

# my life

Issue 13/January 2018

Cardiomyopathy<sup>UK</sup>

The heart muscle charity magazine for people affected by cardiomyopathy

## 'Going above and beyond'

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# CONTACT US

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# WHAT'S INSIDE



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# Welcome from Alison Fielding, Chair of Cardiomyopathy UK

2017 seems to have gone in a flash. Everybody at #teamcardio has done a fantastic job of promoting awareness, providing support and information, sharing knowledge with health professionals and raising the money to keep us going.

We know that when people contact us or come to an event, they are happy with the services and feel better for using them. However, we help a small proportion of the estimated 160,000 people in the UK with cardiomyopathy and the many others potentially impacted, so our aim in 2018, is to get to more people at the time when they need us most - usually at diagnosis, screening or a procedure.

As this takes place in hospital clinics, we are starting a programme of putting volunteers into clinic information

points. We already have teams in Birmingham and Liverpool and hope others will follow shortly. (See page 13.)

We will also build on this year's #MyHeartStory in our ambition to both save lives and make sure the public is more aware of what cardiomyopathy is and its symptoms. The National Conference will also be travelling to the north of England where we hope to see a lot of new faces.

Please read the news about our exciting plans to incorporate the myocarditis charity, The Alexander Jansen Foundation, into our work on page 8.

We think it is an ideal fit, as myocarditis sometimes leads to dilated cardiomyopathy. Clinicians often deal with both conditions and patients and families have similar needs for support.

By joining our efforts, we hope to deliver even more services in a cost-effective way.



## INTRODUCING

## The Services Team



### What are your New Year's Resolutions?



**Ali Thompson**

Head of Services

'To meditate every day'



**Robert Hall**

Helpline Nurse

'To walk 1,000 miles, although not all in one go!'



**Jayne Partridge**

Helpline Nurse

'To get fitter and take part in a running and challenge event'



**Emma Greenslade**

Helpline Nurse

'To go to the gym more and exude more patience!'



**Jo Franks**

Support Group Manager

'To cycle the Taff Trail' (following the River Taff between Brecon and Cardiff)



**Rona Eade**

Information Manager

'To read more classic novels'



**Anne Foster**

Admin Assistant

'Mine is to get fitter'



**Claire Steadman**

Admin Assistant

'To do more exercise'



By Priya Manek  
Cardiomyopathy UK's  
PR and Communications  
Manager

# How knowing your family history can help save lives

During Cardiomyopathy Week 2017, we launched our first national campaign entitled **#MyHeartStory** to highlight how knowing your 'heart story' can save lives

Our first national campaign held in 2017 was all about raising awareness of the signs and symptoms of cardiomyopathy to improve the timely diagnosis of those living with the condition.

Our key objective was to encourage everyone to be aware of the medical history of immediate family members and to find out about their 'heart history'.

Knowing this information can help diagnose a heart condition at any point in your future and your life.

It is estimated that there are at least 160,000 people in the UK living with cardiomyopathy, but figures are thought to be much higher.

Currently, 1 in 3 people are misdiagnosed for other conditions, such as stress and asthma, and far too often, younger people are being undetected altogether because they don't conform to the stereotypes of what a 'typical heart problem patient looks like' which needs to change.

Our campaign launch was extremely positive and well received with media coverage achieved across a variety of TV, print, online and social media outlets.

Key broadcast items were featured on ITV Wales Tonight and BBC Look East, with print coverage featured in the Daily

Mail and Huffington Post, along with a variety of regional newspapers.

Coverage in The Nursing Times, Primary Health Today and Pulse also cascaded our messages across a number of healthcare professionals.

Within one week of the launch, media coverage reached audiences in excess of 242,237,707.

We delivered 80% positive key message delivery across media coverage and seven leading UK media medics were engaged with the campaign, helping to spread campaign messages to 758,889 followers on Twitter.

As we begin a new year, we hope our #Know Your Heart Story campaign will continue to encourage people to check their 'heart history' and make sure that they inform their GP.

We are looking to run another campaign in 2018 so watch this space for details!

Thank you to the hundreds of you who shared your experiences with us about living with cardiomyopathy and took part in our survey

Read the results on Page 12

If you would like to share your story and experiences, please email Priya at [media@cardiomyopathy.org](mailto:media@cardiomyopathy.org)



# Ellie, look at you now...



**Ellie Holman, 19, one of the speakers at our National Conference and a member of Cardiomyopathy UK's CYP&YA Panel says she 'wants to make a difference in 2018'**

Two years ago, I was in hospital waiting for my heart transplant, feeling like my life was over when it was just beginning.

At the age of 13, a routine appointment at the doctor's led to them detecting an extra beat when my GP listened to my heart.

I was referred to a cardiology centre where dilated cardiomyopathy was suspected.

I was monitored for two years, then at a routine appointment, my heart function had decreased and my heart had enlarged.

I was referred for a transplant assessment, however, I was too well for a transplant at this time and was kept an eye on.

Life was 'normal' for me. I did my A levels and worked part time as a care assistant with the idea of going to university to become a nurse.

However, after I completed my exams, I got pneumonia, which made my heart function decrease. I was put on the urgent transplant list in November 2015 and had to wait in hospital.

I lay in my hospital bed thinking things could not get any better and this was it.

I had no idea what was going to happen and always made sure I wasn't left by myself in case something happened, because I was terrified it would.

I avoided hospital visits from friends because I didn't want them to see how poorly and frail I looked and I spent hours scrolling through social media wishing I was anywhere but in hospital - wishing that I was out with friends enjoying myself.

Before then, walking to the shop without stopping due

to breathlessness had been my focus and the joy I felt after all those attempts was surreal.

Life at that time was hard, especially for a 19-year-old and if somebody had told me then, that two years later, I would be at university studying my dream adult nursing, I would not have believed them.

I remember every day in hospital being so hard and thinking I would never get a call for my transplant.

Even if I did, I thought my adult nursing dreams were non-existent.

I did get my call for my heart transplant and little did I know, my life had only just begun.

My transplant is enabling me to live life to the full and study my dream - all thanks to my selfless donor and their family.

I am two years out of transplant in January 2018 and life is amazing and precious. I am telling my story because I want to make a difference.

