaker, the Micra is about the size of a large vitamin capsule. It is fitted via a vein in the leg and is completely self-contained in the heart.

The makers believe it will lead to fewer medical complications and fewer post implant restrictions on peoples' activities.

The registry is an ongoing observational study to assess the safety and effectiveness of the Micra. It was successfully fitted in 792 of 795 people (99.6%) by 149 medical people at 96 centres in 20 countries. In the 30 days after fitting there were 13 major complications in 12 patients (1.51 per cent).

The report concluded that the rates of excess fluid around the heart, device dislodgement, and infection were low, reinforcing the positive results seen in the investigational study.

For more news stories, see cardiomyopathy.org/news

Child heart transplants not always needed

A study looking at how well children affected by dilated cardiomyopathy do concludes that those with the condition in their families are more likely to have a heart transplant and it may not always be necessary.

The multi-centre study, which may influence how children are treated around the world, was published in Circulation Heart Failure, the journal produced by the American Heart Association.

It looked at children with familial dilated cardiomyopathy and dilated cardiomyopathy of an unknown cause seen at 100 children's heart centres in America and Canada.

Researcher Dr Steven Lipshultz, from the Children's Hospital of Michigan, said that children with dilated cardiomyopathy in their families are generally diagnosed at a younger age and are more likely to receive a heart transplant or treatment such as a left ventricular assist device (a heart pump) sooner due to being identified as high-risk.

But he said the study showed that these children may not die sooner or in greater numbers than children with dilated cardiomyopathy whose cause is not known to be familial.

"This is a critical finding since some of those children with familial dilated cardiomyopathy who received a transplant might have survived without having received a heart transplant," said Dr Lipshultz.

Cardiomyopathy UK children's support nurse Sarah Regan said: "This study shows the importance of screening for familial DCM, especially at an early age, and also the importance of fully exploring the cause of all children with DCM. The majority of the children transplanted at Great Ormond Street Hospital in London recently had idiopathic DCM."

For more details, see cardiomyopathy.org/child-hearts

Trusts and corporate fundraising vital to our cause

Sheila Nardone | manager for trust, corporate and major donor fundraising, Cardiomyopathy UK

When I joined the charity a year ago, it was a revelation to me that two of my own friends had cardiomyopathy in their families – a brother and a mother – and I didn't know.

The type of fundraising I do is relatively new to the charity, enabling it to fund vital services and expand its reach to more people affected across the UK in the coming years.

We were delighted to be awarded a three-year grant of £132,340 from the Big Lottery Fund earlier this year to expand our network of support groups. In May, the Garfield Weston Foundation awarded us a generous grant of £20,000 for our core work.

It has been humbling to speak to people who are leaving gifts in their wills because they feel so passionate about helping future generations of people affected by cardiomyopathy.

Talking to people affected by the condition, I have come to understand first-hand how it impacts on peoples' lives, and how our services make a big difference at the crucial times when it is needed the most.

My job as a fundraiser is to engage potential donors to our cause and persuade them that we are the most deserving charity for their support.

A really powerful way of engaging donors is through the words or stories of the people affected. These say more than facts and figures ever can. If you are willing to write your story about cardiomyopathy, please get in touch with me directly.

Fundraising is also about making connections. Corporate social responsibility, where a business contributes to economic, social and environmental benefits is increasingly popular in the private sector and our current corporate partnerships have all come through employees with a personal connection to cardiomyopathy.

We would like to develop some new corporate partnerships. So if you have any connections or a friend or relative works for a company that might help, please feel free to give me a call and we can talk about it.

I'd love to hear from you about any of the areas of fundraising I am involved in so please contact me by phone on 01494 791224 or email **sheila.nardone@cardiomyopathy.org**

Conference for healthcare professionals

The 2017 Cardiomyopathy UK clinical conference is being held on Friday 22 September at the Cavendish conference centre in London.

This year's conference, 'Cardiomyopathy: hidden in heart failure', focuses on the importance of identifying causes of heart failure including cardiomyopathy, and the difference this makes to treatment and management.

