

my life

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

Issue 12| Winter 2017

Coping with worry

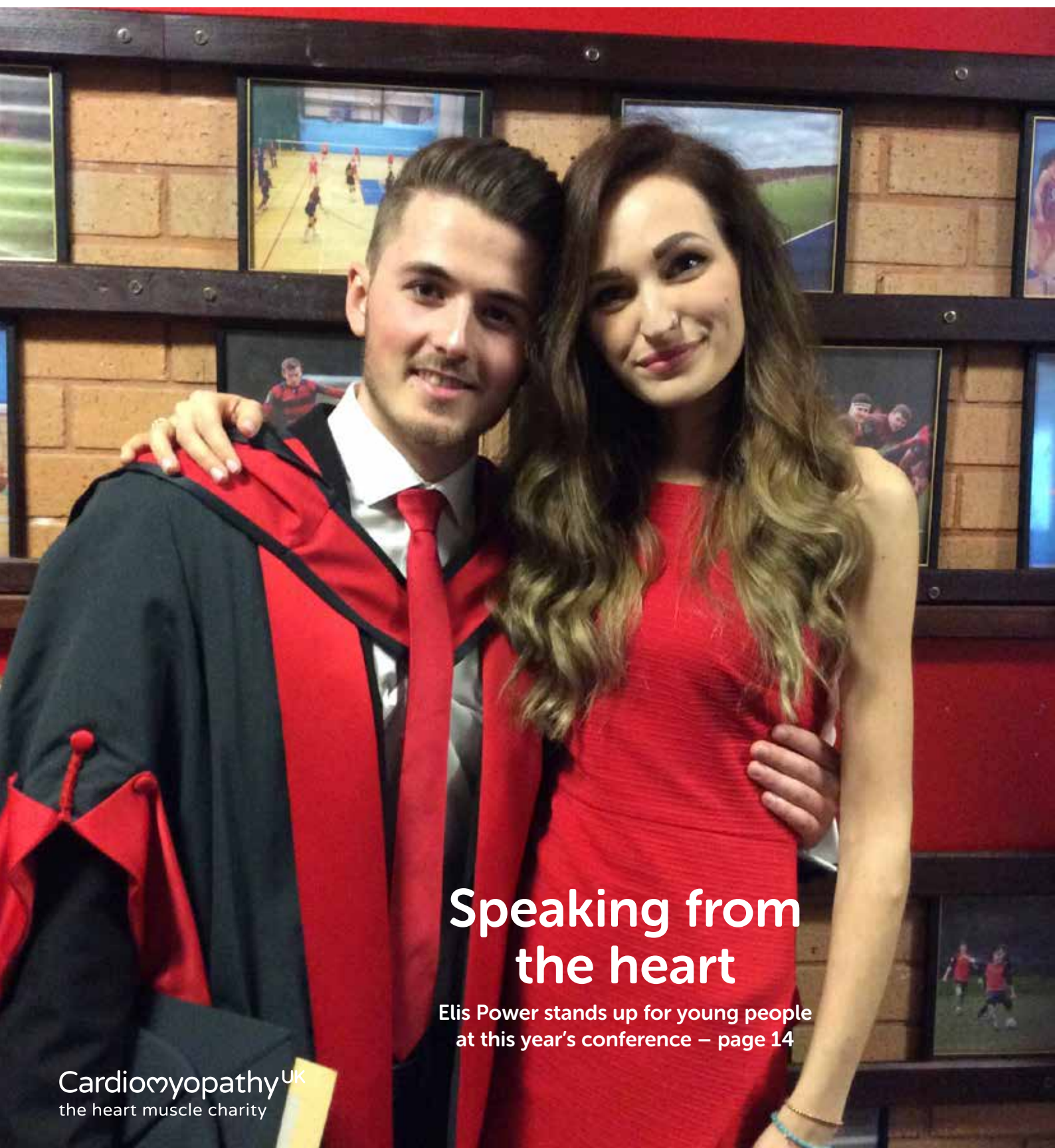
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Speaking from the heart

Elis Power stands up for young people
at this year's conference – page 14

Cardiomyopathy^{UK}
the heart muscle charity

Our services

We provide information and support to anyone affected by cardiomyopathy

- **helpline nurses**

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

- **information packs**

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

- **support volunteers**

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

- **information days**

We hold information days around the UK each year. These days provide people affected by cardiomyopathy and their families with the chance to meet others who have the condition and hear leading experts talk about the disease, developments in care and latest research

- **support groups**

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

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

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

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



HOW TO GET IN TOUCH

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Chesham, Bucks HP5 2PX

Telephone **01494 791224**

Website cardiomyopathy.org

Helpline **0800 0181 024**

(free from a UK landline)

Email contact@cardiomyopathy.org

Like us on Facebook

facebook.com/cardiomypathyyuk

Follow us on Twitter

[@cardiomypathyyuk](https://twitter.com/cardiomypathyyuk)

Join our Facebook group

(closed privacy settings)

facebook.com/groups/cardiomypathyyuk

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

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Holistic approach

By Chair of trustees
Alison Fielding
chair@cardiomyopathy.org

When it comes to living with cardiomyopathy, I try to adopt an approach similar to the successful British Cycling teams.

Their team of sleep coaches, nutritionists, exercise therapists and scientists work with them to produce small improvements that all add up to a winning difference.

Most of us have to work on our own to find the things that help us to feel better. I have worked on what makes me happy and what makes me feel physically better. So I am getting more exercise, having better sleep, volunteering and becoming used to setting realistic goals.

Cardiomyopathy UK is here to help you through the good and bad days.

There isn't a 'one size fits all' when it comes to the information and support people need, so we offer a range of services for you to use.

In our experience, people with the condition like to meet others face-to-face at our support groups, Information days and National Conference, whilst others prefer to watch the conversations on our closed Facebook group or have a one-to-one chat with a nurse or Cardiomyopathy UK peer support volunteer.

This edition is all about taking a holistic approach to living with cardiomyopathy and examples of things that have helped people.

Why not give some a go and let us know how you get on?

The heart of what we do

By Ali Thompson
Head of Services

At Cardiomyopathy UK we are committed to providing the highest calibre of services to children, young people, families and individuals affected by cardiomyopathy.

Our commitment to the diverse and changing needs of our people is reflected by our services.

We recognise that people affected by the condition sometimes require information, advice and support that are beyond medical questions:-

- Some people want to know what their rights are at work following a diagnosis of cardiomyopathy,
- Some might be awaiting an ICD and want to speak to someone, who has had such a device fitted, to find out what life is like post-surgery and,
- Some young people want to talk to other young people of a similar age, to receive peer support and to help normalise the condition when they are the only person in college with a heart condition.

Our services are holistic and look to support people with their mental and emotional wellbeing as well as their physical symptoms.

People are able to call our freephone helpline and speak with an adult cardiac specialist nurse, a paediatric cardiac specialist nurse and a housing, benefit and employment adviser.

People can email or talk to us via our instant messaging service, Live Chat, if they are unable to speak on the phone.



We also offer a peer support telephone service where people can speak with someone who has lived with cardiomyopathy/supported someone with the condition for a while and share strength and hope.

We also have a wide range of information resources available in hard copy and to download from our **website www.cardiomyopathy.org** covering topics of particular interest for people affected by the condition, including resources for young people, parents, carers and medical professionals.

