

my life

The magazine from **Cardiomyopathy^{UK}** the heart muscle charity

Issue 09 | January 2017

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But walking, tai chi and cardiac rehab
have restored my self-worth'**

Suzanne talks about coping with the emotional impact of having cardiomyopathy – Page 5



Photo credit: Jonathan Becker,
News and Star, Carlisle

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 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.



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Like us on Facebook

facebook.com/cardiomypathyuk

Follow us on Twitter

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Join our Facebook group

(closed privacy settings)

facebook.com/groups/cardiomypathyuk

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

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Connecting families



Chair of trustees
Alison Fielding
chair@cardiomyopathy.org

Our theme for this edition of My Life is emotional well-being and we'll be focussing on this issue throughout this year.

We know from speaking to patients and families that the emotional impact of cardiomyopathy takes as much managing as the physical one. Our survey last year to find out how you felt and what would help you most to cope with cardiomyopathy (see page 9) told us that lots of people felt that talking to someone else who is affected had and would make a great deal of difference to them. We are committed to making this much easier and are putting volunteers at the core of our organisation in helping people to connect. We have a broad range of opportunities coming up. So do get in touch if you can help.

We are delighted that the Big Lottery Fund has agreed with us that this is important work and it is now funding the development of further peer support groups across the country (see page 10). Having this grant is a great boost, not only in the welcome funds but in the recognition that the charity is seen to be well run and focussed on achievable outcomes.

From all the trustees and staff, we wish you a happy and healthy 2017.

Livechat with our support nurses

With a grant from the Big Lottery Fund, we have launched an instant messaging service with our support nurses



People affected by cardiomyopathy can now livechat with our support nurses.

Cardiomyopathy UK has introduced the new service for website visitors thanks to a Big Lottery Fund grant of £5,470.

When our support nurses are on the helpline (usually weekdays from 8.30am to 4.30pm and sometimes in the evenings) our website users can start a livechat by clicking on a chat button icon on the home page of our website (cardiomyopathy.org). The button is only present when the livechat instant messaging service is available.

The service started late last year, and has also included a scheduled livechat session with our children's cardiomyopathy support nurse Sarah Regan.

Cardiomyopathy UK chief executive Joel Rose said: "We hope the service will be taken up by people affected by cardiomyopathy and their families, and particularly groups who less frequently use our services, such as the young and black, Asian and minority ethnic groups."

"We want livechat to become an established part of the core services we offer to families."



The charity also wants to see if this method of communication would be suitable for other areas of its work – such as our support volunteers who are all affected by cardiomyopathy in some way and talk to others similarly affected by telephone or email.

'I could ask questions while at work without anyone listening or knowing what I was discussing. I prefer livechat to calling or emailing. It's so simple and you get a response really quickly,' says Danny

Livechat gives people a simple route to medical support, making it easier for them to get the help they need at a time that is convenient for them.

People can get answers to questions they haven't or don't like to ask their medical teams because of a shortage of time at appointments or because they are embarrassed. Livechat also aims to help those who may be at risk of developing the genetic condition to be identified and encouraged to seek treatment quickly.

Mutual support helps



Chief executive
Joel Rose
joel.rose@cardiomyopathy.org

One of the great highlights of 2016 was our national conference. I am really pleased we were able to bring together so many people and the feedback has been incredibly positive. What struck me most was the sight of so many people chatting over lunch or in the coffee break, sharing experiences and supporting each other.

Good mutual support and the honest recognition of the emotional impact of cardiomyopathy plays a massive part in helping people to cope with the condition.

The conference was topped off by the first Cardiomyopathy UK Awards and you can read about the winners, Cathy, Jenny, Gilbert, Sara and Julie on page 14. Their work, and that of all our volunteers and supporters, has changed lives. I'm confident we can do even more this year.

New cardiomyopathy support group

New group for Birmingham holds its first meeting in January

A new cardiomyopathy support group is being set up in Birmingham.

The group, for people with all types of cardiomyopathy and their families, friends and carers, is having its first meeting at the Station pub in Station Street, Sutton Coldfield on Saturday, 14 January at 2pm.

The main speaker is Dr William Bradlow, a cardiomyopathy consultant at the Queen Elizabeth Hospital in Birmingham.

The meetings are being coordinated by Ross MacKinlay, who himself has cardiomyopathy.

He said: "I was diagnosed with dilated cardiomyopathy in 1998 and, in the last year, I decided I wanted to join a support group with other people like me. As there was no group in the Midlands I decided, with the backing of Cardiomyopathy UK, to set up one."

"I hope that meeting others with cardiomyopathy, their carers and medical staff will be as inspirational and informative as I imagine and this will be the same for other people who might join us."

Ross also hopes the support group will provide a network for people affected by cardiomyopathy to informally meet medical staff to talk, give support and ensure they get the best out of their lives.

Meetings will look at cardiomyopathy related medical matters and self-help.

There will also be opportunities for people to share information and help, and provide intellectual and emotional support.

All are welcome. For further information contact Ross at ross@pdsoft.co.uk

• Other new support groups planned for early this year are in Cumbria and at Milton Keynes, Cambridge and Ipswich. More details will be announced shortly.



Focussing on the important things in life can help



Graeme Gillespie | consultant clinical psychologist,
Northumbria Healthcare NHS Trust

Graeme discusses how thinking about our values can help people live with long-term conditions

Being diagnosed with and living with cardiomyopathy are huge challenges which can knock us off track and make us feel vulnerable, frightened and fed up.

Some of the symptoms which cardiomyopathy can lead to, such as shortness of breath and fatigue, can leave us feeling hugely frustrated.

If we have had to stop doing things we really enjoyed or which were important to us, we may feel we are no longer the person we used to be.

This can be extremely painful and can lead to a downward spiral of frustration and increasingly low mood.

Although there is no easy way to deal with this pain and loss, one way of helping bring back a sense of direction is to identify what really matters to us. In other words, what are our values?

Values help us to focus on what is really important to us, whether or not we are living with a heart condition. Values act like a compass bearing or signpost, helping to keep us on the right path, in the right direction, whatever difficult thoughts, feelings and sensations we have to live with.

In order to get in touch with your own values, try to imagine what you would like your friends and family to say about you if they gathered together at a big celebration, such as for a big birthday. If they were trying to sum up the things you stand for, what would you want them to say?

What kind of husband, wife or partner do you want to be? What sort of parent, grandparent, friend? How do you want to be in your working life or leisure? What other things do you care deeply about, such as nature, spirituality, your health or learning?

When reflecting on the questions above, people sometimes fall into the trap of giving a fantasy answer, such as 'I'd like people to say I'd won the lottery!' or 'I'd want them to say I had been cured of all my health problems'.

While we might wish that could happen, they don't really help us get to our values and may just reinforce feelings of frustration and even envy. Try to be truthful to who you really are, with all the strengths you have as well as all the difficulties you face.

When thinking about values, look out too for a tendency to get drawn into what you think you ought to say. Be kind to yourself rather than getting hooked into rules, with words such as must, ought, should, good, bad. Open yourself up to be guided by what you hold dear in your heart.

The box below provides some examples of values which you might find useful but feel free to come up with your own. Remember values are about what really matters to you.

If cardiomyopathy is getting in the way of your goals, it is even more important to be clear about your values.

Clinical psychologist Ray Owen has written two excellent books (Facing the Storm and Living with the Enemy), which focus on ways of coping with the stresses of long-term conditions.

He uses the example of someone who was desperate to teach his son to fish but was unable to, due to worsening ill health. This was a painful loss which was difficult for him to deal with. However, he was able to think about why this activity was so important to him, and what were the essential ingredients of this goal.

In other words, what values did this activity reflect? In his case, the values were something to do with spending time with

his son, teaching him something he could take into adult life and creating some lasting memories for him.

By unpacking what really mattered about this, he was able to come up with an alternative goal of teaching his son to play chess, which was not his first choice but was achievable and which still mattered to him. It reflected his values.

So whether or not things are tough for you at the moment, and your cardiomyopathy, or life in general, is making it difficult for you to do what you'd like to do, spend some time really trying to get in touch with your values.

And then see if you can unbundle what you would like to do into some small actions which are meaningful and important to you.

Is holding on to the past keeping you looking frustratedly in the rear view mirror instead of looking at the road ahead, however tricky it may be?

Is there something you could do in the next day or so, even just a small step, which would connect with your values?

If you can start to take some small steps in the direction which is right for you, it can have a ripple effect which leaves you feeling more fulfilled and more true to yourself.