It includes presentations from expert speakers, interactive case study presentations, and networking opportunities.

The conference is for any healthcare professional interested in cardiomyopathy. For details and online booking: www.cardiomyopathy.org/ncc2017

Heart devices and infections

Rachel Walker | cardiomyopathy support nurse, Cardiomyopathy UK

Heart devices can occasionally lead to infections. Rachel talks about what to look out for, treatment and how to help prevent them

Pacemakers and ICDs are sometimes required to treat some of the symptoms of cardiomyopathy. These devices have been used safely for many years, and the advances in technology have resulted in them being smaller and easier to implant. They can also be individually programmed to give you the best support or protection needed.

As with any medical treatment, there are risks associated with having a device implanted. One of these is the risk of infection.

What is the risk of developing a pacemaker or ICD infection?

Around one in 100 people develop a device related infection. These will often occur within a few weeks of insertion of the device, but can occur up to 12 months after implant. Very occasionally, lead infections can also occur after this time.

What do I need to look out for?

The first sign can be an increased redness and swelling around the device insertion site. Sometimes it is also warm to touch. You may also have a temperature (it is considered significant if it is greater than 38C) and leakage from the wound. If you have any of these signs, you should contact your GP. If you are unable to see your GP, you should contact the cardiology department where your device is normally checked. There may be no evidence of infection around the pacemaker site if there is a lead infection. The symptoms of this may be feeling generally unwell with a raised temperature. If you have these symptoms with no other obvious cause, you should discuss these with your doctor.

How is an infection treated?

If the infection is caught early, it can be successfully treated with antibiotics. Sometimes it is necessary to remove the device and wait until the infection has been successfully treated with antibiotics before replacing it with a new device.

How can I prevent infection?

You will be given a dose of antibiotics before the device is inserted to prevent the risk of the wound becoming infected. This is usually given in the catheter suite where the device is implanted. Follow the instructions given to you regarding care of the pacemaker wound. This may vary according to the way in which the wound is secured. So ask if you are not sure. Once the dressing is removed, you should keep the wound clean and dry. It's very tempting to touch the wound, especially as it is strange to feel the device under the skin. But just look – avoid touching and don't fiddle with it. This only increases the risk of it becoming infected. If you do need to touch the wound, wash your hands before doing so.

Sometimes clothing with shoulder straps such as bras may rub on the wound. If this is the case you should avoid wearing these until the wound has fully healed.

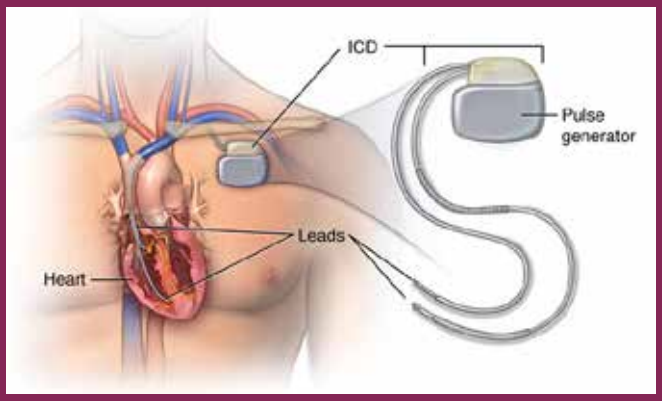
Once the wound has healed, the main sources of infection are through wounds. If you have a wound that becomes infected, you should see your GP as you may need antibiotics.

One of the most common sources of infection into our blood which can result in lead infection is through our gums.

For this reason, it is really important that you maintain good oral hygiene and visit a dentist regularly.

In the past prophylactic antibiotics (to prevent infections) were widely used prior to some medical and dental procedures. This is no longer considered necessary and so is not routinely offered.

If you have any queries about device infections, contact our cardiomyopathy support nurses at supportnurse@cardiomyopathy.org



Join us for a stroll this September

This autumn be part of #teamcardio and organise your very own September Stroll.