Cardiomyopathy UK has a national network of support groups that enable people to come together, hear from expert speakers, share coping strategies and support each other.

In addition, we hold information days throughout the year in various locations hosted by experienced cardiologists, an annual national conference (for the public) and a clinical conference for healthcare professionals.

● **'You're not the only one' - See Page 6**

Making a difference



Chief executive
Joel Rose
joel.rose@cardiomyopathy.org

One of the greatest pleasures of my job is meeting people who have benefited from our services.

We believe that our services make such a difference to people's lives because they are designed to give the right help and support at the right time.

People come to us at different stages of the "cardiomyopathy journey" and while we can't make their cardiomyopathy go away, we can help them to understand more about their condition, get the treatment they need, feel in control and live as full a life as possible.

Of course, there is no way that we could provide these services without our volunteers and fundraisers, to whom we are most thankful.

In this, the final issue of My Life for 2017, we are also letting people know all about our national campaign, MyHeartStory. (See Page 11)

As we do more to raise awareness of cardiomyopathy, then more people will be coming to us in need of help, information and support. I am confident that with your continued support, we can be there for them.

Top professor is our new president

Professor Perry Elliott, (right), has taken over as Cardiomyopathy UK's new President.

Perry is currently the Clinical Lead of the Inherited Cardiovascular Disease Unit at the Bart's Heart centre and Professor of Cardiovascular Medicine at UCL.

Over the past 20 years, Perry has gained an international reputation in the field of heart muscle disease, authoring more than 280 peer reviewed papers on the subject.

Perry said: "I'm delighted to be chosen as the next President. This amazing charity has a strong history of dedication, passion and sheer commitment for helping people and families handle cardiomyopathy."

"It is a fatal condition that affects seemingly young and healthy people and can hit entire families. The support this charity provides to patients, families and the medical community is crucial and I'm privileged to be taking this forward in the hope we can save even more lives."

Supporting Perry in his role is Vice President Gerry Carr-White. Our previous President Bill McKenna becomes an honorary life member.

Joel Rose, Cardiomyopathy UK Chief Executive, said: "Perry has been a long-standing supporter and will be an excellent advocate to help us increase awareness of the condition. We know there will be fewer avoidable deaths if more people can recognise the symptoms and get the treatment they need."



What (worry) lies beneath...

Living with cardiomyopathy often involves feelings of future risk and threat, to ourselves and our family. Understandably, this can lead to worrying.

My previous article highlighted the way worries can prompt you into doing something to look after yourself or your loved one, which can be helpful.

But thinking about possible problematic or even catastrophic futures that we can't do anything to prevent, can leave us in a mental stew, feeling anxious and restless.

Ray Owen's book, 'Living with the Enemy', includes a good example of unhelpful worrying about a long-term condition.

On the surface, one of his fictional characters (Bill) is currently doing quite well, despite having been diagnosed with Multiple Sclerosis ten years ago.

Everyone tells Bill he's coping brilliantly, but what people don't see is what's going on under the surface.

Like seeing only the tip of the iceberg, people don't see Bill's worries.

They don't know how he lies awake at night worrying about his future and thinking about lots of potential difficulties.

What if his symptoms get worse? What if he ends up in a wheelchair, or becomes a burden to his family?

Bill's life has become dominated by thoughts under the surface.

He can keep them at bay by being busy during the day, but at night, he can't turn off the worry thoughts or the feelings of sadness, fear and anger they generate.

His 'unhelpful worries' mean he is living his life now as if all the things he fears have actually already happened.

It's as though he has become tangled up or 'fused' with his own unhelpful worry-thoughts.

Bill's worries are understandable. And some of them may come true.

But what a tragedy it would be, if in a few years' time - should his life become more limited - he looks back and wonders why he didn't enjoy life more when he could do the things he'd now want to do?

For minor worry, gentle distraction, such as engaging in an enjoyable or mentally demanding activity, can be helpful. But for really troubling worries, trying to avoid unhelpful thoughts tends to keep them going.

If we try to get rid of the worry - for example, through being super-busy - the worry often just keeps coming back.

If worry is causing you anxiety and stopping you relaxing or sleeping, it can help to write the worries down.

Although it may seem an odd thing to do, writing down your worries and giving them careful consideration, allows you to see more clearly what's going on under the surface.

By seeing your thoughts 'on the page'



you can see your worries more clearly.

Although this may increase the anxious or upsetting feelings in the short term, if you are able to sit with them for a few minutes, they will gradually start to reduce.

And you can see that your worries are



In the final part of his two-part article, Graeme Gillespie outlines a number of practical ideas for when worrying keeps you awake at night

just thoughts.

By labeling them as thoughts, you can become less tangled up in, or 'fused with' those unhelpful worries.

For example, try reading them back to yourself by adding, "I'm having the thought that..." at the start of each worry.

Another approach involves scheduling a few minutes aside each day to focus on your worries. It may even help to set a timer for 10 to 15 minutes.

During your planned worry time, write down all your worries in a list. Then consider each worry carefully.

Write down if there is anything you can do to help deal with it. (Don't forget to act on this later).

If there isn't anything, go on to your next worry and do the same.

Once your worry time is over, it's time to get on with the activities of the rest of your day.

If a worry should pop into your mind - especially at night - you can jot it down for tomorrow's worry time.

Our minds can work like a time machine, hopping backwards and forwards in time.

By stepping out of our own mental Tardis, we can get more in touch with our current experiences.

The website bemindful.co.uk provides a link to online resources and local mindfulness teachers who follow nationally agreed Good Practice Guidelines.

It's also important to remember that worries thrive when the body is physically agitated, such as through smoking or drinking excessive caffeine or alcohol.

Cardiomyopathy can sometimes cause fatigue and shortness of breath and make it much harder to take regular exercise or engage in activities you used to enjoy.

A trusted healthcare professional, such as your GP or cardiologist/specialist nurse, can advise you about sensibly-paced physical activity to help both the body and the mind to feel better.

If anxiety and worry are dominating your life and self-help approaches don't work or feel enough for you, your GP or nurse can guide you to other sources.

Excessive worry, alongside other symptoms such as restlessness, feeling constantly 'on edge' and irritability, is sometimes referred to as Generalised Anxiety Disorder.

There is evidence for the benefits of psychological therapy and of medication to help manage symptoms such as these.

Worry affects us all. It is part of being human and having such wonderful, but tricky minds.

While writing this article, I have become aware of my own mind's tendency to worry. What if someone feels worse after reading or acting on it? What if these ideas are shown in the future to be mistaken? What if I've missed out something really important?

So 'physician heal thyself' applies to psychologists too. And it's helped to write that down!

Graeme Gillespie is a consultant clinical psychologist at Northumbria Healthcare NHS Trust



Paul's a driving force in York

We have already strengthened our network of local support groups in 2017, with plans to create even more over the next three years using our Big Lottery funding. Self-confessed 'bigmouth' Paul Minton, from York, answered a My Life appeal to set up a support group and this is his story

Nearly ten years ago, Paul Minton, 48, was lying in a hospital bed feeling like the 'last turkey at Christmas' while undergoing an angiogram.

Within days, he was put on betablockers, ramapril, spironolactone and water tablets to help stabilise his condition. Telemetric equipment was installed in his home and a heart nurse visited every day.