Examples of values	What's important to you (tick)
Being loyal	<input type="checkbox"/>
Caring for the people I love	<input type="checkbox"/>
Being creative	<input type="checkbox"/>
Being kind and compassionate towards myself and others	<input type="checkbox"/>
Leading others	<input type="checkbox"/>
Looking after my health	<input type="checkbox"/>
Living in a spiritual or religious way	<input type="checkbox"/>
Learning new things	<input type="checkbox"/>
Being emotionally close to people I care about	<input type="checkbox"/>
Nurturing others/ helping others develop	<input type="checkbox"/>
Being in contact with nature	<input type="checkbox"/>
Being generous, sharing and giving, to myself and others	<input type="checkbox"/>
Another value which is not here?	<input type="checkbox"/>

Suzanne Kelsey's story

Suzanne talks about how a diagnosis of cardiomyopathy came as a huge shock to her and how various activities she took up helped restore her self-worth and keep her positive

Almost seven years ago I was diagnosed with dilated cardiomyopathy. The cause is uncertain but it could be genetic and triggered by a virus. So my family has been screened but fortunately they appear to be fine.

As it is for many people, it was a shocking and unexpected diagnosis, particularly as I have always led an extremely healthy life. I trained in contemporary dance, I was a qualified health and exercise tutor and, ironically, a tutor on the Health Education Authority's Look After Your Heart programme for some years.

I had been feeling exhausted with flu-like symptoms for a long time. I also had quite disturbing heart rhythms and had put them down to a demanding job and helping to care for my sick mother. A total and sudden blackout, which was even more alarming, and bizarre heart rhythms ushered me to the hospital, where I stayed for a few days.

At first I was very frightened by the uncertainty of the long term prognosis. I suddenly lost all confidence and was afraid to leave the house at times in case I collapsed in the street.

After reluctantly deciding to retire from my career and finding myself home alone and missing my work colleagues and students, I knew instinctively it was important to remain positive as going down a spiral of negativity could lead to depression and not help my heart at all. I needed to restore my self-worth that had been stolen from me.

After the initial crisis abated and my symptoms were being managed by the wonderfully dedicated team at the cardiology department at Cumberland Infirmary, I had to adjust to a different way of life to stop myself talking to the walls.

I was advised to rest my heart and so gave up my extremely vigorous exercise and dance regime and took up more gentle forms of exercise. I enjoyed walking in beautiful Cumbria (although the Lakeland hills were a no go area) and the relaxing effects of tai chi. I attended cardiac rehabilitation which restored my confidence about what I could do.

I thought it was important to focus on self-help for the mind and body and also became interested in mindfulness and meditation. These focus on positive energy in the here and now, not regretting the past or worrying about the future but focusing on the present as it is all any of us is guaranteed. I would recommend these disciplines to anyone whatever their state of health to combat stress of any kind and to appreciate the now.

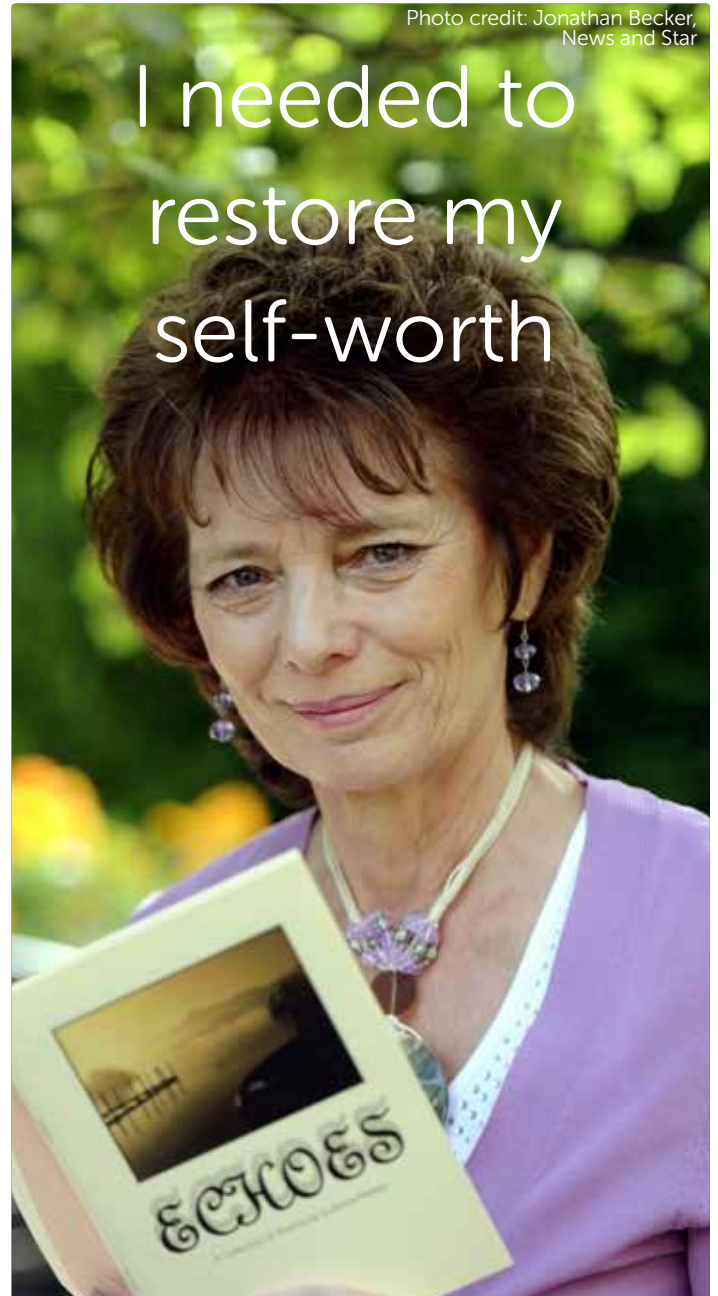
I also felt the need to engage with something that was purposeful, would restore my confidence and possibly help others too.

So I took up some more creative activities. I rediscovered my love of poetry and started writing again and for me it became a wonderful form of therapy. Poetry encourages us to speak to others on a deeper level and opens up our hearts and souls.

My writing has continued to be prolific and I had a 'Eureka' moment when I thought about producing a poetry book that could raise funds for the hospital that had looked after me so well and perhaps my heart-felt words would benefit others. I launched my first poetry book *Echoes* a year later.

During the early days of my diagnosis a cardiac nurse recom-

"I'd always led a healthy lifestyle. So my diagnosis was shocking and unexpected," says Suzanne



mended Cardiomyopathy UK to me and I was very pleased she did. I was so grateful for the charity's support, its up-to-date information and its cardiomyopathy experts. You can chat to and meet other people with the condition and find great comfort in those friendships.

With my confidence back, I now travel to the charity's information days and conferences in London. I have put together another poetry book, called *Out of the Blue*, and sell it to raise money for Cardiomyopathy UK. It contains poems written by me and other supporters of the charity.

I have also written specific poems for the particular needs of people who have posted on the charity's forum and from the feedback I get, it appears people with cardiomyopathy and their families appreciate this. So that is a huge bonus.

The whole experience of writing poetry has been worthwhile in more ways than one. It has opened up many new doors for me, I have met some amazing people and this has impacted positively on my overall well-being.

Currently my heart condition is considered stable but I need regular heart checks at which my heart function is assessed and medication tweaked accordingly.

I thoroughly appreciate our NHS and all those who work in it and of course the on-going support of Cardiomyopathy UK.

My cardiomyopathy has been difficult for the whole family



Steve Lovegrove's story

Steve tells how having cardiomyopathy has led him to have regular bouts of depression and how psychotherapy has helped.

My late mum was a kind, loving woman. So I was surprised when, in later life, she told me quite candidly that I was a sickly child.

She explained how in the winter of 1961 the GP had been called to our home again as I had a chesty cough. In those days the surgery was in the next village and the doctors were happy to make house calls.

During his examination the GP detected a heart murmur. I was two years old. Soon afterwards I was admitted to the John Radcliffe Hospital in Oxford where it was discovered that I had a soft systolic murmur. I continued to attend out-patient clinics until I was 12.

Mum and dad were naturally concerned about me and were a bit over-protective which affected me and my siblings in different ways. I became very shy and introverted while my brothers and sister thought I was the golden child. All of which caused me to struggle with emotional problems and for most of my youth, depression.

In my early twenties I was flourishing at work and in my personal life. However, when I was 25 I started to experience frightening palpitations and blackouts and my GP immediately referred me to the Battle Hospital in Reading where I was diagnosed with cardiomyopathy.