I'm proud to be a member of the Children, Young People and Younger Adults (CYP&YA) Panel for Cardiomyopathy UK. Eight years ago, when I was diagnosed with cardiomyopathy, I would have loved to have the support of the CYP&YA, which seeks to improve the services available to young people who are diagnosed with cardiomyopathy, by letting them know they are not alone and helping to make things easier for them.



**Waiting lists for heart transplants treble**  
- See page 6



We may be  
small, but  
we aim big

A regular gift is the best way to support our work throughout 2018 to help people affected by cardiomyopathy

Regular gifts are so important to us and help make a really big difference to everyone affected by the condition every day.

By choosing to support us with a regular monthly donation, you'll be helping us to plan ahead and keep improving our services. A monthly gift allows us to keep developing and improving the free support services that we offer, because we know that we will have a steady income stream that we can rely on.

We're a small charity, but we aim big and we want to be there for everyone that needs us - for as long as they need our support.

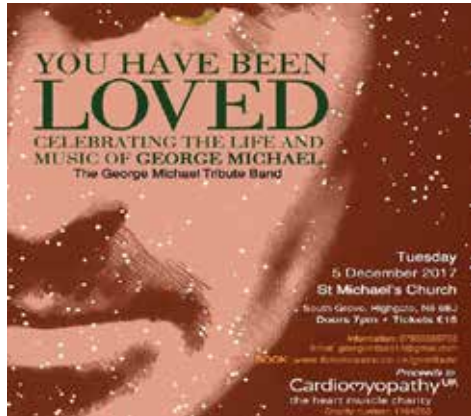
Giving regularly help us do this and makes an ongoing difference to the lives of people affected by cardiomyopathy and their families.

## HOW TO DONATE



If you're interested in supporting us financially, please call us on 01494

791224, or visit our website at [www.cardiomyopathy.org/regulargift](http://www.cardiomyopathy.org/regulargift)



# Remembering George Michael

Global superstar George Michael sadly passed away on Christmas Day, 2016 and Priya Manek, Cardiomyopathy UK's PR and Communications Manager, secured opportunities for us to be the beneficiary charity for several fundraising activities in his honour.

We were lucky enough to be supported by the official George Michael Tribute Band in his memory and worked with The Lovelies Help group, who raised funds for Cardiomyopathy UK as one of several charities in George's honour - holding online auctions for memorabilia to fundraise for us and even running marathons.

To date, they've raised more than £5,000 to support our work.

On December 5, we held a Christmas Concert with the 'You Have Been Loved' tribute band at St Michael's Church in Highgate - the church opposite where George lived.

This was a chance for fans to pay tribute, remember his music and honour their idol. More than 320 fans

bought tickets and the £3,400 raised came to the charity.

Joel Rose, Cardiomyopathy UK Chief Executive, said: "Many fans still feel they haven't been given the chance to say goodbye to George, so this gig remembered the wonderful memories he gave to so many and we were delighted to be a part of it."

David Wright, singer from the 'You Have Been Loved Team' said: "George's fans still feel the grief and loss from his death and we put on these concerts to help the fans pay tribute to their idol."

"The evening was an opportunity for those wanting to come together and remember the genius of George, sing along to his incredible music and enjoy the company of other devoted fans whilst raising money for a worthy cause - Cardiomyopathy UK."

**You can still support our work in George's honour and make a donation.**

**Simply text GEOR16 £5 or GEOR16 £10 to 70070.**

# Could your employer be our corporate partner in 2018?

Our Head of Fundraising Sheila Nardone (right) explains why we need your employer's support in 2018 which is so vital to the work of Cardiomyopathy UK



Corporate income is a vital way of helping us to provide our frontline services and develop new ways to help people affected by cardiomyopathy. Employees who are personally affected by cardiomyopathy are the most effective advocates for us.

We are looking for support from a range of companies in 2018, as our current corporate partnerships come to an end, including our largest partner, Mayer Brown International LLP. Their big-hearted employees have raised over £80,000 for us in the past two years by organising and taking part in a range of fundraising activities, such as 5-a-side football tournaments, fire-walking, a zip wire challenge, a music gig in a local pub and annual carol services.

We really need our supporters and their contacts in the private sector to explore whether their employer could support us in any way in 2018.

For ideas on different types of corporate support, please go to our website, or get in touch with me via email at: [sheila.nardone@cardiomyopathy.org](mailto:sheila.nardone@cardiomyopathy.org)



## Three key employees at Mayer Brown speak to My Life about their involvement:

Former HR Manager and mum, **Sara Day**, (left), who nominated us, explains: "When the email appeared asking for nominations for charity of the year, I didn't think twice about putting Cardiomyopathy UK forward. The charity had been so incredibly helpful and supportive since my daughter Rosie's Restrictive Cardiomyopathy diagnosis, I viewed it as



a way of being able to thank the charity and give something back. I was absolutely thrilled to learn that Cardiomyopathy UK had won the employee vote because any money raised, no matter the amount, would be a huge amount to them."



**Heidi Newbigging**, (left), who is responsible for Corporate Social Responsibility, says: "We believe our charity of the year partnerships should be for at least two years, which enables us to really get to know the charity and for them to get to know our business. We established a strong partnership with Cardiomyopathy UK that thrived as our people learnt more about the condition of cardiomyopathy and were able to share this with others, which was just as important as fundraising."

Legal Assistant, **Cliff Carder**, (right), who organised many events, including the football tournaments, says: "Having met with the team at Cardiomyopathy UK and hearing what the charity does to help people and their families affected by the condition, I wanted to help in whatever way I could. It has been a real pleasure working with the charity as their passion and enthusiasm for what they do rubs off on you. I combined my love of football and organising events to great effect with our very successful 5-a-side tournaments and challenges, such as our exciting firewalk and abseil."



## Here's how you can get involved this year



Nominate us as your employer's Charity of the Year



Get your employer to match any funds you have raised for us



Give regularly through your firm's payroll giving scheme



Ask your employer to sponsor us for one of our many events



Hold fundraising events and help to raise awareness in the workplace

# 'We can expect big things'

## Plans to build on the success of 2017



By Joel Rose  
Chief Executive

2017 was another successful year and we are especially proud of the great work we have done to support more people than ever before, improving healthcare professionals' ability to spot cardiomyopathy and ensuring more people are aware of the condition.