Up to that point, Paul had been fit and healthy - passing every medical during his 13 years in the Merchant Navy - and living life to the full.

But then he found himself struggling to breathe following a bout of flu, and what followed was months of banging on doctors' doors in a bid to find an explanation for his acute breathlessness, which meant he couldn't sleep unless propped up against a wall.

As he explains: "I'd got the flu very badly in 2006 and it just didn't go away.

"I started to struggle to breathe and it got worse and worse. If I laid down, within a few minutes I'd be breathless and choking.

"I kept going to the doctors virtually every day, but they wouldn't listen to me and no one seemed to care how bad my life was becoming.

"But I kept bugging the doctors and eventually, they referred me to a lung consultant. But the only help I got was inhalers.

"However, they just didn't grasp all the sprays in the world were making no difference at all.

"I wouldn't accept their answers. I knew my condition was growing very serious and finally, one night, I took a nosedive."

Paul refused to go into intensive care, but was sent home with water tablets, convinced he was 'going home to die'.

He added: "I didn't die, but I did pee for England! It seemed

half of the North Sea had passed through me that night and my breathing became easier. My system had been full of fluid and I lost around 28lbs of fluid."

Later, Paul had an emergency appointment with a cardiologist and the angiogram results revealed he had ARVC.

He recalls: "I could hear the consultant keep asking for dye and he seemed a little agitated.

"When I asked how the heart was looking, His answer was 'shocking' and his response will stay with me forever."

Following his diagnosis, Paul tried to get his life back to normal and resume running his haulage business.

But, before long, he had to give it up and take a job as a driver for a company that delivered across Europe.

"I worked mostly in Formula 1, but also doing concerts across Europe. I was on tour with a lot of the big names, including Simple Minds and George Benson.

"Nobody had any idea how ill I was and for a while, I managed. Then I started to struggle again and during hotter spells, fatigue and breathlessness combined to produce a living hell."

Eventually, Paul was forced to give up work. But even though he is ill, Paul is still living life to the full, enjoying track days and microlight flying.

"If you can't change the illness and you can't your health, then the only thing that you can change is how you think about it," he says.

"Life doesn't end when you get ill - it just changes pace.

"I've still got a brain and with the support of my wonderful partner Dawn, we are running the first Cardiomyopathy UK support group in York.

"I want to give other people the confidence to get the help they need when they speak to doctors.

"We held our first meeting in May and we're going from strength to strength with plans to get some interesting speakers and although that's important, it's just as important for people to chat together and to create a network."

Jo Franks, Cardiomyopathy UK's Support Group Manager, said: "Paul's blend of a warm, friendly personality, a great sense of humour and a real ability to listen to people's stories and feedback - adjusting his approach as needed - together with his enthusiasm to network and seek out interesting and relevant group discussion leaders who share of their professional expertise, make him a great asset to Cardiomyopathy UK."

●Turn to Page 19 for details of support groups in your area

Do you have a few hours free a month, good organisational and communication skills? Could you set up a new support group in your local area? Email jo.franks@cardiomyopathy.org

'You're not the only one'



Elis Power, 23, is a founder member of Cardiomyopathy UK's CYP&YA Panel which was set up this year to ensure young people's voices are being heard

After his father died unexpectedly at the age of 30 from hypertrophic cardiomyopathy, three-year-old Elis Power went on to experience a very different childhood from the one anyone was expecting.

"You think it's only old people who have spent their lives smoking and drinking who get diagnosed with a heart condition," admits Elis, who is now 23 and enjoying working in his first job as a specialist investigator for the NHS, based in Cardiff.

As a boy, Elis was forced to stop contact sport - giving up rugby was especially hard being Welsh - and instead, he had to wear a 24-hour monitor and take time off school to attend regular hospital trips as part of a family screening programme.

"As you can imagine, it made me feel very different and you think you are the only one," he says.

Thankfully, the continuous monitoring and seeing both his grandfather and uncle test positive with HCM, helped to make Elis' diagnosis last year less of a shock.

"Being diagnosed with HCM, as well as being a carrier of the faulty gene, didn't really come as a surprise for me since I had been surrounded by the condition and testing my whole life," adds Elis.

"But emotionally, being diagnosed wasn't easy by any stretch of the imagination - the constant thought of having something wrong with you, and for me, having the same heart condition that killed my father.

"But I have gradually come to accept it and think life is too short to spend time dwelling on it. I stay as positive as I can by leading the most 'normal' life that I can.

"Luckily, I have incredible support of my family, friends, my girlfriend Jasmine and Cardiomyopathy UK. I know that eventually, I'll

Elis will be making a keynote speech at this year's Annual Conference on Saturday, 18 November
email events@cardiomyopathy.org for details

most likely need medication and an implantable defibrillator (ICD) within the next couple of years, but at the moment, I'm continuing to be monitored regularly."

Elis is now using his experiences to help other young people through his contribution to our CYP&YA Panel, which was launched earlier this year to help children and young people affected by the condition, aged 5 -11, 12- 17 and 18-25.

"Being proactive has helped me and I want to show other young people that there is support to make their diagnosis a lot easier."

At its first meeting, the Panel, whose members come from across the UK, set up a closed Facebook group (14-25 Cardiomyopathy UK), and a Twitter group (@Cardio1425) to connect young people and get them talking with each other.

As Elis, explains: "We're still playing around with ideas, but the aim is to get young people talking more about cardiomyopathy.

"Being part of something that helps people my age with their diagnosis is something I'm both proud and excited to be doing."

Elis will also be making a keynote speech at Cardiomyopathy UK's Annual Conference on Saturday, 18 November.

"I'm excited, but very nervous. I went to last year's conference and it was so encouraging to meet so many others who understand and have been through similar situations.

"My conference message will be: 'You're not the only one.'"

• **Young people's section launched on website - See Page 14**

Top, the members of our new CYP&YA Panel and below: Elis Power



Portrait of artist Andy

Talented Andy Leach has always been good with his hands and this summer, raised £650 for Cardiomyopathy UK from an exhibition of his paintings

Grandfather Andy Leech left school at 15, convinced his breathlessness during cross-country runs and on the football pitch had been down to being "a weakling".

"Being good with my hands, I started furniture making. This led on in my 20s to yacht-building and house-building in my 30s," says Andy, 69.

"Hard physical work was no problem, although exertion often left me breathless," he recalls.

It was only in his mid-30s, when he landed his "dream job" as a maintenance man for Seeboard electricity board, that a routine medical discovered Andy had a heart murmur.

"This foxed me as I felt okay," he explains. "An hour or two before, I'd been running up and down scaffolding, but not wanting to lose this chance of getting this wonderful job, I arranged a private X-ray and examination with a heart and chest specialist. He said I had a heart murmur, but so did lots of people. That clinched it - I got the job and that was that."

However, the specialist insisted on a yearly check-up and when Andy was 39, he was diagnosed with HCM.

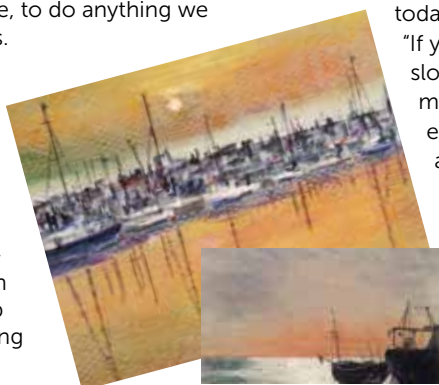
"I do remember thinking, 'Why me? only for a moment or two, then thinking again, 'Why not me?'," Andy adds.