After a couple of years I was diagnosed with hypertrophic cardiomyopathy (HCM) with obstruction to blood flow out of my heart. In a research study, I embarked on a programme of trying different drug combinations. Unfortunately I had more blackouts and in 1996 had a pacemaker fitted. After this, my symptoms stabilised and I was able to lead a happy and active life with my wife Isla and three children.

I was offered genetic screening and my children started to be regularly checked for HCM. This really helped my wife and me to cope with the worry of our children inheriting my condition.

I am pleased to say that my son Jordan, now 22, and my daughters Olivia, 19 and Anya, 15, are showing no signs of cardiomyopathy. My whole family has also been offered screening and counsel-

ling from Professor Watkins' wonderful team at Oxford. After having some more blackouts in 2002 I had an internal defibrillator (ICD) fitted and was not able to drive for six months.

For the first time it made me realise that I have a fairly significant disease which could have killed me but for the wonderful treatment at the John Radcliffe and elsewhere.

At first I was quite anxious about the ICD and benefitted from support from other ICD patients and Cardiomyopathy UK who helped to put my mind at rest.

In 2006 one of my ICD leads became damaged and I had inappropriate shocks. A faulty lead was found and the ICD and leads replaced.

Afterwards it took me a long time to get my confidence back and to feel how I had felt prior to the lead malfunction. It also took some detective work by Dr Matthew Daniels to adjust my ICD settings so that I now have more capacity to exercise. I also have home monitoring of my ICD and only need to go to the ICD clinic once a year.

The combination of the death of my parents in 2010 and on-going difficulties with my physical health triggered a further bout of depression. I was unable to work for 10 months.

During this difficult time for my whole family, I had regular psychotherapy sessions where I was encouraged to talk about my life and it helped me enormously.

My employer was also very supportive and referred me to an occupational health doctor who advised me to lose weight to help improve my mental and physical well-being.

The doctor also suggested that I might be a candidate for weight loss surgery. I am now going through the assessment programme at the Royal Berkshire Hospital in Reading and hope to have surgery sometime this year. Hopefully this is the push I need to get as healthy as I can be.

It is true to say that my heart condition has had an impact on my life and also my family's. There have been emotional and worrying times for my wife and children and I have not always been the best patient. I have struggled to stay positive and have regularly suffered with depression. But thanks to many caring and brilliant professionals, I am looking forward to many more years of enjoying a rich and active life.

• Pictured above are Steve Lovegrove (second left) with Isla (centre) son Jordan and daughters Olivia and Anya

The emotional issues have been hard



Jenny Rees' story

After finding the psychological effects of cardiomyopathy particularly difficult to handle Jenny, who has dilated cardiomyopathy, is researching the issue for her PhD

I was diagnosed with cardiomyopathy at six weeks old. I am one of four sisters and a large family but I am the only one to be diagnosed, making it a bit of a mystery.

My ejection fraction (EF), a measure of how our hearts pump, was always around 27%, half of what it should be, until I reached the age of 14 when it dropped to 19%. I also developed a heart conduction problem and became very unwell. But thanks to a biventricular pacemaker and internal defibrillator (ICD), I improved greatly over the next few years and my EF is now 45%.

I have always found the psychological effects of living with cardiomyopathy extremely difficult. I realised this was an under-recognised aspect of the disease which inspired me to get involved in research about it. I carried out my own research for my undergraduate psychology degree and am now taking this forward into my PhD. I was happy to join Cardiomyopathy UK in its work looking at the same issue.

With the help of Cardiomyopathy UK, 200 people with cardiomyopathy completed a questionnaire I put together asking them about the association between cardiomyopathy and psychological distress – anxiety, stress and depression – an area that had not previously been extensively studied.

With people living longer with the disease because of better diagnosis and treatment, the impact on emotional well-being is becoming more and more important.

My study looked at the relationships between heart function, frequency and severity of symptoms and psychological distress. The results showed a high prevalence of severe anxiety, depression and stress, indicating a general high level of psychological distress, regardless of the cardiomyopathy cause and the level of heart problems. But there were significant associations between symptoms and symptom-related stress, with fatigue being the most distressing symptom.

The findings not only highlight the need for more psychological support for people with cardiomyopathy but also suggest new ways support can be delivered – from dealing with anxieties relating to specific symptoms to identifying people who would most benefit from psychological support. I am now continuing my studies into my PhD in clinical and health psychology. During these studies I will gain a teaching qualification to allow me to lecture nursing students on illness-related mental health.

With my fiancé Mark and my stepson Nate, who is four, I am looking forward to a long and fulfilling life. I am determined to overcome any barriers that cardiomyopathy brings, while hopefully encouraging others to do the same. I also help my mum run the Cheshire and Merseyside Cardiomyopathy Support Group.

• Jenny is pictured with fiancé Mark and her stepson Nate

Limiting exercise can cause emotional problems

Exercise restrictions in sport-loving adults with hypertrophic cardiomyopathy can cause lasting psychological problems, including uncertainty while exercising and feeling limited, says a new survey.

People at greatest risk of emotional problems are those who have competed at a high level, perceive themselves as an athlete, and who then spend much less time exercising, said researchers from Stanford University and the University of South Carolina Greenville in America.

They say doctors need to identify people at greatest risk of emotional problems and help them to adapt and cope with their new way of life.

Some said that exercise served multiple purposes in their lives prior to their diagnosis. It helped to create and maintain friendships and romantic relationships, cope with stress, maintain fitness, and manage other health concerns.

For more see cardiomyopathy.org/exercise-restriction



Our cardiomyopathy information days

We are planning to hold six information days this year, each on a Saturday. These are at:

- Nottingham Conference Centre – 18 March
- Wrexham University – 1 April
- Novotel, Grey Friars Rd, Ipswich IP1 1UP – 22 April
- Edinburgh Training and Conference Centre – 13 May
- Bradford (venue to be confirmed) – 3 June
- Southampton (venue to be confirmed) – 24 June

Our information days are an opportunity to find out more about cardiomyopathy and meet other people with the disease, and their families and friends supporting them.

More details, including the speakers, will be announced shortly. See cardiomyopathy.org/info-days



Improving psychological



Dr Ian McPherson | clinical psychologist and Cardiomyopathy UK trustee

Ian talks about the work Cardiomyopathy UK is doing to ensure people affected by cardiomyopathy get more emotional support

As someone who has worked in mental health throughout his career and has a particular interest in improving psychological support for people with long-term physical health conditions, I was delighted to find that Cardiomyopathy UK had already identified this as a priority when I became a trustee a year ago

This priority has been chosen because of feedback from our support group leaders and those involved in our helpline and our Facebook groups. All had said that the emotional impact of cardiomyopathy was a major issue both for people living with the condition and for their families.

Our clinical advisory group, which consists of specialists in cardiology and genetics, had also highlighted its concern that psychological support was not readily available, even in our leading heart centres.

We were fortunate that two of our support group leaders had already been carrying out research on this topic. Jenny Rees, who helps run our Cheshire and Merseyside Cardiomyopathy Support Group, has studied the association between the collective symptoms of cardiomyopathy, heart function and psychological distress and found high levels of anxiety, depression and stress among cardiomyopathy sufferers. (See her article on page 7).

Cathy Stark, with colleagues in the North East England Cardiomyopathy Support Group, has taken a different approach interviewing both people with the condition and their families. This also found that emotional impact was a very significant factor for many people and sometimes had a greater impact on family members than the person with cardiomyopathy. Cathy and her colleagues will be reporting their findings in more detail later this year.

This work encouraged Cardiomyopathy UK to undertake a survey asking people what their mental health experiences had been and what type of psychological support they would like. The details

of this are described in the column on the right, but again this confirmed that most people are affected by the emotional impact of living with cardiomyopathy and are keen to have psychological support given in a variety of ways. The survey highlighted that many of the services currently offered by the charity are seen as useful ways of providing emotional support, such as our support groups, our helpline and the closed Facebook group. But some people also wanted more specific support focussed on their emotional needs.

To look at how this might be organised we held a discussion in October which brought together representatives from the cardiomyopathy community and senior people from the mental health community to discuss:

- the need for psychological support for patients and carers
- what barriers and opportunities there are for good psychological support
- what needs to happen to ensure patients are offered good psychological support

The discussion generated some very stimulating debate and, more importantly, a commitment to work together to develop better ways to provide support. This included:

- piloting mental health first aid training for staff and support group leaders to help them provide the best support to those experiencing emotional difficulties
- reviewing existing online resources for people with cardiomyopathy or family members who are experiencing psychological distress and seeing how they can best be used to support people
- exploring ways of introducing into routine cardiology care questions about how people are coping emotionally with their condition
- examining the potential of people getting more support for emotional well-being from primary care and pharmacists

The emotional impact of cardiomyopathy is a major issue for people living with the condition and their families

Psychological support is not readily available for people with cardiomyopathy, even at our leading heart centres



care

Diagnosis constantly affects emotional well-being for many

People don't ask their healthcare team for help because appointments are too short and they are embarrassed, says survey

More than nine in ten people with cardiomyopathy say their diagnosis has affected their mental well-being. That is among the results of our survey about mental health in people with the disease.