Last year, we saw a 30% rise in the number of people contacting our Helpline Nurses over the phone, via email, Facebook or live-chat.

Feedback from people who use our helpline has remained incredibly positive.



Our information events and resources also continued to be popular in 2017.

We held seven events last year, welcoming 456 people.

Our events are designed to give people the information they need and help them to feel better able to cope with their cardiomyopathy.

We ask people how they feel after coming to one of our events and were really pleased with the results.

Our comprehensive range of resources also continue to be popular. Last year, we were able to produce new



materials including information for parents of young people.

In all, during 2017 more than 100,000 people accessed our information, which is fantastic.



## Charity joins forces with Cardiomyopathy UK

In Summer 2017, we started talking to the Alexander Jansons Foundation about how we could work together.

The foundation is named after Alexander Janson, who died from myocarditis in July, 2013 at the age of 18.

Since its establishment, the foundation has focused on raising funds to support research into the condition - one that can lead to cardiomyopathy.

The knowledge gained from the research the foundation has funded will add to the body of existing knowledge and increase our understanding of myocarditis and how it can be prevented and cured, therefore saving lives in the future.

From 2018, the Alexander Jansons Foundation will become part of Cardiomyopathy UK.

We will take over the foundation's research commitments and start to support people with myocarditis through our Helpline, information resources and events.

We will also be working to help raise awareness of the condition among the general public and among clinicians to improve diagnosis and treatment.

At the same time, the foundation team will continue their highly successful fundraising efforts to support outstanding research.

We believe that by joining forces in this way we can expand the scope of our support services and play an important role in the development of myocarditis knowledge, diagnosis and treatment. I look forward to keeping you up to date with progress.





Above: the CYP&YA Panel and the media coverage, left, created by our '#MyHeartstory' campaign

In 2017, we also saw a huge increase in the number of people coming to one of our support groups - and seven new groups were launched.

Thanks to funding from The Big Lottery Fund and to our team of outstanding support group volunteers, we were able to welcome 467 individuals to our meetings.

As well as this, 200 people use our peer support service, taking the opportunity to speak to someone else with cardiomyopathy over the phone.

Speaking to another person, who has experience of cardiomyopathy, can be incredibly helpful, especially early in a 'cardiomyopathy journey'.

That's why last year, we tested a new service placing volunteers at cardiomyopathy clinics in Birmingham and Liverpool. This has been very well received and

we hope to build on this work in 2018.

It has been a real pleasure over the past year to see how hard our youth panel has been working to support others and to help develop our services for young people affected by cardiomyopathy. I know that we can expect big things from them in 2018.

We believe that as well as providing excellent support and information services, we have to work hard to make sure that healthcare professionals are able to detect and treat cardiomyopathy.

In 2017, we held our National Clinical Conference entitled 'Hidden in Heart Failure'.

We wanted to show clinicians how important it is to make a proper diagnosis of cardiomyopathy rather than lumping everyone together under the term 'heart failure'. It was pleasing to see that

we were able to get this important message across.

For me, another highlight of 2017 has to be our national awareness campaign.

We worked hard to get over the important message that everyone should know about their heart history. We were able to secure a great deal of media coverage - something that we will be building on in 2018.

Of course, none of this work would have been possible without the work of our volunteer fundraisers. Last year, we had 446 people volunteering to raise money for us. Their efforts along with the generous support of other donors, charitable trusts and corporate friends enabled us to do this great work.

Knowing that we have been able to achieve so much in 2017, makes all of us at the charity excited about what we can do in 2018.



## *Top tips to support us in 2018*



1. Use our support services any time you need help or advice
2. Become a media case study and share your story through the local media
3. Join (or set up) a support group
4. Do what you love - bake, jump, sew, sing - whatever you enjoy can be a fundraising activity
5. Come to our national conference, or one of our regional Information Days
6. Sort out your paperwork - update your will and leave a gift to Cardiomyopathy UK
7. Organise a stroll in September
8. Follow us on social media - Facebook, Twitter or Instagram
9. Show your support - buy some of our merchandise at **[www.cardiomyopathy.org/shop](http://www.cardiomyopathy.org/shop)**
10. Nominate us, or ask a friend or relative to nominate us, as their Charity of the Year at work

## Heart failure and cardiomyopathy - the differences

**Heart failure** is not a diagnosis, but a term to describe the reduced function of the heart by a condition or an injury to the heart.

Sometimes the heart's pumping chamber is stiff and does not relax easily, reducing the heart's ability to fill with blood causing heart failure symptoms.

Heart failure is diagnosed when the heart is not pumping enough blood around the body to meet its needs. This can cause a range of symptoms including tiredness, shortness of breath, swollen ankles/ feet or tummy.

When the left side (pumping side) of the heart is unable to generate enough force to distribute blood throughout the body, blood accumulates in the left sided chambers of the heart and subsequently, fluid can then build up in the lungs. The lungs become congested with blood and excess fluid can build up causing breathlessness, this can happen slowly overtime or sometimes quite quickly.

There can be many causes of heart failure including coronary artery disease, heart valve problems, high blood pressure and cardiomyopathy.

**Cardiomyopathy** is a disease of the heart muscle. It is a group of conditions that affect the muscle of the heart.

In cardiomyopathy, the heart muscle becomes enlarged, thick or rigid, and in some rare cases, the muscle tissue is replaced by scar tissue.

The different types of cardiomyopathy are: hypertrophic cardiomyopathy, dilated cardiomyopathy, restrictive cardiomyopathy, arrhythmogenic right ventricular cardiomyopathy or arrhythmogenic cardiomyopathy, Takotsubo cardiomyopathy and left ventricular noncompaction cardiomyopathy.

Cardiomyopathy can be either inherited or acquired. Inherited means that your parents may have passed the gene change for the condition onto you and acquired means that you may have developed it due to another condition or factor ie: a toxin.

Some people who have cardiomyopathy, have no signs or symptoms and need no treatment and it can affect people of all ages.

The heart can sometimes become weaker affecting its ability to pump blood around the body, this can lead to heart failure. Cardiomyopathy can cause heart failure, but this doesn't always happen.