"After I was fitted with my first pacemaker, my life carried on and my wife Alison and I immersed ourselves in bringing up our three children and working."

Seeboard gave Andy early retirement and at just 46, he was determined to make the most of it.

"When I was young I thought you retired at 65. Then a few years on the allotment and that was about it. But how things have changed? We now have that precious thing time, to do anything we wish for," he insists.

"With hopefully still some life left in the motor, I signed up at my local adult education centre for water colour painting for beginners - even though I'd never picked up a brush since leaving school."



Above: Andy Leach at his art club

Andy soon developed a love for his new hobby and shares his passion with his fellow artists at the weekly art club he attends.

"I lose myself when I'm painting, but have to do it with other people. You spark off each other, you encourage each other and support each other," he explains.

"That took care of my brain, now I had to look after my body. I had become a couch potato and breathlessness was always a problem in the background.

"I would have liked to have joined my son in his sporting activities - taekwondo - but did not want to get my pacemaker kicked. I could only watch football and couldn't play golf because my chest muscles still ached from the heart operation. But I needed to do something," Andy admits.

The answer was tai chi and today, Andy is an instructor.

"If you're breathless walking up slopes and climbing stairs like me, then tai chi is an excellent exercise system. The muscles and tendons are alternatively stretching and relaxing, making for looser joints, which help with blood flow, increasing circulation," he explains. "I say, why not give it a try?"

New factsheets published



At Cardiomyopathy UK we constantly review and update our information as well as producing new resources.

To sit alongside our booklets on the most common types of cardiomyopathy, we now have three new factsheets on these topics. 'Dilated cardiomyopathy', 'Hypertrophic cardiomyopathy' and 'Arrhythmogenic right ventricular cardiomyopathy' are available online and in print. These A4 factsheets are a basic introduction to the different conditions and are suitable for anyone new to the condition.

As well as information about cardiomyopathy, we are also developing factsheets on some of the causes of the condition. Our new factsheet 'Myocarditis and cardiomyopathy' joins one on haemochromatosis. Both can be found on our website.

Visit www.cardiomyopathy.org/info to read more about any of these factsheets, or call the office if you would like to be sent a printed copy.

Coming soon!

We are currently working on a new booklet on cardiomyopathy, mental health and emotional wellbeing.

We are developing this booklet in response to feedback. Many of you have told us that the impact of cardiomyopathy on your wellbeing can be even greater than on your physical health, and it is a subject that is often misunderstood and little talked about.

Informed by your responses to our 2016 survey on this subject, the booklet will include personal stories from people living with the condition and those supporting them, as well as details of different sources of support and how to access them.

The booklet will be available in the autumn and details will be included in the next edition of My Life.

On the end of a phone,



Jayne Partridge (speciality: cardiac) has been a nurse for nearly 30 years and thought: 'Wow - that would be a fantastic opportunity,' when a friend emailed her details about becoming a Cardiomyopathy UK support nurse

“I have been a nurse since I started my training in 1988,

My speciality is cardiology and I was lucky enough to be asked to go to a newly-opening coronary care and post coronary care unit by my ward manager two years after I qualified.

I enjoyed caring for patients with heart conditions and after I was sent the advert by email, I emailed Cardiomyopathy UK's Head of Services Ali Thompson and she asked me to apply.

At first I was unsure in case I did not have the experience to help the patients

and families with their questions, but I wanted to help and support them.

In the NHS, we didn't seem to have time for people and I want to be in a role where I do have time to listen.

I was busy from day one, taking calls from many different patients and concerned relatives needing advice.

I've been asked a variety of questions - from theme park rides to drones and ICD interactions and cooker hobs and pacemakers.

I'm there to listen and offer factual information.

I'm looking forward to providing support to patients and their relatives and having the time to listen - offering advice where needed.

I am just hoping that I can make a difference to them.”

Living with cardiomyopathy can be a huge challenge, but speaking to our specialist Helpline Support Nurses can make the daunting seem manageable.

Our helpline offers support when you have medical questions and queries about living with cardiomyopathy. Jayne Partridge, (left), and Emma Greenslade, (right), speak to My Life about their new roles as Cardiomyopathy UK Helpline Nurses.

When you need to talk - we're here to listen

Call the Cardiomyopathy UK helpline on **0800 0181 024** and we'll put you in touch with Emma, Jayne, Robert or Ali.

Or email supportnurse@cardiomyopathy.org or talk to them online via our **Livechat** system. Simply go to our homepage and if a nurse is available, there should be a device on the bottom right-hand corner of your screen saying '**Chat Now**'. Livechat is available Monday-Friday, between 8.30am and 4.30pm and we hope to extend the hours in the near future.

Our nurses are available on our closed **Facebook** group.

or the click of a mouse



Emma Greenslade (speciality: paediatric) spent three years working in the inherited cardiac service at The Royal Brompton Hospital and says working with Cardiomyopathy UK is 'right up her street'

“I'm married with three children so the role of working from home without commuting was very appealing.

My background is paediatric intensive care and cardiology.

Nursing away from a hospital setting without my usual support network is daunting, but something the community of cardiomyopathy clearly needs.

I loved the idea of supporting and educating children and families out of the hospital setting and being able to focus and become an expert on cardiomyopathy, which I've always found to be a fascinating disease.

I've been nursing for 13 years and I'm originally from Australia. I did my nursing degree back in Melbourne and came travelling over here ten years ago.

Then I met my husband and the rest is history!

I've always been in paediatrics, but just fell into paediatric intensive care cardiology whilst in the UK.

I developed a passion for looking after sick children and families and the camaraderie nursing can bring.

I got stuck into my new role from day one - having caught up with fellow Nurse Jayne and a pep talk from Cardiomyopathy UK's Helpline Support Nurse Robert Hall.

And although I didn't actually speak with anyone over the phone on my first day, I did answer loads of questions on the Facebook page and the Live Chat and emails.

It was really interesting and it's been great to sink my teeth back in to the world of cardiomyopathy.

I'm really looking forward to seeing how the role develops.”

Helpline makes a difference

Ali Thompson, Cardiomyopathy UK's Head of Services says: "I am extremely proud of our helpline. We are able to provide medical and expert housing, benefit and employment advice.

"Having cardiac specialist nurses, one of whom specialises in paediatrics,

is a real strength to our services. Our nurses have a wealth of experience, they are warm, approachable and empathetic.

"Our helpline really does make a difference to the lives of people living with, and those affected by, cardiomyopathy."

We're here for you



Call our helpline



Email our nurses



Live Chat

Checklist plan to help stop misdiagnosis on discharge

New research shows Barking, Havering and Redbridge University Hospitals Trust are taking steps to improve discharge summaries for patients.

A three-month audit was undertaken to review the existing quality of heart failure discharge summaries from hospitals managed by the Trust.

Researchers found more than a quarter of patients had been incorrectly coded/diagnosed as heart failure and the overall standard of discharge summaries was found to be 'very poor'.

More than a quarter of discharge summaries for heart failure had an incorrect primary diagnosis and important clinical details were often omitted.