It couldn't be simpler; choose a date in September, a route for you to explore and invite as many friends and family as you can to join you. Whether you walk through woodland or march up a mountain you will be helping to raise awareness as well as funds to support everyone affected by cardiomyopathy.

We can provide you with everything you need to make your walk a success, including fundraising pack, collection tins, banners and t-shirts. So get in touch and let us know where you will be holding your stroll in 2017.

www.cardiomyopathy.org/sep-stroll

Wear your heart on your sleeve (or your lapel)

Show your support for Cardiomyopathy UK and be part of #teamcardio by buying some of our merchandise.

All of the proceeds from purchases go towards our support services, including our nurse helpline, young people's services and our medical education and training.

Every pinbadge, pen and t-shirt sold helps us be there for everyone that needs us, so please buy yours today!

Visit our shop at **www.cardiomyopathy.org/shop**

Pinbadge

Car sticker

Some of the Emmerdale cast in their #teamcardio t-shirts

Heart greetings card

In the summer time

Now that the good weather has finally arrived why not enjoy some sunshine filled activities and fundraise for Cardiomyopathy UK?

We've got lots of suggestions to help you get started, but the sky's the limit - whatever you enjoy can be a great fundraiser. For more ideas and to request a fundraising pack visit our website **www.cardiomyopathy.org/summer**

A few ideas to get you going...

Flower power - sell plants or seedlings and donate the profits

Sports day challenge - organise a day at your school, and ask for donations

Have a street party - really get to know your neighbours and have a party together

Outdoor movie night- choose a theme (beach movies, summer classics), sort the snacks and ask your friends and family for donations to attend

Treasure hunt - ask for donations to take part and get prizes donated from local businesses

#teamcardio highlights

Interested in being part of #teamcardio? Get in touch with our fundraising team at **fundraising@cardiomyopathy.org** or visit our website **cardiomyopathy.org/support-us**

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

Perfect pampering

Fundraiser Jenna Byrne and her friends organised a Valentine's pamper day at her beauty college in Shrewsbury complete with beauty treatments and a cake sale, raising over £170 for us

Gearing up

Lucy Dye along with sisters Rachael and Lauren, completed the Great East Anglian Run (GEAR) 10km at the end of April in memory of their father Stephen.

Between them they raised over an amazing £1,500 for us

Getting tough

Our challenge events fundraiser Sarah joined Clare Gilrtow and friends for a Tough Mudder obstacle course in Henley in honour of their friend Jill who was diagnosed in 2016. They wanted a challenge and got it! So far they have raised over £6,000

Driving success

Jackie Parker nominated Cardiomyopathy UK as her captain's charity of the year - and kick started her fundraising with a 'Drive In' during March. The London Beach Ladies Team braved the rotten weather and had a fantastic time for #teamcardio

Welsh wonders

Thank you so much to the Pencoed Ladies group who chose Cardiomyopathy UK as their charity of the year during 2016. The ladies took on events all year for us, including a sponsored walk, and raised a wonderful £1,000 to support our work

Memorial match

The 5th annual Mitchell Cole memorial football tournament was held on 13 May. Mitchell's brother Ben and friend Keith Bell, yet again organised this event and raised a record £2,200 for us. Thank you to everyone involved for their continued support

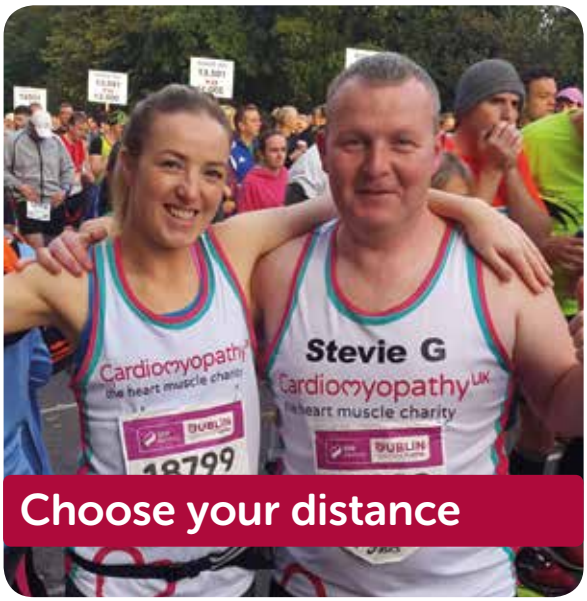
Great Birmingham Run

Join #teamcardio along with 20,000 others and take on the leading half marathon in the Midlands.