Of the 385 who responded, a fifth said the condition affected their mental health all the time and just eight per cent said it did not affect them at all. Nearly three in ten said their mental well-being was affected some of the time, and just over one in ten occasionally or rarely.

The figures were also stark among people supporting them at home. Only three per cent of the 70 family members who responded said their mental well-being had not been affected.

Asked what support they would find helpful, more than four in ten with cardiomyopathy said a chat with someone with similar experiences and almost one in three said sharing experiences in a support group. A quarter asked for informal face to face meetings and one in five wanted online support. The figures were similar for people supporting them.

Around half of people with cardiomyopathy (47%) and most people supporting them (70%) had never asked a healthcare professional about mental health. Of those who had, most with cardiomyopathy had spoken to their GP rather than their cardiologist or specialist nurse.

Those who felt they couldn't bring up the subject, even if they wanted to, said appointments were too short or they felt embarrassed to ask.

Family members said they felt they couldn't ask as they were not the ones with the condition and they didn't want to bring up the subject in front of the person with the disease.

More than six in ten people with cardiomyopathy said their medical team had never brought up the subject. GPs were most likely to raise the issue. More than half of people with the disease felt their GP should ask them, but over a third felt their cardiologist should ask.

People with cardiomyopathy were slightly more likely to bring up the issue with partners and friends but a third of both groups said they had never discussed it with anyone.

Awareness of support services

Services and support for mental health were generally known about but not necessarily used. Nearly four in ten people with cardiomyopathy had used drug treatments to help and just over a quarter had used support groups.

The least well-known treatments were talking therapies and mindfulness/meditation.

Information manager Rona Eade said: "People felt that emotional and mental health should be mainstream or part of all services, but that there were not enough services in this area, and they did not have sufficient time to help.

"Ultimately Cardiomyopathy UK wants to start the conversation about this subject so that more people feel able to discuss it and ask for help as an integral part of their condition management."

People are aware of mental health support services but are generally not using them

People with cardiomyopathy are more likely to talk about their mental health with family or friends rather than a medical person

Mental health is not routinely addressed by healthcare teams. More than half of people thought GPs should ask them

When looking for support, people asked their GP or looked on the Cardiomyopathy UK website

- developing specific resources and support for the psychological needs of carers and young people
- working with professional bodies and other charities to promote awareness of the emotional impact of long term physical conditions

At our national conference in November we held two very well attended workshops on coping with the emotional impact of cardiomyopathy, one for those with the conditions and one for family members.

Consultant clinical psychologist Graeme Gillespie also held a workshop which looked

at enhancing emotional well-being. He will be writing a series of articles on the topic for My Life, including his first on Page 4, which talks about focussing on the important things in life.

How cardiomyopathy impacts on the lives of both patients and their families came up in many other sessions at the national conference.

This has confirmed that there is much more for us to do in this area particularly to explore the best ways to encourage people to talk about the emotional impact of the condition and to encourage hospital cardiomyopathy services to see this as a significant issue for many people.

Cardiomyopathy UK is determined to be a driver of innovation in services to address the emotional impact of cardiomyopathy and we will be telling you more about our future work in My Life.

Cardiomyopathy UK is determined to be a driver of better services to address the emotional impact of cardiomyopathy

Could you help on our helpline?



Cardiomyopathy UK is looking for people to become volunteers on our helpline.

We are looking for those who have a few hours to give each week to answer helpline and online requests and ensure people are directed to the correct support services.

Volunteers, who will receive training, will be responsible for understanding the callers' needs, introducing our services, such as our support nurses, information days, support groups and our peer support volunteers, and passing people on to the appropriate services.

Alison Thompson, head of services at Cardiomyopathy UK, said: "If you are interested in helping people with cardiomyopathy and making a genuine difference to their lives, we would like to hear from you."

"Ideally you'll have experience of volunteering, be flexible and reliable, and have excellent communication skills."

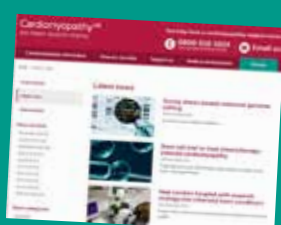
Volunteers need to be able to give one morning, afternoon or evening a week to answer calls, take details, give information and refer people on, which may sometimes be to our fundraising or media sections.

Training is expected to take place in London.

For more information, see cardiomyopathy.org/helpline-volunteers

See more news

For news about cardiomyopathy, see cardiomyopathy.org/news



Big Lottery Fund will help us provide more support groups

The Big Lottery Fund has awarded Cardiomyopathy UK a £132,340 grant to help us double our number of cardiomyopathy support groups by 2019.

Our support groups, which meet regularly around the country, enable people affected by cardiomyopathy in some way to meet informally and share experiences with others affected by the condition.

In a recent survey involving four of our support groups, 88% of members told us that they felt better supported and less isolated as a result of attending a support group, and 68% felt better able to cope.

Our support group manager Jo Franks said: "As cardiomyopathy can feel isolating and difficult to manage, we want people affected to feel better supported and better able to cope with day-to-day life."

"At support group meetings, information is provided on a range of topics increasing understanding and helping people to manage their symptoms and live a full a life as possible."

Jo will be recruiting, guiding and supporting volunteer group leaders so they can share good practice, and the groups become more sustainable and meet a wide range of needs that people with cardiomyopathy have.



LOTTERY FUNDED

For more information about our support groups around the UK, see cardiomyopathy.org/support-groups

What people say about our support groups

I always feel good coming away from meetings. It helps meeting others and hearing how they cope

Support groups are a great source of advice and support for people of all ages affected by cardiomyopathy

Meetings help you to realise that the condition is not as limiting as you may have thought

Marguerite's legacy educates hundreds of doctors and nurses

Hundreds of heart specialists, including cardiologists and cardiac nurses, have learned more about cardiomyopathy thanks to a legacy from supporter Marguerite Hicks.

Marguerite, who died aged 70 in 2012, left the charity £116,005.05 in her will to help us educate the medical profession.

Her gift paid for four national and six regional cardiomyopathy conferences attended by 660 doctors and nurses.

Marguerite used the charity's services for many years after being diagnosed with dilated cardiomyopathy in 2001.

Professor Perry Elliott, who chaired the medical conferences, said: "Marguerite's legacy has made a lasting impact. The conferences that she funded have helped hundreds of clinicians to develop a better understanding of cardiomyopathy and ultimately do a better job for their patients."

The legacy enabled the charity to hold the conferences over the last four years. Those who attended told us that afterwards they

felt more confident about diagnosing and treating people with cardiomyopathy.

Their feedback included: "The conference gave me practical tips on how to screen sensibly, taught in such a way that one can very easily incorporate these ideas into practice" and "I have increased confidence to recognise and differentiate when I see a patient's echocardiogram".

Cardiomyopathy UK's chief executive Joel Rose said: "This result spurs us on to educate even more doctors and nurses in the future so that every patient with cardiomyopathy can have the earliest possible diagnosis and access to good treatment."

Last year Cardiomyopathy UK received a total of £24,631.61 from nine people who remembered our cause in their wills.

"A legacy of any size is most valuable to our work and is a meaningful way of making a difference in the future for people affected by cardiomyopathy," added Joel.

For details about leaving a gift to us in your will, see cardiomyopathy.org/legacies

Q&A

Independent financial adviser
Bill Bartholomew answers your
questions on life insurance and
critical illness cover



Q: My life and critical illness insurance policy will not pay my claim for critical illness after my recent diagnosis of hypertrophic cardiomyopathy, although it is one of the critical illnesses they provide cover for. What would you advise?

A: As many people set up their policies to protect a loan or mortgage, they can be many years old. Yours might not offer cardiomyopathy as one of the illnesses covered, although a newer plan with the same insurer does. This is just one of the reasons why you should have your protection plans regularly reviewed by an independent financial adviser to ensure they remain suitable for your needs and offer maximum protection.