The study concluded that implementing a simple checklist for doctors - especially junior doctors - would improve the quality of the discharge summary and potentially contribute to better post-hospital care.

Plans are now in place to introduce a 10-point checklist (providing specific guidance on what to include when composing an optimal heart failure discharge summary) for doctors to follow when assessing patients.

Essentially, the aim of discharge summaries is to share clinical information about a patient's hospital experience with their GP and other healthcare professionals responsible for providing continuing care.

Robert Hall, Support Nurse at Cardiomyopathy UK, commented: "The discharge summary is a crucial communication between the hospital and the patient's GP and the information contained can inform many decisions regarding their future care.

"The inaccurate information the study revealed is concerning.

"The success shown by the introduction of a simple checklist showed an improvement in the quality of the summaries, which we hope other hospitals will take note of."

Embryo editing breakthrough

Genetic testing moves forward

A new landmark study that focused on hypertrophic cardiomyopathy (HCM) has suggested that scientists could soon edit out genetic mutations to prevent babies being born with diseases.

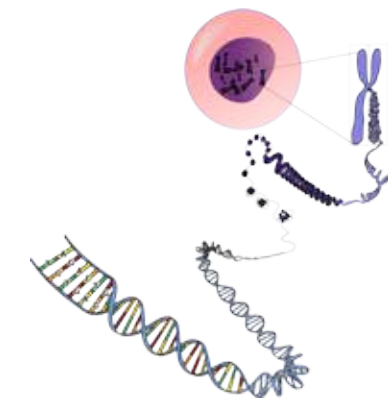
Scientists in the US reached a new breakthrough by successfully altering DNA in defective embryos so they were no longer programmed to develop heart failure.

This is the first time the powerful gene-editing tool Crispr-Cas9 has been used to fix a mutation responsible for a common inherited disease.

In the study, teams from Oregon Health and Science University and the Institute of Basic Science in South Korea injected sperm carrying the gene for hypertrophic cardiomyopathy, a common heart disease, into healthy eggs.

They then applied the genome editing technique of CRISPR to successfully eliminate the faulty gene.

This could mean that the development could open the door to banishing thousands of hereditary disorders for



good.

Others, however, believe it threatens to flare up fresh debate over the morality of gene-editing.

Hypertrophic cardiomyopathy affects 1 in 500 people.

Some people have few symptoms while others are severely affected and it usually runs in families.

Joel Rose, Cardiomyopathy UK Chief Executive said: "This is a major step forward which raises the possibility of preventing the inheritance of hypertrophic cardiomyopathy in the next and future generations in families.

"It's an early finding and a lot more research is required."

Scientists embark on four-year study of heart muscle molecules

Researchers in America have begun a four-year project to study three important proteins involved in causing cardiomyopathy.

The grant, from the country's National Institutes of Health, will help the team from Washington State University to understand the molecular causes of heart muscle disease.

Heart muscle is made of tiny thick and thin filaments of proteins. With the help of electrical signals, the filaments bind and unbind allowing heart muscle to beat.

The researchers will use state-of-the-art knowledge in their bid to identify the components and molecular mechanisms that regulate the thin filaments, whether diseased or healthy.

"Better understanding of the thin filament's function and its regulation is critical to understanding muscle disease, to improving diagnostics, and to potentially identifying novel drug targets," said Professor Kostyukova.

Cardiomyopathy UK Support Nurse Robert Hall, said: "We will watch the progress of this research with interest."

Share your experiences with us

Cardiomyopathy UK launches new national campaign

Two years ago, we conducted a national survey focusing on the experience of diagnosis and treatment for cardiomyopathy.

We were overwhelmed by the number of responses we received and shocked to see how many people had been misdiagnosed.

We used evidence from the survey to help inform a parliamentary inquiry into heart failure and to inform our own work with clinicians.

We now want to run another survey to look again at your experiences of diagnosis to see whether there has been any changes

since 2015 and to use these current figures for our national campaign - 'MyHeartStory'.

We also would like to know more about how you coped with your diagnosis, so we can shape our services to better support people affected with cardiomyopathy.

Please get involved and take our online survey at:

www.cardiomyopathy.org/MyHeartStory

Q&A

Cardiomyopathy UK's new PR and Communications Manager Priya Manek talks to us about the exciting new campaign she is running for the charity



Q: What is the campaign about?

A: The campaign is called MyHeartStory and aims to raise awareness of the signs and symptoms of cardiomyopathy.

Currently one in three 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 patient looks like" which needs to change.

We encourage everyone to be aware of the medical history of immediate family members and to find out about their own 'heart story'.

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

Our campaign will tie in with our awareness week (31st October- 7th November 2017).

Q: What are you trying to change?

A: We are the UK's only specialist charity for people affected by cardiomyopathy.

We campaign to promote public awareness about cardiomyopathy and press the issue on the national health agenda.

Currently, cardiomyopathy is not seen in its own entity and doesn't have any specific NICE guidelines about the condition – we want the condition to be recognised in its own right rather than banded under the generic term of 'heart failure'.

We want people to recognise the signs and symptoms of cardiomyopathy so it can be found earlier.

We are champions for you and the cause; your personal stories bring the condition to life. We also want to stimulate debate about the condition and help more families find us.



Q: How can people get involved and support the campaign?

A: Firstly, we encourage everyone with cardiomyopathy to fill in our national survey so we can get the most up-to-date picture of how this affected you and your family.

You are the key to giving us the insight we need to shape our services to help more of you.

We want to make it easy for you to get involved and there are a number of materials available to download on our website to share with friends, families, colleagues and healthcare professionals.

Finally, you can use your own social media accounts and keep talking about #MyHeartStory, sharing your own personal stories, sharing our updates and highlighting the work we do to increase awareness for us and for the cause.

If you are willing to share your story as part of our campaign, please speak to your local media and see if they can cover it as part of our campaign.

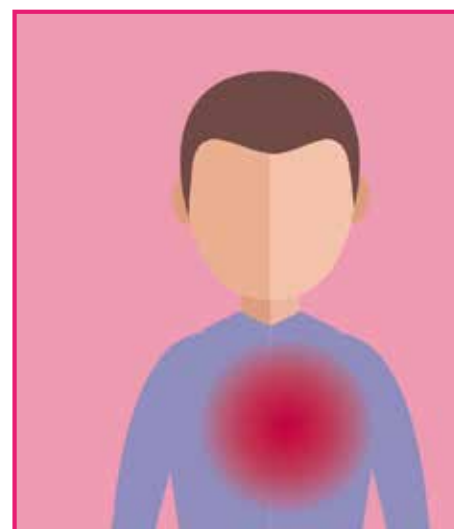
Q: Can people fundraise for the campaign?

A: Absolutely! There are a number of events we hold across the country for you to get involved in and be part of #teamcardio. And as a charity, we rely on donations to make a difference.

Q: Are there volunteer opportunities while the campaign is running?

A: Our awareness week will run on 31st October- 7th November 2017 and we would welcome volunteers up and down the country to hand out posters, share our posts across social media and spread the word.

Thanks to all our volunteers, donors and fundraisers, we are doing more than ever to get the right information to everyone who needs it. We would love your support as 'Cardiomyopathy Campaigners' to take this even further and make help us make a real difference with our campaign.