Treatment for cardiomyopathy often reduces the likelihood of heart failure developing or controlling or reversing the symptoms.

If you are diagnosed with heart failure, you may be given a classification of how severe it is known as the New York Heart Association classification of heart failure (NYHA).

The NYHA classification is a functional classification based on the ability to perform physical activities and is a common and widely-used measure.

The classification is split into four classes:

Class I: Unaffected activities are unlimited, and ordinary activity doesn't cause symptoms; Class II: Mildly affected, activity is limited a little, comfortable at rest, ordinary activity results in symptoms; Class III: Marked limitation of physical activity, comfortable at rest, less than ordinary activity causes symptoms, and Class IV: Inability to carry out any physical activity without discomfort, symptoms are present at rest.

Knowing your classification can help doctors decide on the best treatment for you.

Medications which may be prescribed include Angiotensin Converting Enzyme (ACE) inhibitors or Angiotensin Receptor Blockers (ARB) and beta-blockers, which are prescribed to help control and reduce the symptoms of heart failure.

Some patients may also be prescribed a diuretic, which helps the body excrete excess fluid to help reduce the symptoms of breathlessness and swelling of the ankles or feet.

There are many other medications that can be prescribed according to a person's specific symptoms.

The effects of heart failure can also be lessened by changes to lifestyle, including maintaining a healthy diet, maintaining a healthy weight, minimising salt intake, minimising alcohol and caffeine intake.

Some patients will have access to a cardiac nurse, who can advise on lifestyle and exercise at specialist clinics at the hospital or local GP surgery.

**By Jayne Partridge**  
**Cardiomyopathy UK**  
**Helpline Nurse**

## Waiting lists for heart transplants treble in 10 years

New figures from the NHS Blood and Transplant service show the number of people on the waiting list for a new heart in the UK has increased by 162% since 2008

Since 2008, the number of people waiting for a new heart has increased from 95 to 249 this year.

However, the number of heart donations has not kept pace, with 127 donations in 2008 and 199 in 2017 - an increase of 57 per cent.

On the 50th anniversary of the first human heart transplant, carried out by South African cardiac surgeon Christiaan Barnard, a leading clinician said it was time to switch to artificial pumps and stem cell therapy, which could help

thousands more people in Britain each year.

Professor Stephen Westaby, GP at John Radcliff Hospital, said: "I am a great supporter of cardiac transplantation. Some patients live for 20 years with excellent quality of life, but we can only treat one per cent of people.

"How does a society value a treatment that needs another young person to die first and is applicable to less than one per cent of those who might benefit?


"I think within ten years we won't see any more heart transplants, except for people with congenital heart damage, where only a new heart will do.

"I think the combination of heart

pumps and stem cells has the potential to be a good alternative, which could help far more people."

Currently, around 15,000 people under 65 each year in Britain could benefit from a heart transplant, but there are only around 150 organs available annually.

Joel Rose, Chief Executive of Cardiomyopathy UK said: "The growing transplant waiting list highlights how important it is that we don't give up on promoting organ donation and encouraging everyone to have a conversation with their loved ones about becoming a donor."

 [Read the latest news online at cardiomyopathy.org/news](https://cardiomyopathy.org/news)





## ASK THE EXPERTS

**From left: Head of Services Ali Thompson and Helpline Nurses Robert Hall, Jayne Partridge and Emma Greenslade answer your questions**

### **Q: I have dilated cardiomyopathy and am having problems with erectile dysfunction. Can I take Viagra?**

#### **Helpline Nurse Robert says:**

Some men find resuming their sex lives problematic due to erectile dysfunction or impotence.

This is a common condition, affecting 50% of men between the ages of 40 and 70, becoming increasing prevalent as men get older.

There are many factors that can cause erectile dysfunction. As with any illness, anxiety can be a factor that may contribute to the problem.

Also, it may occur as a side-effect of drugs, such as beta-blockers. It's very important to discuss the issue with your doctor.

Viagra may be a treatment option, although it will depend on what other drugs you are taking. It can enhance the action of anti-anginal nitrate drugs, such as isosorbide mononitrate, and other drugs that lower the blood pressure. It should only be taken under medical guidance.

### **Q: Entresto: What is this medication used for and how do I take it?**

**Helpline Nurse Jayne says:** This medication is used to treat certain types of heart failure. It may help you live longer and lower your chance of having to go to the hospital for heart failure.

This product contains two medications: sacubitril and valsartan. Sacubitril belongs to a class of drugs called neprilysin inhibitors and valsartan belongs to a class of drugs called angiotensin receptor blockers (ARBs). They work by relaxing blood vessels so that blood can flow more easily, which makes it easier for your heart to pump blood to your body. This product should not be taken with ACE inhibitors (such as

captopril, enalapril) since your risk of serious side-effects may increase. Do not take this product for at least 36 hours before or after taking an ACE inhibitor.

Consult your doctor or pharmacist for more details and use this medication regularly to get the most benefit from it. This drug is only used within the criteria set by NICE guidelines

To help you remember, take it at the same times each day and tell your doctor if you do not get better, or if you get worse.

### **Q: How do I help my child cope better with tiredness?**

**Helpline Nurse Emma says:** Being tired is one of the hardest things children and teenagers struggle with and can lead to missed schooling and valuable lesson time. Use the following tips to help:

- Ensure the child/teen isn't over-doing things like excessive clubs activities

- Ensure they are getting enough sleep Also, be aware of your child's screen time as this can affect the quality and time needed for sleep)

- Ensure a diet rich in iron and vitamin C & D. Many toddlers can be lacking in iron and vitamin D due to fussiness

- Make sure they are screened regularly at cardiology appointments for adequate levels and if not, ensure supplements are prescribed

- If children are very tired at school and on a beta-blocker, make sure they take it early evening as this can ensure they won't suffer with undue tiredness as a side-effect during the day

- Keep a diary of your child's

tiredness - look for patterns and then discuss with your cardiologist

- Keep active. Take your children out for walks and gentle cycles. Maintain a good level of fitness within the restrictions of their cardiomyopathy

### **Q. What is Universal Credit and how will it affect me?**

#### **Head of Services Ali Thompson says:**

Universal Credit (UC) is a benefit that is gradually being phased in by the Department for Work and Pensions (DWP) and will replace six means tested benefits - housing benefit, income-related Employment and Support Allowance, income-based Jobseeker's Allowance, Child Tax Credit, Working Tax Credit and Income Support.