If cardiomyopathy is covered under the critical illness conditions listed in your policy, then it will depend on the severity of your diagnosis as to whether your claim will be met. In the insurer's policy conditions, it will explain how severe each critical illness will need to be before a payment can be made. For cardiomyopathy, the main benchmark used by many insurers is that the claimant needs to be at least level three of the NYHA heart failure classification scale before a claim can be paid. Other insurers may use a measurement of the heart's ejection fraction (EF), a measure of how well the heart pumps. For example an EF of below 35% is needed for a pay out to be considered. If you believe you qualify for a payment and the insurer still refuses, consult the financial ombudsman. Insurers do not intentionally look to remove themselves from their obligations, and they all publish their annual payment rates to show where they stand among their peers.

For critical illness payments the "claims

paid rate" across the industry is usually in the low 90% figure. There will always be examples where they have not made a payment but these cases usually revolve around either fraud or non-disclosure of a medical condition at application stage.

Q: Following my brother's diagnosis of cardiomyopathy, I had an ECG, an echocardiogram and a gene test, all of which showed no signs of cardiomyopathy. However, all the insurance companies my financial adviser has spoken to have indicated that they will not offer me standard rates for my life cover, even though I am in good health, a non-smoker and have a BMI of 30. What would you advise?

A: As your brother has been diagnosed with cardiomyopathy, it means that there is an immediate family history of the illness. So even though all your tests have shown that you are clear of any signs of the illness, you still represent a higher risk to the insurance industry than someone of the same age and BMI who is also in good health and has no family history of cardiomyopathy.

In the eyes of the insurance industry, risk means reward. So if they are willing to offer you terms it must reflect the extra risk that approving your application will mean to them. This is likely to mean an extra loading to the cost of any life insurance benefit. If you are also considering critical illness cover or income protection, then the insurer may very likely add an exclusion around cardiomyopathy, but will not add any extra loading on the cost of this part of the insurance benefits package. Again, all insurers have different individual criteria. So it is recommended that you consult an independent financial adviser to ensure that

suitable cover at a competitive price can be arranged.

Q: My fiancée and I are planning to get a mortgage to buy the flat we currently rent. However, my fiancée is worried she will not get approval for a mortgage because she has been diagnosed with cardiomyopathy and does not think that she will be able to get life insurance.

A: While life insurance is a very sensible benefit to have in place if you have a mortgage, especially if you have a partner and children, it is not an obligation when lenders consider a residential mortgage application. Quite simply, they will look at the property, rather than you or your fiancée, as the security for their loan. They may very well recommend that you consider life insurance when taking any mortgage, but they will not insist on it. If you wanted to arrange a business loan, a bank might insist that you have suitable life insurance arranged so they can get their money back if you were to die.

- For more information about these issues, get our new factsheet called **Cardiomyopathy and life insurance**. See cardiomyopathy.org or order a paper copy from us in the post.

If you have a question you would like Bill Bartholomew to answer in **My Life**, send it to Sarah Dennis at sarah.dennis@cardiomyopathy.org

Andrew's Mount Everest expedition for Rosie

Forty-year-old Andrew Stallard has climbed to Mount Everest's base camp in support of his young neighbour who has just had a heart transplant.

Andrew, from Maldon in Essex, was raising money for Cardiomyopathy UK in aid of four-year-old Rosie Day who had a transplant last year.

Andrew, who completed the long, arduous journey in October, said: "It was the hardest thing I've ever done but I thoroughly enjoyed the experience." He has raised almost £6,000.

Rosie was diagnosed with restrictive cardiomyopathy when she was two. Andrew said: "Being so young the odds of a match being found soon were significantly reduced, but her fighting spirit and cheeky determination saw her and her family overcome so many obstacles.

"In July Rosie got her new heart. It goes without saying that the donor's family in such dark times made a selfless and brave decision. Their gift has enabled Rosie to live her life to the full."

Rosie's parents, Sara and Barry, continue to promote organ donation and fight for an opt-out donor system to help others waiting for transplants.

It was while Rosie was waiting for her heart that Andrew contacted Cardiomyopathy UK offering to raise money to help affected families. He flew from London to Nepal and over the next ten days joined a team climbing to 5,364m where many experience extreme exhaustion and altitude sickness. Andrew managed to play football with monks at 4,000m and spend several hours enjoying the base camp scenery.

Andrew has raised £5,856 which will help us to support even more affected families and offer more medical training, information days and support groups across the UK.

Rosie is pictured with her parents after the family won an Ultimate Pride of Essex Award.



S-ICD is an effective treatment, says study

An internal defibrillator (ICD) that does not have leads into the heart has shown itself to be an effective treatment for those who have already experienced a dangerous heart rhythm and those thought to be at risk of having one.

That is the result of an international study involving doctors in the UK, Netherlands, Czech Republic and America.

Subcutaneous ICDs (or S-ICDs) are an alternative to the more traditional implantable cardioverter defibrillators (ICDs).

ICDs can detect a life-threatening heart rhythm and give a shock to restore normal heart rhythm. But unlike traditional ICDs, S-ICDs cannot also pace the heart. So they are not suitable for people who have significant heart failure or need a

pacemaker.

Because the leads are outside the heart, complications that can occur with ICD leads are reduced.

The researchers looked at 856 people with an S-ICD, first comparing 600 patients thought to be at risk with 253 others who had already experienced a dangerous rhythm.

They saw no differences in mortality, complications, inappropriate or appropriate therapy.



For more details, see cardiomyopathy.org/S-ICD-study

Genetics of restrictive cardiomyopathy examined

Advanced genetic testing of families with restrictive cardiomyopathy (RCM) has revealed some of the genetic origins of the disease.

A team of international researchers from Russia, Sweden, Germany and Estonia used next generation gene sequencing to look at the causes of the disease in 24 people.

They looked at 108 cardiomyopathy and arrhythmia-associated genes. Multiple gene mutations were detected in just over half (13) of the RCM cases.

A combination of sarcomeric gene mutations, which relate to the heart's ability to contract, and cytoskeletal

gene mutations, affecting how cells maintain their shape and internal organisation, were the most common. These mutations contributed to almost four in ten cases of the disease.

The researchers said that while about half of the genetic causes of other types of cardiomyopathy were known, the genetic spectrum of RCM was largely unknown.

So they wanted to identify the background of the disease and compile a list of genetic variants.



For more details, see cardiomyopathy.org/restrictive-genetics

Stem cell treatment for chemotherapy disease?

Cardiologists in America have begun early trials of using stem cells to treat chemotherapy-induced cardiomyopathy.

The team, at the University of Florida, have begun injecting adult stem cells taken from bone marrow into the hearts of patients with dilated cardiomyopathy caused by the cancer drug anthracycline. It is hoped the stem cells will stimulate regeneration or repair of their hearts' damaged tissues.

The doctors have recently treated their first patient, a breast cancer survivor who developed heart failure after treatment with the common chemotherapy drug.

Researcher Dr Carol Pepine said

that around four per cent of cancer patients given anthracycline develop heart failure. The drug has been used for more than forty years to treat people with breast cancers, lymphomas, leukaemia and sarcomas.

"We hope the cells will cause the heart tissue to regenerate and repair itself by attracting other repair cells," fellow researcher Dr Anita Szady told Life Science Daily.

The team said their first patient's heart function was poor and her options limited. She will be monitored closely over the next year.



For more details see cardiomyopathy.org/stem-cell-trial

Too many women die of heart disease in pregnancy

Too many women are dying from heart diseases, including cardiomyopathy, in pregnancy or soon after giving birth because doctors miss symptoms, says a new audit.

Heart disease is the largest single cause of women dying in pregnancy or up to six weeks after giving birth, says the report looking at maternal deaths in the UK from 2012 to 2014. These deaths include the different types of cardiomyopathy, and peripartum cardiomyopathy brought on by the pregnancy itself.

Just over eight women in every 100,000 die, two of whom have heart disease. The report's key messages are:

- Severe chest pain spreading to the left arm or back may be heart related
- Persistent breathlessness when lying flat is not normal in pregnancy and may mean heart problems
- Good care can make a difference

- Women with known heart disease should get specialist care

The report, from the Maternal, Newborn and Infant Clinical Outcome Review Programme, says care for women with many other issues has improved but death rates from heart disease have increased.

The authors say there were many instances when women displayed clear symptoms and signs of heart disease which were not recognised. This may be because the medical profession does not consider heart disease while looking after a young pregnant woman.

Cardiomyopathy UK has organised and contributed to medical conferences to improve expertise in the medical profession around cardiomyopathy and pregnancy.



For more details, see cardiomyopathy.org/pregnancy-care

Heart pumps can lead to complete recovery

People with heart failure can sometimes make a full recovery after having a left ventricular assist device (LVAD) fitted, say researchers.

"LVAD-induced cardiac recovery is a real and under-recognised phenomenon", say the team, including experts from the Utah School of Medicine in America.