If you would like to share your story or have a question about the campaign, please email media@cardiomyopathy.org

Write your will for peace of mind

By Alison Fielding
Cardiomyopathy UK
Chair of trustees

I know from personal experience that dying without a will can leave a practical and emotional mess.

I spent many years working for the Citizen's Advice Bureau, offering legal advice and emotional support to grieving people picking up the pieces, so I have always known the importance of having a will.

At a time when bereaved people need support and peace, many are thrust into the harsh reality of finding out that have been left at risk of eviction, poverty and family breakdown.

Others see the estate going to people who the person who has died didn't expect or want to benefit, their children without guardians or are landed with unexpected tax bills.



I know that many charities rely on legacies to survive, so shortly after I was diagnosed with cardiomyopathy, I did some research into Cardiomyopathy UK and saw that there was an opportunity to help them to maintain and expand their services by leaving a gift in my will.

As cardiomyopathy is often inherited, I also saw this as a chance to help distant relatives and future generations of my own family.

I decided to leave a percentage of my estate to each of my beneficiaries as this future-proofed the will against the effects of inflation, rather than leaving an absolute amount as the value gets distorted over time.

It also helped me ensure that I could take advantage of current inheritance tax (IHT) laws that offer a lower rate of

IHT for people who leave more than 10% of their estate to charity.

We all know that tragedy can happen to anyone at any time, so please do something about one thing you can control and make updating or making your will a priority.

It gives me peace of mind to know that my wishes will be carried out after my death and that I can make a real difference to the thousands of people with cardiomyopathy that will come after me.

I would urge other people to get advice on how to write a will that will protect those that they love and leave a legacy to those people and organisations that have been important in their lives.

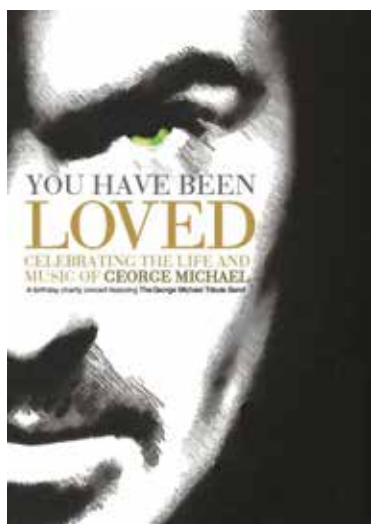
If you would like to discuss leaving a gift to Cardiomyopathy UK - no matter what size - please get in touch with Sheila Nardone at Sheila.nardone@cardiomyopathy.org or 01494 791224. This will be in the strictest confidence.

Have faith in us

Cardiomyopathy UK are lucky enough to be supported by the official George Michael Tribute Band, in memory of superstar George Michael.

The band are organising a Christmas concert in Highgate in December, almost a year since he tragically died, raising funds to support our work.

Joel Rose, Chief Executive, Cardiomyopathy UK said: "George was found to have dilated cardiomyopathy, which is a leading cause of sudden cardiac death.



"This gig will remember George and the wonderful memories he gave to so many and we are delighted to be a part of it."

If you would like to attend the concert you can find out about tickets via the band's website.

If you would like to support our work in George's honour you can text a donation, simply text GEOR16 £5 or GEOR16 £10 to 70070 to donate today, or contact fundraising@cardiomyopathy.org to pledge in his memory.



Help us through your work

Employer support is an important way we can fund our services and every donation means more people affected by cardiomyopathy can get the help they need.

We have plenty of ideas to help you organise a fundraising event at work - whether it's a simple cake sale, or a crazy fancy-dress event in the office - the more people who hear about Cardiomyopathy UK, the more things we can achieve.

As an employee, did you know you can also donate via your payroll as Give as you earn (GAYE)? Every month, many of our supporters give a small donation from their salary to help us support people affected by cardiomyopathy, so please ask your HR department about this easy and tax-effective way of giving.

Then why not ask your employer to match your fundraising (or gift), but even better, why not nominate Cardiomyopathy UK as your company's **Charity of the Year?**

Discuss your ideas with Fundraising Manager Sheila Nardone (below) on 01494 791224, or email her at Sheila.nardone@cardiomyopathy.org





It's beginning to look
a lot like Christmas...



With Christmas on the horizon, our brand new Christmas Collection is now here! We have a selection of cards and gifts available both via our catalogue and online, with all proceeds helping to support our work. Each pack of cards sold helps us be there for everyone that needs

us – and there's even a free gift if you spend £20. Why not have a look today? Visit our shop at www.cardiomyopathy.org/christmas or request a catalogue on 01494 791224.

Perfect stocking fillers

What better time than at Christmas to support our vital work by buying our branded merchandise. Pictured below: a Cardiomyopathy UK pen, wristband, window sticker, pin badge and heart balloon greetings card.



All our merchandise is available from our online shop at: www.cardiomyopathy.org/shop



Heart conditions misdiagnosed as stress

An estimated 620,000 people in Britain are living with genetically inherited heart problems – yet the vast majority have no idea they are at risk.

New research from the British Heart Foundation has revealed six in ten patients living with inherited heart conditions have their symptoms attributed to other conditions before doctors realise what is wrong with them.

The research found that the majority of patients (60%) had initially been diagnosed with another condition. This failure to make a diagnosis and start treatment puts patients at an increased risk of sudden cardiac death.

This research echos Cardiomyopathy UK's own survey of diagnosis experience undertaken in 2015 which showed how stress as well as asthma were often given as an initial diagnosis. The was especially the case for younger people.

Emma Greenslade and Jayne Partridge Cardiomyopathy UK support nurses commented: "It is paramount to raise awareness across the board of these heart conditions that can have severe consequences if discovered too late.

"Therefore, it is vital to recognise symptoms of inherited cardiac conditions (ICC) in the general population and work with our primary care healthcare professionals so that all patients can be identified and referred to a ICC specialist sooner.

"Family history information and relevant symptoms in patients and their wider family asked early on may help facilitate early detection of those patients at risk.

"We believe more research is also needed into gene testing so new ways to target treatments for those diagnosed with inherited cardiac conditions are discovered."



National Heart Failure Audit results

The National Heart Failure Audit found that 8.9% of patients died in 2015-16, down from 9.6% the previous year, which has saved around 500 lives.

The report assessed patients admitted to hospital between April 2015 and March 2016 with heart failure at NHS trusts.

It showed more people were being provided with crucial medicines for heart disease and had better access to specialist treatment.

It also went on to reveal that 80% of sufferers reporting heart failure at hospitals in England and Wales were seen by specialists, and that nine in 10 hospital patients received an echocardiogram – a key diagnostic test in heart failure conditions.

It also found an increase in the percentage of patients prescribed three key medicines for heart failure – but highlighted there was still room for further improvement.

A key outcome from the report was the need for further improvements to close the gap in variations of heart failure care and in different wards within a hospital.

It also found that leaders should "understand and act upon variations in their care of people with heart failure" across England and ensure more people receive the best treatment possible.

Joel Rose, Chief Executive of Cardiomyopathy UK, said: "While this report shows a positive trend, it is important to remember that it examined 'heart failure' – a broad catch-all term.

"As such, it does not tell us much about how some of the less common causes of heart failure such as cardiomyopathy, are being treated.

"What we need is much more specific information so that we can get a true understanding of how cardiomyopathy is being treated and put people with the condition in a position to know more about how their local services are performing."