Starting in the heart of Birmingham, the route meanders through the city streets and past famous sights including Edgbaston Cricket Ground and Cadbury World before a city centre sprint finish.

Location – Birmingham City Centre
When – 15 October 2017
Distance – Half marathon

To register or get more information, please visit: cardiomyopathy.org/great-brum



Bournemouth Marathon Festival

Be part of this stunning seaside festival by running in 2017. With races from 5km right up to a full marathon, there is a distance to suit everyone.
Bournemouth Marathon Festival is one of only five races in the UK to have also been awarded a bronze status by the International Association of Athletics Federations.

There are even junior races on offer so bring the whole family. What will you choose?

Location – Bournemouth
When – 7 - 8 October
Distance – 5km, 10km, half and full marathon

To register or get more information, please visit: cardiomyopathy.org/bournemouth-marathon

Tough Mudder

Mud, ice, water and monkey bars – what more could you want?

With a choice of 5 or 10 mile courses, Tough Mudder offers you an obstacle challenge like no other. With locations all over the UK this summer, find your Tough Mudder experience. There are no stop watches and everyone receives a finisher t-shirt. So join the fun with your fellow mudders and sign up today!

Location – Various throughout UK
When – July - September
Distance – 5 mile / 10 mile

To register or get more information, please visit: cardiomyopathy.org/tough-mudder

GET INVOLVED

To take part in any of these events just email **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!

Italian Great Lakes Cycle
4 - 9 Sept 2018

See on two wheels some of the most beautiful Italian scenery. This six day trip will see you cycle over 400km tackling alpine foothills as well as the leg busting climbs of the Giro d'Italia. After flying to Milan you will make your way to Lake Como to start your challenge.

Push yourself further and take in gorgeous mountain views.

To register or get more information, please visit: cardiomyopathy.org/italian-lakes

Scottish Half Marathon
24 September

If you are looking for a half marathon personal best, you have come to the right place.

This flat course starting just outside Edinburgh takes you along the magnificent East Lothian Golf Coast before finishing in the final furlong at Musselburgh Racecourse.

To register or get more information, please visit: cardiomyopathy.org/scot-half

Dates for your diary

July

Thursday 13 July 7pm-9pm
South London Support Group
Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY
Financial advisor Bill Bartholomew, who has cardiomyopathy, will be talking about life insurance and pensions. He will also answer questions on other financial matters.
For details: Jo Franks, 01494 791224 or email jo.franks@cardiomyopathy.org

Saturday 15 July 2pm-4pm
North East England Support Group
Function Room 137, Education Centre, Freeman Hospital, Newcastle, NE7 7DN
Dr Graeme Gillespie, consultant clinical psychologist, Northumbria Healthcare NHS Trust, on self management and goal setting for people with cardiomyopathy
For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

Saturday 15 July 2pm-4pm
Surrey Support Group
Post Graduate Education Centre, St Peter's Hospital, Guildford Road, Chertsey, Surrey, KT16 0PZ
My experience of heart transplant by Peter Field, and a talk on benefit entitlements
For details email tracey.bradshaw@asph.nhs.uk

Saturday 15 July 2pm-4pm
Birmingham Support Group
Private meeting room at Station pub, 44 Station Rd, Sutton Coldfield, Birmingham, B73 6AT.
Learn more about self-help techniques with GP Dr Sam Finnikin.
For details email Ross MacKinlay at ross@pdsoft.co.uk