If you are receiving any of these benefits you will likely have to apply for UC instead as the Government want all claimants to be receiving UC by 2019.

UC can be quite confusing as separate benefit payments, such as housing benefit and ESA, will now be paid together under UC and housing benefit will be paid to the individual and not the landlord.

One of the biggest difficulties people experience when transferring to UC is that they are not paid for the first few weeks leaving some people in financial hardship.

If you have any questions about UC, please call the Helpline or email me at [alison.thompson@cardiomyopathy.org](mailto:alison.thompson@cardiomyopathy.org)

If you have questions you would like us to answer, email them to: [contact@cardiomyopathy.org](mailto:contact@cardiomyopathy.org)

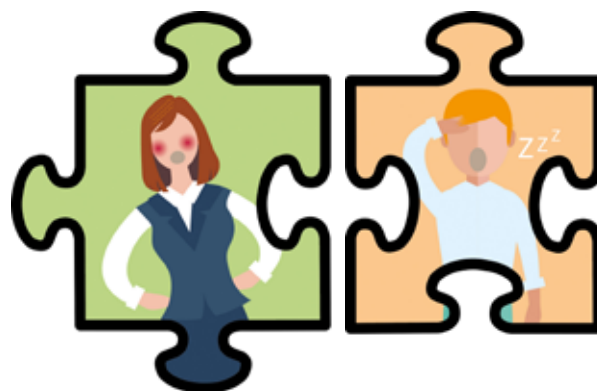
# Protecting loved ones



A central theme of our #MyHeartStory campaign was to encourage people to talk about their family history and help protect loved ones, who potentially, may be at risk of heart disease

As part of our campaign, we commissioned independent research to find out the experiences and opinions of those already with cardiomyopathy. This insight was used to inform our campaign messages and was open for a month in September 2017 ahead of the campaign launch. We had over 500 responses which was amazing and are thankful to you all for taking part and sharing your experiences of being diagnosed with cardiomyopathy.

Current estimates show that 160,000 Britons are affected by cardiomyopathy but we believe prevalence is much higher. Many people who may have the condition are overlooked as they currently don't fit the stereotypical 'heart patient's profile. It's essential we need people to abandon preconceptions of what a patient with a heart condition looks like. Family history is a crucial indicator of risk, and we all need to take action and finding out about family history to identify people at risk earlier.



*Symptoms can include breathlessness and tiredness*

Perry Elliott, President of Cardiomyopathy UK said: "It's vital people inform their doctor about their family history so patients who are at risk of heart disease can be identified and receive screening."

Joel Rose, Chief Executive of Cardiomyopathy UK, says: "At the start of this new year, we urge anyone with symptoms of cardiomyopathy, or a family history, to speak to their GP. Sudden cardiac deaths can only be prevented if people at risk are identified and it's essential that families start talking to each other about heart disease within the family."

**Go online to find out more at the #MyHeartStory campaign section on our website**

**We are grateful to the more than 500 people who took part in our online survey and shared their experiences of being diagnosed with cardiomyopathy**

## What type of cardiomyopathy did they have?

Hypertrophic (48%)  
Dilated (38%)  
Arrhythmogenic right ventricular cardiomyopathy (6%)  
Left ventricular non-compaction (3%)  
Peripartum (3%)  
Restrictive (1%)



## When and how were people diagnosed?

The largest group (44%) of people were diagnosed more than five years ago, although 15% had been diagnosed for less than a year.

Most people (66%) went to their GP when they started having symptoms, 19% went to A&E, 12% went straight to a cardiologist and 3% to a walk-in centre.

53% of people were diagnosed with cardiomyopathy straight away. However, 44% were diagnosed with another condition, before being diagnosed with cardiomyopathy. This may be because the symptoms of cardiomyopathy can be the same as other conditions, and it can be a condition hard to diagnose. For this reason, knowing any family history of heart conditions can be an important clue in the diagnosis of cardiomyopathy.

## What tests did people have?

Most people were diagnosed by a cardiologist (95%). This is reassuring as the condition should be diagnosed in a hospital setting and by a specialist.

Most people had tests that would normally be considered standard, with 90% having an echo and 86% having an ECG.

However, only around half of people had a physical exam (50%) or a medical history (50%).

## Were people asked about their family history?

86% of people had been asked, during diagnosis, whether they had a family history of heart disease or sudden death. Only 9% said that they were not asked.

86% said that their healthcare professionals had told them that cardiomyopathy can be a genetic condition.

Of these people, 58% were told at the point of diagnosis, and 35% were told at some time after their diagnosis.

## What happened after diagnosis?

63% of people had been asked about a family history of heart disease and drawn up a genetic family tree (which helps to identify family members with the same condition).

After their diagnosis, 69% of respondents had family members who were screened for cardiomyopathy.

47% of people had been given genetic testing for their cardiomyopathy, and 52% of them being confirmed with a genetic cause to their condition. This means that over half of respondents did not have genetic testing.

The majority of people (92%) spoke to their relatives about their diagnosis and its impact.





## A helping hand from the start

In Summer 2017, Cardiomyopathy UK introduced its first ever in-clinic peer support service at the Queen Elizabeth Hospital in Birmingham.

The charity believes it's essential that it is available to people affected by cardiomyopathy at the point of diagnosis, when they are most likely in need of reassurance and information.

That's why three volunteers started to attend the weekly cardiomyopathy clinic to meet with patients before, or after, their cardiology appointment at the Queen Elizabeth.

The volunteers have direct experience of cardiomyopathy: one has HCM and an ICD, one has DCM and one has a daughter with the condition.

### Reassuring

Talking to someone who has lived with the condition for a long time and knows how to manage the physical and emotional challenges that often accompany a life-changing illness, can be reassuring.

Many of the patients who speak to our volunteers have just been diagnosed and are, understandably, in shock and unable to process what they had been told by their clinical team.