For more new stories, see
cardiomyopathy.org/news

Helping children and young adults

By Ali Thompson
Head of Services



Throughout the past year, Cardiomyopathy UK has significantly developed its work with, and services for children, young people and younger adults.

The charity has always wanted to offer services specific to the needs of people under the age of 25 and this year, we began to realise that wish.

We advertised via our social media outputs for young people who had been diagnosed with a cardiomyopathy or supported someone with the condition to form a CYP&YA (Children, Young People and Younger Adults) Panel with a view to helping the charity's services understand better what young people really need to live more positively with the heart muscle disease.

A group of young people, aged between 14 and 23, met with the charity in March to share the key issues facing young people; bullying, education, personal relationships to name but a few.

The young people had experienced incredulity from a society who could not accept that a 21-year-old seemingly well-looking individual could have heart failure.

Others were ridiculed and scorned by their peers for "faking" and being lazy.

Often they were the only people in their school, college, university or workplace with cardiomyopathy and this further compounded feelings of isolation and difference.

The young people agreed that raising awareness through education both within the public and healthcare arenas was imperative to young people living more positively.

The Panel meet regularly and have recently been looking at the types of resources that would most benefit children, young people and younger adults.

These resources will be available from the end of the year. We have developed a Peer Support Helpline where young people aged up to 25 can call our helpline number 0800 018 1024 and be put in contact with a member of the Panel who has experienced similar issues. Cardiomyopathy UK plans to further develop our services for children, young people and younger adults so please take a look at our website and social media channels for regular updates.

Pictured below: Ali Thomspson with the CYP&YA



And our survey says...

Joel Rose, Cardiomyopathy UK Chief Executive, reflects on the results of the My Life readership survey and how they will impact on 2018

In this, our final issue for 2017, we're looking forward to a happy new year, in which we take on board the results of our recent My Life readership survey.

We are delighted to reveal hundreds of readers responded to the survey, with many saying how much they look forward to receiving the magazine.

A total of 12,000 copies of the magazine are sent to individuals, doctors' surgeries and hospital waiting rooms and our survey revealed that for some readers, My Life is their only contact with other people living with cardiomyopathy.

Nearly all of you say you read every edition of the magazine after it drops through your letterboxes and more than 60% read it from cover to cover before passing it on to family and friends.

The feedback was very positive with comments such as, "a very helpful publication", "fantastic resource" and "knowledge is key to a healthier life."

More than 80% of those who took part in the survey are living with cardiomyopathy and nearly 20% are relatives of someone who has - or had - the condition.

This is why our articles are always underpinned by the desire to help everyone affected by cardiomyopathy lead long and fulfilling lives.

The majority of respondents particularly like reading articles about the latest research and treatment – telling us they "know more about cardiomyopathy" afterwards and feel better equipped to ask the relevant questions when seeing their cardiologist.

It was therefore no surprise that more than 90% of readers say their favourite My Life sections are those featuring medical topics - including our regular Q&As with health professionals.

Alongside the facts and figures, more than half of you



Cardiomyopathy^{UK}
the heart muscle charity

Tell us what you think
Please spare a few minutes to fill in our survey about our My Life magazine and send it back in the free returns envelope before Friday, 17 February, 2017. We would be very grateful for your help.

About you:

Title: Name:

Email: Age:

Telephone number:

Are you?

Living with cardiomyopathy ☐

A relative of someone with cardiomyopathy ☐

A friend of someone with cardiomyopathy ☐

A medical professional ☐

Other

Rate the overall quality of My Life

also love reading the personal stories about people living with cardiomyopathy.

The survey revealed these real-life stories provide inspiration about how others are managing their struggles and worries, which is comforting to readers.

However, this poignant comment from one respondent, revealed how these stories can also: "...make it all so real and close to home, which unfortunately, it is."

As the UK's specialist heart muscle charity, we're taking on board all your comments as we plan future issues of My Life.

We'll continue to report on important issues so patients and their families get the best care and support available.

At the time of going to press, we are about to launch our national campaign – MyHeart Story – to raise awareness of cardiomyopathy and highlight the current levels of misdiagnosis.

The campaign will feature in the first issue of My Life in 2018, but you can find full details on our website, www.cardiomyopathy.org

Carry on receiving our magazine

My Life magazine is really important to us as it's a great way to tell you about latest developments in cardiomyopathy; to answer questions you may have about living with the condition and to share real-life stories.

We also use the magazine to make sure you are up to date with our work and how you can play a part in it.

It is a real pleasure to read the great feedback that we received from our recent My Life survey. We know that living with cardiomyopathy can be a real challenge, but believe our work can help people to feel better able to cope with the condition.

My Life is a big part of this and we are proud that people tell us they feel better after reading the magazine.

You may know that there are new regulations coming in that change the way charities and companies can contact you.

So if you have received a letter with a form asking you to "opt-in" please read it and follow the instructions.

If your letter does not have an "opt-in" form then don't worry, you will automatically keep receiving your My Life.





'I'll do anything to support my family'

When concerns were raised about his wife's blood pressure during a routine midwife appointment, little did Bob Frake know how much his life was about to change

Devoted dad Bob Frake, was "the world's unhealthiest man" until the shock of finding out his wife Cath had severe heart failure while pregnant with their second child.

The couple were briefed about the risks childbirth could have on Cath's heart and as a C-Section wasn't an option, a normal birth with epidural was chosen.

Thankfully, Cath went on to deliver a beautiful baby daughter Erin – now three – at 38 weeks with a cardiac team present throughout.

Bob took time off work to care for their son Ryan as Cath underwent scans and tests as she struggled with severe fatigue, breathlessness, palpitations and light-headedness.

As Bob recalls: "It was a very stressful time. Our ideal picture of a normal, happy family was shattered. I had a five-year-old son, a newborn baby and an ill wife to help."

Cath was diagnosed with dilated cardiomyopathy with left ventricular non compaction, along with left bundle branch block, which increased her symptoms on exertion.

"Cath had many difficulties around the home, especially with the stairs and because of this, we ended up selling our forever home and moved to a more practical bungalow," Bob explains.

Cath had a CRTD-Pacemaker fitted and in August 2015, was medically retired from her job at Tesco's where she'd worked for 20 years.

As the impact of Cath's illness hit Bob, he realised the importance of being healthier and fitter for his family.

He says: "I began doing sit-ups waiting for the baby to get back

to sleep after night feeds and shed 10lbs in the first week. This gave me the incentive to carry on exercising."

Bob, a training officer for the Royal Mail, set up a multi-gym in his garage and took out a lot of his stress and frustration on working out.

Regular exercise and a healthy diet led him to getting the results nobody imagined he would achieve.

The "world's unhealthiest man" disappeared and Bob lost a total of 3½ stone over 12 weeks.

Nine months ago, Bob started running and within a few weeks, had worked himself up to a 10KM run.

"I never particularly liked running, but I found it quite addictive. I wanted to get quicker, then go further," he explains.

Bob decided to put his achievements to good use and had always intended to raise funds and awareness for Cardiomyopathy UK, when the time was right.

"That time is now," he says.

Bob signed up for The Robin Hood Half Marathon on September 24 and topped the £1,000 mark in his first week of fundraising.

"Cath is proud of me and my efforts to raise money for a charity that means a lot to both of us," he adds.