The researchers looked at 15,000 people who had had the heart pumps fitted, either while they were waiting for a heart transplant or as a treatment. In the UK, LVADs are only used on the NHS as a bridge to transplant.

A total of 192 patients (1.3%) experienced heart recovery after a median of 11 months and were able to have the pump taken out

or avoid transplantation altogether.

These patients tended to be under 50 years old, with dilated cardiomyopathy, have had the pump for less than two years after being diagnosed, and not having had an internal defibrillator (ICD).

The researchers said that little work had been devoted to understanding the heart's potential for recovery, which could lead to LVAD removal and avoiding a transplant.

Recovery did not often occur early after LVAD implantation. But it did increase over time, with 80% occurring two years later.



For more details, see cardiomyopathy.org/LVAD-recovery

Biventricular pacing can help valve flow problems

Biventricular pacemakers can reduce mitral regurgitation in people with dilated cardiomyopathy (DCM), improving heart failure symptoms and people's ability to exercise, says a new study from Spain.

Mitral regurgitation is the leakage of blood backwards through the mitral valve from one chamber of the heart to another each time the heart contracts.

The mitral valve controls blood flow from the left atrium to the left ventricle.

Mitral regurgitation is common in people whose hearts do not pump well and can often be seen in people with DCM.

So the research team looked at using cardiac resynchronisation therapy (a biventricular pacemaker) in people with symptoms including moderate to severe

mitral regurgitation and left ventricle pumping problems.

Some people with dilated cardiomyopathy have a heart that beats in an unco-ordinated way, and traditionally biventricular pacemakers are used to help improve this.

The study, published on the European Society of Cardiology website, concluded that use of the pacemaker can control and even improve the basic cause of the disease.

The researchers included Dr Ivan Keituaqwa Yañez from the University Hospital Rafael Mendez in Murcia.



For more details, see cardiomyopathy.org/pacing-helps-leakage

New cardiomyopathy factsheets

Cardiomyopathy UK has produced seven new factsheets which tell you more about cardiomyopathy and help you live with the condition.

So as well as our detailed booklets on dilated, hypertrophic and arrhythmic right ventricular cardiomyopathy and living with the conditions, we now have the following factsheets:

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

Information manager Rona Eade said: "Over the last 12 months we have been reviewing and improving the range of information we offer our supporters about cardiomyopathy to help them and their families. We are also producing practical factsheets to help with day-to-day life."

All the factsheets can be found on our website and can be downloaded as a PDF or call the office on 01494 791224 and ask for a copy in the post.



What do you think of My Life?

Please tell us what you think of My Life by filling in and returning our readership survey.

Many readers will get a survey with this magazine, but if you need a copy please contact our office.

Alternatively, you will be able to complete the survey online. See our website cardiomyopathy.org/readership-survey



Drugs with links to heart failure named

Many commonly used nonsteroidal anti-inflammatory drugs (NSAIDs) are associated with an increased risk of hospital admission for heart failure, a study of European national healthcare databases shows.

Use of any NSAID in the previous 14 days was associated with a 19% increased risk of hospital admission for heart failure compared with use more than six months before, researchers from the Safety of NSAIDs Project Consortium reported in the British Medical Journal (BMJ).

Dr Giovanni Corrao from the University of Milano-Bicocca in Italy and colleagues in the consortium said the increases were significant for the following drugs: diclofenac, ibuprofen, indomethacin, ketorolac, naproxen, nimesulide, piroxicam, etoricoxib and rofecoxib

The effects appeared dose-dependent. The risk of heart failure doubled for diclofenac, etoricoxib, indomethacin, piroxicam, and rofecoxib used at twice or more the recommended daily allowable dose. But the researchers said: "Even medium doses of indomethacin and etoricoxib were associated with increased risk."

Cardiomyopathy UK support nurse Robert Hall said: "We have known for several years that people with heart problems need to use NSAIDs with care. People who take these drugs every day should discuss this with their GP, as they need to be prescribed carefully. Where possible the lowest dose, over the shortest period of time, should be used."



For more details of the study, see cardiomyopathy.org/painkiller-risk



Genetic testing can cause uncertainty

Genetic testing of young people who die suddenly from heart diseases can lead to their families being left in an uncertain situation, a new study says.

The likely cause can be found in 16 per cent of deaths, a "plausible" cause in 24 per cent and a "speculative" discovery in 28 per cent of cases. But that left nearly a third of cases unsolved. Thirty-two per cent of the time the researchers found no link whatsoever between sudden death and DNA, said Dr Ali Torkamani who co-authored the study from the Scripps Translational Science Institute in America and medical examiners in San Diego.

The study, published in the Journal of the American Medical Association, used gene sequencing to analyse 25 cases of unexpected sudden death in people aged 45 or younger. The researchers wanted to pinpoint genetic mutations that could have caused the death, and give that information back to family members who may also carry the mutation.

Dr Torkamani, assistant professor and director of drug discovery, said the approach was relatively new. So it was possible that he and his colleagues had missed relevant gene mutations. But "a lot of the answers are not as clear as one would hope they would be."

Cardiomyopathy support nurse Robert Hall said: "While this is a small study, it raises the issue that genetics does not always give a straightforward answer."



For more details of the study, see cardiomyopathy.org/genetics-uncertainty

Supporters honoured for commitment to our charity

Five people who showed outstanding commitment to helping the fight against cardiomyopathy have been honoured in our new annual Cardiomyopathy UK Awards.

The volunteers (pictured) were recognised for going "above and beyond" the call of duty and inspiring others to help, said our chief executive Joel Rose. The awards were:

Community award: To Cathy Stark who helps run the North East of England Cardiomyopathy Support Group. With cardiac genetics nurse Julie Goodfellow, she conducted research into the impact of cardiomyopathy on the lives of people with the condition and their carers, and also volunteered at numerous events for the charity, including the Great North Run.



Impact award: To Gilbert Wheeler who has run the Wiltshire Cardiomyopathy Support Group, founded the social forum the Big Heart Club on Facebook, and worked with many health organisations to raise awareness of the condition and give the patient view.



Development award: To Sara Day who, after her young daughter Rosie developed cardiomyopathy, nominated our charity as her company's charity of the year and has gone on, with her family, to raise over £30,000 for us. She has also raised awareness of the condition and campaigned for more people to join the organ donor register.



Carolyn Biro founders award (Carolyn started the charity in 1989): To Jenny Rees for using her experience of cardiomyopathy to educate, support and inspire others. She has spoken to MPs, peers and health officials at Westminster and helped to educate doctors and nurses at our medical conferences. With her mother Julie, she runs the Cheshire and Merseyside Cardiomyopathy Support Group. While gaining a degree in psychology, she carried out research into the psychological needs of people with cardiomyopathy and is now researching this issue further as part of a PhD with Liverpool John Moores University.



Clinical excellence award: To Julie

Goodfellow, a cardiac genetics nurse at the Freeman Hospital in Newcastle, for making a significant difference to families affected by cardiomyopathy. People using Cardiomyopathy UK's website and social media chose the winner of this category



The 2016 awards were presented at our national conference in London in November.

Resuming sex after a diagnosis of cardiomyopathy



Robert Hall | support nurse
Cardiomyopathy UK

Robert discusses a subject many people find difficult to talk about



A diagnosis of cardiomyopathy can bring with it many anxieties, particularly those focussing on survival and what the future may hold.

In the early stages there will be the need to deal with various symptoms, learn about and understand the condition, and adjust to treatment and the many life changes that may be necessary.

As things progress, issues of returning to a degree of normality in life begin to take more prominence. These will be different for each individual but may include thoughts on how, when and if to return to work and about resuming a range of previous activities.

The need for structure and normality is strong and, depending on the severity of symptoms, there may be a need to establish what is a new normal. Normal may be something that evolves and changes over time.

Part of this normality may be the resumption of sexual activity. This may not be seen as a high priority, particularly in the early phase of diagnosis, and it is an aspect of recovery where advice may be limited and you may feel uncomfortable asking about it.

Symptoms such as fatigue and breathlessness on exertion may understandably reduce desire. There will often be fear that such activity could be dangerous for the heart.

This will, of course, have an effect on partners. They have to interpret the information their partner is giving out and build their own understanding of how cardiomyopathy has changed their partner's and their lives.

When someone has a diagnosis of cardiomyopathy, it can understandably become easy for them to focus on their own needs, putting the needs of their partner aside temporarily.

Partners may perceive a lack of desire as rejection and be confused at the change in their loved one. They may also be fearful of resuming sex in case it causes harm to their loved one. So communication is crucial as they both search for their new normal.