Our volunteers are able to decode some of the more technical medical terms and explain what a diagnosis means in personal terms.

Patients can chat in confidence with

our volunteers, receive information resources, and find out about the charity's other services, such as the helpline (where they can access clinical advice and benefits advice) and peer support services.

Many people who have spoken to the volunteers have been diagnosed with a cardiomyopathy for a long time, but not heard of Cardiomyopathy UK and were amazed at the diversity of services we offer to people diagnosed and these supporting them through our website, support groups, helpline and social media outputs.

### Expanding

Working with Dr William Bradlow, the consultant cardiologist at the hospital, ensures we provide a service that is responsive to the needs of the hospital's patients.

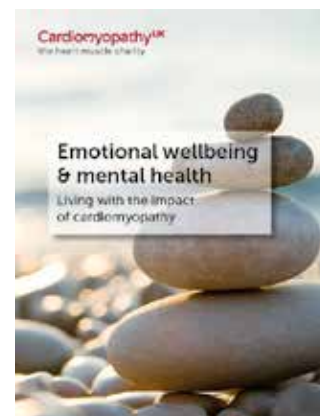
The service is the first of its kind for the charity and we have recently developed the model at the Liverpool Heart and Chest Hospital.

People living with the condition have told us that having access to support at point of diagnosis is particularly important in those first months when they are trying to get to grips with the condition.

Cardiomyopathy UK is committed to expanding this service even wider in 2018 and will look to establish more peer support services in hospitals throughout the country.

## Emotional wellbeing

Many of you have told us about the impact cardiomyopathy can have on you, beyond 'just the physical' impact: the effect it can have on your emotional wellbeing and mental health.



Using feedback shared through our online survey last year, and bringing together information about emotional wellbeing and services available for support, we have written a new booklet.

**'Emotional wellbeing and mental health - living with the impact of cardiomyopathy'** is for people with the condition, as well as those supporting them. It includes the stories of four people, who share their experiences about the impact on their emotional wellbeing and what has helped them.



Download or order online at [www.cardiomyopathy.org](http://www.cardiomyopathy.org) or call 01494 791 224 for a copy.



Sometimes it's the little things in life that can help you get through difficult times, or manage the everyday challenges of having a heart condition.

Life hacks are helpful shortcuts and top tips on how to manage life - such as saving you energy, managing your symptoms, or making you feel more in control. Take a look at some of these life hacks suggested by those who came to our National Conference and why not give them a go?

"I had my hair cut short so it was less tiring to deal with (and it made me more confident!)."

"Don't spend energy worrying about the future or the past - appreciate today."

"I know writing in a journal has definitely helped me. Taking time to jot down worries and feelings when you're having a bad day, but also when you're having a good day."

"Organise clothes to get ready for bed to limit

Do you have any life hacks to share?

Email them to:

**contact@cardiomyopathy.org**



# Knowing ore, living better

Knowing more, living better - Cardiomyopathy UK's National Conference 2017 was held on Saturday, November 18 at the Royal National Hotel in London.

Many of the 199 people who attended had the opportunity to meet other people affected by cardiomyopathy and to take part in the range of sessions on offer, as well as view exhibitions and join self-management and holistic therapies groups.

People were able to meet our trustees and staff and to hear from medical experts and ask questions at the four sessions, which included:

**Living with treatment** - focusing on treatment options for cardiomyopathy and how people can be supported to make informed decisions about treatment, and prepare and come to terms with the impact of treatment

on lifestyle.

**Genetics and the family** - on the role of genetics in the development of cardiomyopathy and the emotional aspects of living with a genetic condition on the individual and on the family.

**The impact of cardiomyopathy and the family** - on the impact that cardiomyopathy can have on the individual and those close to them.

**Cardiomyopathy and lifestyle** - on managing some of the practical aspects of the condition.

During the day, we also held our annual awards ceremony to recognise and thank inspirational individuals who 'go above and beyond' to show commitment to Cardiomyopathy UK.

- See pictures of our 2017 award winners on page 16.





# Dedicated to change

One of the speakers at our 2017 National Clinical Conference  
Tootie Bueser talks to My Life



Tootie, right, has been a specialist nurse in inherited cardiac conditions (ICC) since 2008 and works across Guy's & St Thomas' Hospital and King's College Hospital.

She is currently studying for a PhD and her research is focused on the care of patients undergoing cardiac screening and/or genetic testing in ICCs.



## How did you get into nursing and then into your particular role?

I wanted a job where I could be useful to society, be involved in science and travel. I thought nursing would be perfect as this provides all these opportunities and indeed, I have worked in the Philippines, the US and presently, in the UK.

My interest in cardiac genetics was piqued by a member of Cardiomyopathy UK, who turned up one day to my cardiac rehabilitation class and I didn't know what to do with him in terms of exercise and lifestyle advice.

I was stumped! He then sat down, brought out some leaflets and proceeded to educate me on his genetic condition.

I learned so much about cardiomyopathies because he got me so interested.

When the British Heart Foundation posts came up for the first cardiac genetic nurses, I did not hesitate to apply, even if that meant leaving my bucolic existence in Wiltshire.

I have grown with the service and with the help of the other clinical leads, and guidance from our patient groups, we've been able to expand and I now lead a team of very enthusiastic and dedicated nurses.

## What are the biggest challenges of your job?

I think it is both an advantage and a challenge that the scientific techniques in genetics/genomics is moving very quickly.

On the one hand, there are now answers to questions we had before such as 'What is the genetic basis of this condition?' but at the same time, we are dealing with more uncertainty as to whether patients with a particular genetic trait will develop an ICC.

## What are the biggest joys?

For me, the greatest reward in this job is seeing patients overcome the challenges of the ICC and making the most of their situation.

To have been part of seeing a patient through probably the toughest times of their life makes my job worthwhile.

It is also a privilege to interact with patients through my research as this deepens my knowledge and appreciation of their resilience and how they cope with ICCs.

## What do you hope to achieve in your role and do you have any specific aims for 2018?

We are currently expanding our services and bringing it closer to home to patients who live further in our region, so I hope this project takes root and becomes a successful model for others to follow.

I also hope to complete my in-depth studies on family members of patients with ICCs, with a view to applying this knowledge very quickly to clinical practice to improve services.