Sunday, 16 July noon-3pm
West Scotland Support Group
Glasgow Royal Infirmary, Castle Street, Glasgow, G2 3NY
Group discussion on resources and sources of support for people affected by cardiomyopathy
For more details contact Stephen Kirkham at sg.kirkham@btinternet.com

Enquiries

If you have questions about
- **support groups**
- **how to register for one of our events**
- **how we help people affected by cardiomyopathy**

Phone us on **01494 791224**, email **contact@cardiomyopathy.org** or visit our website at **cardiomyopathy.org**

Thursday 20 July 6pm-8.30pm
Late Helpline opening
Cardiomyopathy UK cardiomyopathy support nurse Robert Hall answering medical questions in real time through our website. Head of services Ali Thompson will be handling queries on other issues such as benefits.

Saturday 22 July 2pm-4pm
Cheshire and Merseyside Support Group
Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL
Speakers are cardiomyopathy support nurse Robert Hall, Cardiomyopathy UK and Gilbert Wheeler, Cardiomyopathy UK patient ambassador and heart transplant recipient
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

Saturday 22 July 2pm-4pm
Dorset Support Group
Best Western Hotel Rembrandt, 12-18 Dorchester Road, Weymouth, Dorset, DT4 7JU.
British Red Cross will be teaching CPR
For details Jo Franks, 01494 791224 or email jo.franks@cardiomyopathy.org

August

Saturday 19 August noon -2pm
Wiltshire Support Group
New Hall Hospital, Bodenham, Hampshire, SP5 4EY
Subject to be confirmed
For details, contact Mark Blackburn mark_b_869@hotmail.com

Tuesday 22 August 2pm-4pm
Cornwall Support Group
Inn for All Seasons, Treleigh, TR16 4AP
Community pharmacist Jacob Solarz, Boots, St Austell on pharmacy services and support in your community
For details contact Eric on 01736 351439

September

Saturday 9 September 2pm-4pm
Hampshire - Fareham, Portsmouth and Gosport Support Group
Wallington Village Hall, Broadcut, Fareham, PO16 8ST
Retired GP Dr Michael Watson, who has cardiomyopathy, on how a normal heart develops and how problems arise.
For details Sue Bailey on 01329 285733 or sabailey53@btinternet.com

Friday 22 September.
Cardiomyopathy UK national clinical conference
Cavendish Conference Centre, Duchess Mews, London W1G 9DT
Event for cardiologists and heart nurses. Let your medical team know.
For more details contact Rona Eade on 01494 791224 or email rona.eade@cardiomyopathy.org

October

Thursday 2 October 7pm
South London Support Group
Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY
Cardiomyopathy support nurse Robert Hall, Cardiomyopathy UK, on latest advances in cardiomyopathy treatment
For more details see panel below

Saturday 7 October 2-4pm
Dorset Support Group
Best Western Hotel Rembrandt, 12-18 Dorchester Road, Weymouth, Dorset, DT4 7JU
"The reasons why- Development of the heart" Dr Watson

Saturday 7 October 2pm-4pm
North East England Support Group
Function Room 137, Education Centre, Freeman Hospital, Newcastle, NE7 7DN
Dr Chris Eggett, cardiac scientist and senior lecturer at Newcastle University, on heart investigations, including echos, in cardiomyopathy
For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

Saturday 7 October 11am-2.30pm
South Wales Support Group
Education centre, top floor of new main entrance, Morriston Hospital, Swansea SA6 6NL
Topic to be confirmed
For details hannah.goss@wales.nhs.uk

Thursday 19 October 7pm-9pm
Cheshire and Merseyside Support Group
Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL
Heart failure nurse Diana Astbury on her role and her recent research into how effective information packs are after diagnosis
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

November

Saturday 18 November
Cardiomyopathy UK national conference
Royal National Hotel, 38-51 Bedford Way, Bloomsbury, London WC1H 0DG
More details to be announced shortly.
See our website

Cardiomyopathy UK

the heart muscle charity

Come and join #teamcardio this autumn and organise a September Stroll in your local countryside for Cardiomyopathy UK

See page 16 for details

Join us for a stroll this September

contact@cardiomyopathy.org