Some men may find resuming their sex lives problematic due to erectile dysfunction or impotence. This is a common condition in people with and without cardiomyopathy, affecting 50% of men between the ages of 40 and 70 and becoming increasingly prevalent as men get older.

Common causes are coronary artery disease, high blood pressure, diabetes and psychological issues such as anxiety and depression.

The effects of some drug therapies, such as some types of beta-blocker, may also contribute to causing erectile dysfunction. This can lead to a vicious circle of anxiety and distress which can get in the way of the individual's return to normality.

We live in an age where information is more accessible than ever before and treatments for erectile dysfunction, such as drug therapies and other treatments, are available on the internet.

It can be tempting to self-manage the condition with drugs. However, managing the problem in isolation by ordering drugs

and supplements on the internet from less reputable sources could risk you getting a fake product. There is also the possibility of interactions with other drugs being taken to treat cardiomyopathy.

For example, drugs such as Viagra should not be taken if a person is taking nitrate based drugs, such as the angina preventative isosorbide mononitrate, or if they have a low blood pressure.

While it is possible for some people with cardiomyopathy to use Viagra and similar drugs, it must be discussed with your cardiologist first. Where drugs are not an option there are other non-medication treatment possibilities that can help.

The resumption of a sex life after being diagnosed with cardiomyopathy is not commonly discussed. Many people feel unable, either due to time constraints or embarrassment to raise the issue with their doctors.

There may also be the wrong assumptions made that it isn't a priority. Patients may sometimes feel they are so pleased to be alive that their sex life is something that they can afford to sacrifice. But usually this is not so.

The lack of focus on this area of recovery needs to be challenged. People need to be given permission to ask about erectile dysfunction and reduced libido, and any sense of loss they have in this area. This should not seem a taboo subject.

So if resuming your sex life is proving difficult, speak to your cardiologist or nurse specialist. Other patients will have previously asked them these questions and your medical team will be happy to answer yours.

Having sex is just one of the many challenges people with cardiomyopathy face, and should be given equal levels of attention as other lifestyle issues.

Living with cardiomyopathy

For more information about living with cardiomyopathy, get our special booklet.

The 92-page, full colour A5 publication, provides information about living with the disease and getting on with your life.

The practical booklet covers diagnosis and care, looking after yourself, coping emotionally, involving family members and partners, carrying on with life and getting support from others.

Issues looked at include coping with tiredness and the side effects of drugs, sleeping, exercise, handling your feelings, living with a device, sex, pregnancy, working, driving and finances.

Contact us to get your free copy.



Indie band joins #teamcardio at Great North Run

UK top 40 album charting indie band Little Comets (pictured below) were among our #teamcardio runners in the Great North Run in September.



The indie rock group, whose latest album Hope is Just a State of Mind reached no 31, were running in support of their 21-year-old friend Jim Lynskey who has cardiomyopathy and is awaiting a heart transplant.

They made their way into the history books by becoming the first band ever to perform their music all the way round this iconic half marathon. Even with all their singing they completed the run in a brilliant 2 hours 30 minutes.

A total of 28 people from #teamcardio completed the 13.1 mile course that winds its way from Newcastle city centre to South Shields.

Our challenge events fundraiser Sarah Moore said: "All our runners completed the course with a smile and were lucky enough to be greeted at the finish by volunteer Cathy Stark and family, who kindly provided hot drinks and food. The team raised an incredible £17,000 for families affected by cardiomyopathy. Thank you."



September is for strolling

Every year we ask supporters to take part in a September stroll for Cardiomyopathy UK

September is our walking month. Last year six groups of supporters from all over the UK got their walking boots on to explore the surrounding countryside and take part in their very own September strolls or join Cardiomyopathy UK's own one.

The autumn weather didn't dampen any spirits, with all groups enjoying walking, marching and strolling to raise funds as well as awareness of cardiomyopathy and Cardiomyopathy UK

These walks included Cardiomyopathy UK staff and their dogs joining local supporters on a walk in the beautiful Chiltern hills on a soggy Saturday morning.

Thank you so much to everyone who took part and helped to raise £2,800. We really do appreciate it.

If you are interested in organising or taking part in a September stroll this year, contact our challenge event fundraiser Sarah Moore at sarah.moore@cardiomyopathy.org or call her on 01494 791224.

• Pictured right are:
(top) Shalini Anita Chellaraj and family
(middle) Elizabeth and Gordon Todd with their family
(bottom) Nathan Skuse and friends



Put your willpower to good use

If you've made some New Year's resolutions why not put your willpower to use this year and support Cardiomyopathy UK at the same time?

Your resolutions can be a fantastic way to fundraise, and you'll have an even bigger incentive to stick to them if you're fundraising too.



- Quitting smoking? Get sponsored to give up, or donate what you would have spent on cigarettes
- Learning a new language or skill? Then show off your new talents for sponsorship
- Planning for a fitter 2017? Aim for a sponsored walk or 5K run, getting fit and fundraising too
- Try giving up a favourite treat for a month for sponsorship

Whatever you're planning, our fundraisers Sarah Moore and Bex Noble can give you lots of help and support.

For more information please visit cardiomyopathy.org/do-your-own-thing

#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
or visit our website
cardiomyopathy.org/support-us

Fantastic firewalkers



Twenty intrepid firewalkers took on a firewalk in November in central London raising an incredible £2,500 for our work. Congratulations to everyone who took part and well done!

A family affair



In September Vanessa Murphy, her nephew Max and father Tony completed the Wire FM Family Mile in memory of Anthony (Vanessa's brother and Max's father). They did amazingly well and had enough for a sprint finish. A big thank you to all of them for raising over £1,000

Team dare



Freddie Dare (second left) teamed up with family and friends for the Bournemouth Marathon festival in October. Between them they took part in the 5K, 10K, half and full marathons. A huge thank you

Club of the year



Golfer John Gatland (left) nominated us for his senior team's charity of the year in 2016. The team raised over £2,300 through several tournaments and special competitions. Thanks to everyone involved

Peak performance

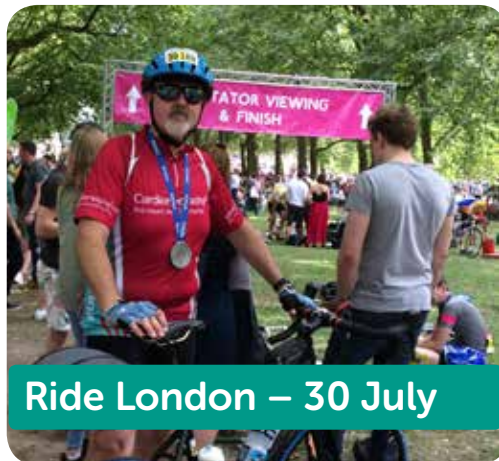


The Coope family and 45 others took on the Three Yorkshire Peaks in honour of their son George who has hypertrophic cardiomyopathy. The group raised an incredible £9,400. Thank you

Bourne supremacy



Fourteen cyclists from the Bourne Group were brought together by Craig Galway for the 100 mile cycle around the New Forest in September, raising over £2,500 in memory of Craig's brother Dean



Ride London – 30 July

Ride London

This London Marathon of cycling is back for its fifth year. Ride London – Surrey 100 is part of a weekend of cycling in July. Celebrating the cycling legacy of London 2012 and Team GB's success in Rio, Ride London brings elite closed-road racing to the masses. Starting at the Queen Elizabeth Olympic Park, you and 26,000 other amateur cyclists will tackle the Surrey hills, including Box Hill, before returning to the capital and finishing on The Mall.

Location – London
When – Sunday 30 July
Distance – 100 miles

To register or get more information, please visit:
cardiomyopathy.org/ride-london



Skydiving – 25 March

Skydiving day

Skydive for FREE!

Join our skydiving day in March and take on one of the ultimate adrenaline challenges. Trained on the day, you'll be paired with an experienced instructor before taking to the skies and climbing to 10,000ft. You'll free fall at speeds up to 120mph before your parachute opens and you float gently back to earth. You even get to jump for free if you raise £450!

Location – Salisbury
When – Saturday 25 March
 To register or get more information, please visit:
cardiomyopathy.org/skydive2017

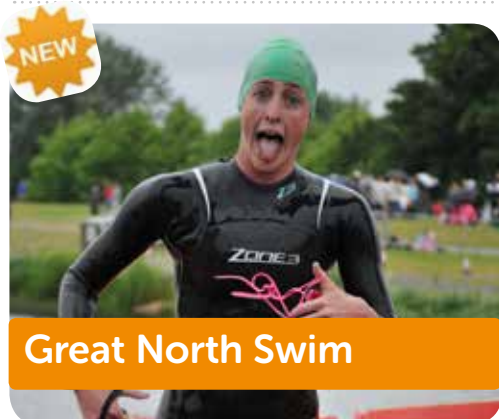


Ultra challenge series

Ultra challenges

Walk, jog or run one of five ultra challenges as part of #teamcardio. With a variety of distances and the option to take part as an individual or in a team, these events have something for everyone. New this year is the Cotswold Way challenge from Bath to Cheltenham through stunning countryside.