My personal New Year's resolution is to read for pleasure more and manage my tasks better so I can spend more time with family, friends and the bike!

## What were the key points of your speech about the different long-term needs of people with cardiomyopathy at our Clinical Conference.

Patients with cardiomyopathies have different long-term needs compared to other patients with other heart conditions. It not only affects patients individually, but has implications for their family.

They need specialist, multi-disciplinary care that can address their needs in terms of cardiac, genetics and psychosocial aspects.

Clinical input and psychological support needs to be tailored according to the patients' physical condition and psychosocial situation, as well as where they are in their life stage.

Peer support is also important as patients can help support each other deal with the day-to-day aspects of the condition.

## Do you any key advice for cardiomyopathy patients and their families?

Getting specialist advice from an ICC service, even if it is just a one-off assessment, is key to plugging into a resource that cardiomyopathy patients can tap into as needed.

Make sure you link in with the cardiac genetic nurse or counsellor, as they can give immediate advice most of the time.

This is also a time to rally all the personal support you can get - whether it is your own family, friends or Cardiomyopathy UK. As the saying goes, 'It takes a village to raise a child' and this also applies when coping with a long-term genetic condition.

## What do you think of our #MyHeartStory campaign?

I think it's really important to be aware of your family's health history and to share medical information.

Sharing your experiences can also inspire others to open up, increase awareness and give the support to those at risk to look into screening or genetic testing, if appropriate.



You can watch videos from our Clinical Conference at: [www.cardiomyopathy.org/ncc-videos](http://www.cardiomyopathy.org/ncc-videos)



**THE DEVELOPMENT AWARD**  
**Winner: Sarah Bishop**

(Above: Sarah pictured with Trustee Pete Thomas)

This award was given to Sarah in recognition of her incredible fundraising for Cardiomyopathy UK. Sarah has raised in excess of £22,000 for the charity, as well as helping to raise our profile and awareness of the condition on an incredible scale.



**CLINICAL EXCELLENCE AWARD**  
**Winner: Lucy Girdler-Heald**

(Above: Lucy pictured with Trustee Graham Otter)

Nominated by patients through our website, Lucy's award recognised her dedication and the outstanding support she has given to patients and people affected by cardiomyopathy, as well as to healthcare professionals.

# 'Going above and beyond'



**THE COMMUNITY AWARD**  
**Winner: Elis Power**

(Above: Elis pictured with Chair of the board of Trustees Alison Fielding)

Elis, who is a founding member of the CYP&YA Panel, won the award for personally supporting a number of young people who have struggled to cope with their cardiomyopathy.



**THE CAROLYN BIRO FOUNDERS AWARD**  
**Winner: Richard Corder**

Named after the founder of the Cardiomyopathy Association, Carolyn Biro, this award went to Richard (left) for his incredible commitment and tireless work as a support group leader and patient ambassador for Cardiomyopathy UK.



**THE IMPACT AWARD**  
**Winner: Julie Rees**

Julie (left) has provided support to countless people affected by the condition through her work as a support group leader, peer support volunteer and latterly, as a clinical support volunteer at the Liverpool Heart and Chest Hospital.



# #teamcardio highlights

Whether it's with family, friends or work colleagues, #teamcardio supporters raised thousands of pounds through a variety of charity events last year - thank you, as we couldn't do our work without you - and here's to plenty more fantastic fundraising in 2018

The fantastic **Neopost Tough Mudder Team**, (right), ran a 12-mile muddy obstacle course to raise £2,452. Thank you!



Caroline Neill, (left, centre), organised a September Stroll for us with her friends and family, including a tombola and a cake sale to kick off the day. They raised a fantastic £1,050. Thank you!



Connor Blount successfully ran the Great North Run for us in September, and was joined by one of our youngest #teamcardio members Marty, (above), on the final stretch to the finish line. Their family supports us year, in year out - thank you all so much



Jackie Parker, (left), chose us as her Ladies Golf team Captain's charity for 2017 and the club raised a fantastic £2,145 for us. Thank you so much to all the members of the **London Beach Golf Club** for their kind support

Are you interested in being part of #teamcardio in 2018?

Please get in touch with our fundraising team at [fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org)

## Leave a gift in your will for future generations



A gift to Cardiomyopathy UK in your will would help to transform the outlook for families affected with heart muscle disease.

After you have considered everyone you care about, if you are also able to leave a gift, of whatever size, you'll be making a real difference to future generations with cardiomyopathy. A percentage of your estate or a fixed sum gift will make a real difference to their lives.

Thank you so much if you have already made provision for Cardiomyopathy UK

in your will. If you would like to make an amendment to your existing will for 2018, you can download a form from our website.

To discuss leaving a gift to Cardiomyopathy UK, no matter what size, please get in touch with Sheila Nardone, Head of Fundraising, on 01494 791224, or fill in our website contact form. Together, we can help future generations affected by cardiomyopathy. Thank you.

Pictured left: One of our trustees Rita Sutton with her granddaughter Rosie

Cardiomyopathy UK the heart muscle charity



# New Year, new challenge

Make 2018 a year to remember by taking on a challenge for #teamcardio. Whether you want to run a marathon or take a stroll through the countryside, we've got something for you. There's everything from gentle walks and jogs, to skydives and exhilarating obstacle courses.

Included in your magazine is our new events leaflet, with details of a selection of events for 2018. For more information on any of the challenges and to see everything available visit our website [www.cardiomyopathy.org/events](http://www.cardiomyopathy.org/events)



## Reach for the sky



## Skydiving Day 2018 - jump for free

Come and join us for the ultimate adrenaline challenge at our Skydiving Day 2018. On 9 June, we're organising a #teamcardio skydive in Oxfordshire, and if you raise £450 you get to **jump for free!**

All the training you need takes place on the day, and you get to make a day of it with family and friends to support you. Brave speeds of 120mph and take the leap of a lifetime!

**Location:** Brackley, Oxfordshire

**When:** 9 June, 2018

**Distance:** Up to 13,000ft!

To find out more visit [www.cardiomyopathy.org/skydive](http://www.cardiomyopathy.org/skydive)



## Great North Run 2018

Would you like to be part of the world's largest half marathon? This iconic run is a must on the running calendar. Whether you've been lucky enough to get a ballot place or want one of our charity places we'd love you to run for #teamcardio. We give all of our runners all the help and support they need, including a training day.