Location – five locations around the UK
When – April – September
Distances – 25K, 50K, 100K
 To register or get more information, please visit:
cardiomyopathy.org/walks



Great North Swim

Great North Swim – new for 2017

Dive into fundraising

Become part of the UK's biggest weekend of open water swimming. Set in Lake Windermere in the Lake District, the Great North Swim is an inspiring outdoor swim with distances of one mile to 10K. Get a place with Cardiomyopathy UK and swim surrounded by spectacular scenery.

Location – Lake Windermere
When – Friday 9 June to Sunday 11 June
 To register or get more information, please visit:
cardiomyopathy.org/gns

Vitality London 10,000



Take on a 10K that shows off the sights and sounds of London. Starting and finishing at St James's Park you'll be on the Olympic 2012 marathon route passing famous landmarks including the Houses of Parliament, St Paul's Cathedral and Big Ben. Whether you are new to running or a regular runner, this 10K offers a fantastic experience.

To register or get more information, please visit:
cardiomyopathy.org/london-10000

Overseas events



Get adventurous with your fundraising this year and challenge yourself in some of the most beautiful places in the world. Our overseas challenges include trekking along the Great Wall of China, and cycling from Vietnam to Cambodia to see the world famous Angkor Wat temples. So why not take on the ultimate adventure and visit some of the world's most spectacular locations all in aid of Cardiomyopathy UK?

To register or get more information, please visit:
cardiomyopathy.org/overseas

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!



Dates for your diary

January

Thursday 12 January, 7pm

South London Support Group

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY

Main speaker is Helen Creasy, senior specialist physiotherapist at St Thomas's Hospital, talking about activity and exercise

For more details, see panel below

Saturday 14 January, 2pm

New Birmingham Support Group

Station pub, Station Street, Sutton Coldfield, B73 6AT

Main speaker is Dr William Bradlow, consultant cardiologist, Queen Elizabeth Hospital, Birmingham

For details email Ross MacKinlay at ross@pdssoft.co.uk

Saturday 21 January, 3pm

North London Support Group

Finchley Memorial Hospital, Granville Road, London N12 0JE

Main speaker is Julian Bostock, cardiac physiologist at Guy's and St Thomas' NHS Foundation Trust, on treatments for heart rhythm disorders

For details contact Jane Barnett on 0208 343 1940 or email jane@email58.co.uk

Thursday 26 January, 7pm-9pm

Cheshire and Merseyside Support Group

Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL

Main speaker is Professor John Somauroo, consultant sports cardiologist, Liverpool Heart and Chest and Countess of Chester Hospitals

For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

Saturday 28 January, 2pm-4pm

Surrey Support Group

Post Graduate Education Centre, St Peter's Hospital, Guildford Road, Chertsey, Surrey KT16 0PZ

Main speaker is Dr Adam Jacques, consultant interventional cardiologist and clinical lead for Surrey Heart and Stroke Network

For details contact Tracey Bradshaw, email tracey.bradshaw@asph.nhs.uk

February

Saturday 4 February, 2pm-4pm

North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle

Main speaker Cardiomyopathy UK support nurse Robert Hall

For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

Saturday 18 February, 2pm-4pm

Dorset Support Group

Best Western Hotel Rembrandt 12-18 Dorchester Road, Weymouth, DT4 7JU

Main speaker is consultant cardiologist Dr Chris Critoph on exercise and cardiomyopathy

For details Jo Franks, 01494 791224 or email jo.franks@cardiomopathy.org

Tuesday 28 February, 7.15pm

West London Support Group

St Stephen's Church and Centre, St Stephen's Road, Ealing, London W13 8HB

Main speaker Bethan Cowley, inherited cardiac conditions specialist nurse, Royal Brompton Hospital

For details contact Willson Hau, 07777 6333398, email willsonhau@gmail.com

March

Saturday 11 March 2pm-4pm

Cheshire and Merseyside Support Group

Outpatient Department, Liverpool Heart and Chest Hospital, Thomas Drive, Liverpool L14 3PE

Support group leader Jenny Rees and Professor Ian Jones, Liverpool John

Moore's University, on Jenny's PhD research into the the psychological effects of cardiomyopathy and how the hospital is to use the findings to support patients and families
For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

Saturday 18 March, 9.30am-4.30pm

Cardiomyopathy information day

Nottingham Conference Centre, Burton Street, Nottingham NG1 4BU

For more details, see the panel below

April

Saturday 1 April 9.30am-4.30pm

Cardiomyopathy information day

Wrexham University, Mold Rd, Wrexham LL11 2AW

For more details, see the panel below

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

Saturday 22 April 9.30am-4.30pm

Cardiomyopathy information day

Novotel, Grey Friars Rd, Ipswich IP1 1UP

For details, see the panel below

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 more details, see the panel below

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@cardiomopathy.org or visit our website at cardiomopathy.org



Tell us

your story

My Life is your magazine and we welcome contributions on any cardiomyopathy-related topic.

If you would like to share your story with other people who are affected by cardiomyopathy, contact My Life editor Sarah Dennis at sarah.dennis@cardiomopathy.org

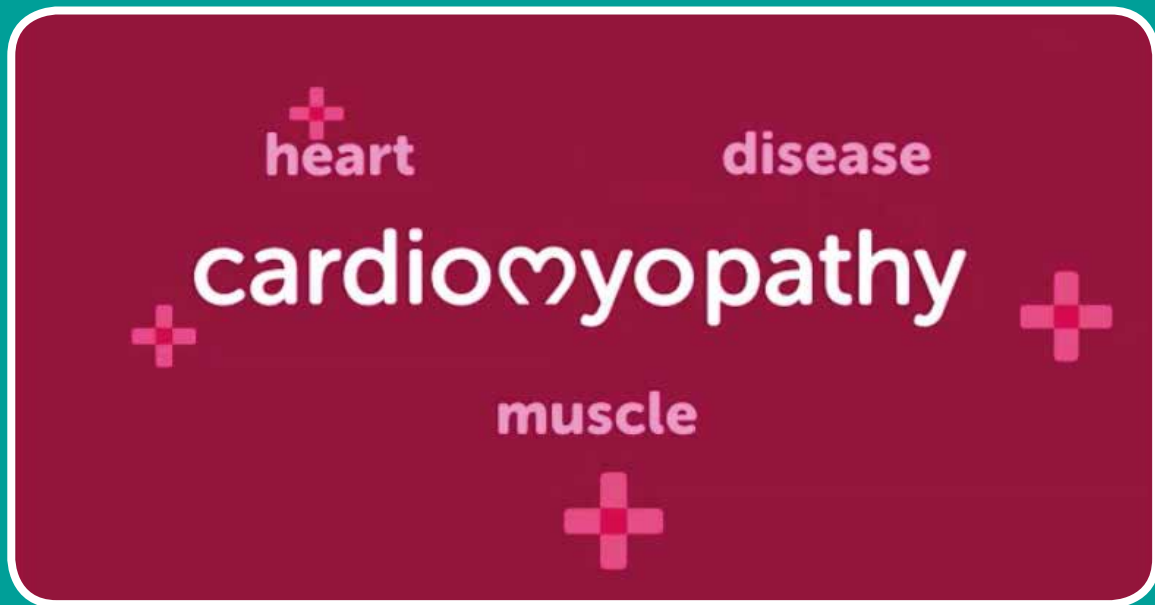
New cardiomyopathy support groups

are starting soon in Cumbria (February or March), Milton Keynes, Cambridge and Ipswich.

Dates and venues will be announced soon. To find out more call us on 01494 791224, email contact@cardiomopathy.org or see cardiomopathy.org/support-groups



We've launched a new video!



We've launched our first animated video, An Introduction to Cardiomyopathy



Ideal for people new to cardiomyopathy, the video gives a brief introduction to the heart, the condition and its typical symptoms

It also highlights the treatment options available



Watch: www.cardiomyopathy.org/intro_video
or www.youtube.com/cardiomyopathyuk

Please share the video with your friends and family, and your medical team



Cardiomyopathy UK

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t: 01494 791224

f facebook.com/cardiomyopathyuk

t [@cardiomyopathy](https://twitter.com/cardiomyopathy)