**Location:** Newcastle

**When:** 9 September 2018

**Distance:** Half marathon 13.1 miles

**Pledge:** £375

Visit our website to find out more:  
[www.cardiomyopathy.org/great-north](http://www.cardiomyopathy.org/great-north)



## Hampton Court Half Marathon

The original Hampton Court Half Marathon is run over a fast, flat and visually interesting course that borders the riverside grounds of the magnificent Hampton Court Palace to the South West of London – and it gets better for 2018. This fast flat route offers definite PB potential, while also offering great scenery. The closed road start and finish add to the big race feel and runner security.

Whether it's your first half marathon or fifth, join #teamcardio and we'll give you all the help and support you need.

**Location:** Hampton Court Palace

**When:** 18 March 2018

**Distance:** 13 miles

**Pledge:** £250

**Visit our website:**  
[www.cardiomyopathy.org/hampton](http://www.cardiomyopathy.org/hampton)



## Gung-Ho!

Take part in this incredibly fun 5km-course over giant inflatable obstacles. You will run, jump, and bounce your way around the course. Be part of the biggest 5K in the world and have a great time doing it. Gung-Ho is open to everyone, whether you're a seasoned runner, or if you just fancy joining in the fun – everyone can take part.

**Location:** Throughout the UK

**When:** March - September 2018

**Distance:** 5km

**Pledge:** Raise what you can

Visit our website to find out more:  
[www.cardiomyopathy.org/gung-ho](http://www.cardiomyopathy.org/gung-ho)



## GET INVOLVED

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



## January

Saturday 27th January, 2-4pm

### **Surrey Support Group**

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

Topic: With Robert Hall, Support Nurse from Cardiomyopathy UK

For details: Tracey Bradshaw, Heart Failure Specialist Nurse, 01932-723600, tracey.bradshaw@asph.nhs.uk

Saturday 27th January, 2-4pm

### **ARVC Support Group**

Venue: Northolt Methodist Church, 240 Church Road, Northolt, Middlesex, UB5 5A

Topic: to be confirmed

For details: cathryn@yourtimematters.co.uk or call Jo Franks, 01494 791224

Saturday 27th January, 2-4pm

### **Birmingham Support Group**

Venue: The Lapworth Museum of Geology, Aston Webb Building, University of Birmingham, Birmingham, B15 2TT

Topic: With Professor Leyva talking about cardiomyopathy and answering your questions

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

## February

Saturday 3rd February, 2-4pm

### **Dorset Support Group**

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

Topic: The Red Cross will be leading an interactive session on CPR, please bring a donation to help cover their costs

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

### **West Scotland Support Group**

Venue: Glasgow Royal Infirmary, Castle Street, Glasgow, G4 0SF

Topic: Diagnostic genetic testing

For details: Stephen Kirkham at sg.kirkham@btinternet.com or Jo Franks 01494 791224

### 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**

Saturday 10th February, 2-4pm

### **North East England Support Group**

Venue: Function Room 137, Education Centre, Freeman Hospital, Newcastle, NE7 7DN

Topic: 5th Anniversary meeting with Robert Hall, Support Nurse from Cardiomyopathy UK

For details: email Susan suze.saunders@btinternet.com or Jo Franks 01494 791224



Saturday 10th February, 2-4pm

### **Sussex Support Group**

Venue: Peacehaven Evangelical Free Church, 132 South Coast Road, Peacehaven, East Sussex, BN10 8RD

Topic: to be confirmed

For details: Lucy cardiomyopathysussex@gmail.com or Jo Franks, 01494 791224

Saturday 17th February, 2-4pm

### **West London Support Group**

Venue: The Friends' Meeting House, 17 Woodville Road, Ealing, London, W5 2SE

Topic: to be confirmed

For details: Peter and Denisa ealingcardiogroup@yahoo.com or Jo Franks 01494 791224

Saturday 24th February, 2-4pm

### **Bristol Support Group**

Venue: Brookway Activity Centre, Brook Way, Bradley Stoke, Bristol, BS32 9DA

Topic: Louise from the Heartful Dodgers team who will talk about the work of the team and 'Exercise, activity and cardiomyopathy'

For details: Jo Franks jo.franks@cardiomyopathy.org or call 01494 791224.

## March

Saturday 3rd March, 2-4pm

### **Fareham, Portsmouth and Gosport Support Group**

Venue: Wallington Village Hall, Broadcut, Fareham PO16 8ST

Topic: Gilbert Wheeler 'My heart transplant story'

For details: Sue Bailey sabailey53@btinternet.com or 07585 336463

Saturday 10th March, 2-4pm

### **Bridgend Support Group**

Venue: Pencoed Welfare Hall, Heol-Y-Groes, Pencoed, Bridgend CF35 5PE

Topic: Robert Hall, an overview of cardiomyopathy

For details: Ann Harrison-Power anniepj@btinternet.com or call 07970 669239

### Online Support Groups

Our new online support groups can be accessed from your computer, tablet, smartphone or by phone. Places are limited, so book early to avoid disappointment.

Wednesday 17th January, 2:30-4pm

### **Rurally Isolated online Support Group**

For anyone affected by cardiomyopathy who is unable to travel to a support group because they live in a rural location with Jo Franks, Support Group Manager and Emma Greenslade, Cardiomyopathy UK

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

Thursday 8th February, 2:30-4pm

### **Supporter & Carers online Support Group**

For anyone who supports someone with cardiomyopathy with Jo Franks, Support Group Manager

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

Thursday 8th March, 2:30-4pm

### **ARVC online Support Group**

For anyone affected by ARVC with Jo Franks, Support Group Manager and Robert Hall, Cardiomyopathy UK Support Nurse

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



# Be courageous for Cardiomyopathy UK

Skydiving day  
9 June 2018



Sign up now  
01494 791224

[www.cardiomyopathy.org/skydive](http://www.cardiomyopathy.org/skydive)  
[fundraising@cardiomyopathy.org](mailto:fundraising@cardiomyopathy.org)

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