Meanwhile, the couple try to remain positive that maybe one day, they can something that resembles "normal family life".

As Bob says: "Cath is still hoping for symptom improvement. Life is tough and she often has to sit on the sidelines as I do all the activities and outings with the children and wherever we go, it has to be somewhere with a minimum amount of walking. But I will do anything I can to support her and my amazing family.

"Despite all the difficulties we face, we do it all together."



#teamcardio highlights

Thank you very 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 fundraising team at fundraising@cardiomyopathy.org or visit our website cardiomyopathy.org/support-us

Very fast velociraptors



Trustee Pete Thomas and a team of runners ran the Leeds 10K for us in July, including one in full Velociraptor style! The team ran in memory of Pete's daughter Esme, and so far have raised £3,500.

A brilliant birthday



Our Cheshire and Merseyside support group celebrated its third birthday in July. Group organisers Jenny and Julie Rees, went all out, even making a special cake to mark the occasion. Thank you so much to Jenny and Julie for all of their hard work over the years, and to all the group members.

Staging success



Supporter Jan Gregory organised her annual dance show 'Dance-a-Cise' for us in July at her dance school in Kent. The show was a great success, with the excellent performers raising £400 to support our work, in memory of Jan's husband John.

Fantastic footie



The annual Lisa Freeman Memorial Shield football match took place in April, in memory of Lisa who passed away in 2005 aged just 30. The match has taken place every year since in her honour, and its twelfth year raised a fantastic £500 for our work, complete with Elvis as referee. Thank you so much to everyone involved.

Relay great success



Donagh Nugent, Emma Gribben, Philly Gribben, Niall Nugent and Aoife Nugent completed the Deep RiverRock Belfast City Marathon between them as a relay team in May. Between them the team have raised an incredible £4,000 to support our work – thank you so much!

Diamond celebrations



Eileen and Roy Matthews, pictured with their daughter Kim, celebrated their diamond wedding anniversary in July. The happy couple raised over £300 for us at their party, by asking for donations instead of gifts in honour of their grandson Ryon who passed away in 2005. Thank you so much to the whole family for their wonderful support.



Go the distance

London Marathon 2018

Would you like to be part of the world's more famous marathon? 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 with our professional marathon coach, and a post-race reception with massages and showers.

Location: London

When: 22 April 2018

Distance: Full marathon 26 miles

Pledge: £1,650

Visit our website to find out more:

cardiomyopathy.org/vlm2018

Ride London 2018



Join #teamcardio and conquer the famous 100-mile cycle from the Queen Elizabeth Park, through the closed roads of London and into the picturesque Surrey Hills.

With leg-testing climbs and a route made famous by the world's best cyclists at the London 2012 Olympics, this three-day annual festival is famous for attracting some of the biggest names in cycling. Why not support #teamcardio and book your place today?

Location: London - Surrey

When: 28-30 July, 2018

Distance: 100 miles

Go to: www.cardiomyopathy.org/ride-london



Unleash your inner Santa

Santa Dash

What better way to start the festive season than donning a suit and joining forces with 4,000 other Santas in this year's Santa Dash? Whether it's a 5km or 10km that you decide to walk, jog or run, your free Santa outfit will help

you along the way. Open to ages 8+.

Location: London

When: 3 December, 2017

Distance: 5km or 10km

Visit our website: www.cardiomyopathy.org/santa to find out more



Sky's the limit

Skydiving Day 2018

Come and join us for the ultimate adrenaline challenge at our Skydiving Day 2018. On 24 March, 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: 24, March, 2018

Distance: Up to 13,000ft!

To find out more, visit our website:

www.cardiomyopathy.org/skydive

Cotswold Way Challenge

This stunning setting provides the perfect location

for an amazing challenge, with footpaths and trails and some tough hills that stretch across the scenic countryside of Bath and Cheltenham.

Choose 25, 50 or the full 100km and walk jog or even run – it's up to you!

Whether you are a walker, marathon runner or new to endurance events, join #teamcardio and we'll give you all the help and support you need.

Location: Bath - Cheltenham

When: 30 June - 1 July, 2018

Distance: 25, 50 or 100km

Go to: www.cardiomyopathy.org/cotswold



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

September

Thursday 21 September, 7-9pm

Cheshire and Merseyside Support Group

Venue - Liverpool Heart and Chest Hospital (Research Conference Room) Thomas Drive, Liverpool, L14 3PE

Christina Ronayne, Research Nurse at LHCH will be talking about the genetics of cardiomyopathy and the 100,000 Genome Project.

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

Friday 22 September

Cardiomyopathy UK National Clinical Conference

Cavendish Conference Centre, Duchess Mews, London W1G 9DT

Event for cardiologists and heart nurses. Let your medical team know.

For details: Rona Eade on 01494 791224, or email rona.eade@cardiomyopathy.org

Saturday 23 September

York Support Group

Venue - Friargate Quaker Meeting House, Friargate, YORK, YO1 9RL

'Sharing personal experiences & signposting to local services' led by Dawn Broughton.

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

October

Saturday 14 October, 2-4pm

ARVC

Venue - Northolt Methodist Church, Church Road, Northolt, Middx UB5 5AE (Free parking in the church car park on Harewood Ave, UB5 5DB)

Our new leaders Cathy and Deborah are relaunching this group dedicated to people with arrhythmogenic right ventricular cardiomyopathy (ARVC) and their families. A group discussion 'Your Journey' led by Jo Franks, Support Group Manager, followed by 'The Way Forward' - an opportunity to explore your ideas for the future of this group and a chance to get to know each other over free refreshments.

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

Monday 2 October, 7-9pm

South London Support Group

Venue - Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8T
Cardiomyopathy UK's Support Nurse Robert Hall, will talk about the latest advances in cardiomyopathy treatment. For details: Jo Franks 01494 791224, or email jo.franks@cardiomyopathy.org

Saturday 7 October, 11am-2.30pm

South Wales Support Group

Venue - Education centre, top floor of new main entrance, Morriston Hospital, Swansea SA6 6NL

Hosted by Hannah and Wendy, joined by Alison Thompson, Cardiomyopathy UK's Head of Services.

For details: email hannah.goss@wales.nhs.uk

Thursday 19 October, 7pm-9pm

Cheshire and Merseyside

Venue - Holiday Inn, Centre Island, Lower Mersey Street, Ellesmere Port CH65 2AL
Heart failure nurse Diana Astbury on her role and her recent research into how effective information packs are after diagnosis.

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

Sunday 29 October, 12pm-3pm

West Scotland - Glasgow

Venue - Glasgow Royal Infirmary, Castle Street, Glasgow, G2 3NY.

'Echocardiograms - the sonographer's story'

For details: Stephen Kirkham: sg.kirkham@btinternet.com or call Jo Franks 01494791222



Saturday 7 October, 2-4pm

Dorset Support Group

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

"Development of the Heart" - a discussion led by Dr Watson, hosted by Meg Longman.

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

Saturday 7 October, 2pm-4pm

North East England Support Group

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

Dr Chris Eggett, cardiac scientist and senior lecturer at Newcastle University, on heart investigations, including echoes, in cardiomyopathy.

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

November

Saturday 18 November

Cardiomyopathy UK National Conference

Royal National Hotel, 38-51 Bedford Way, Bloomsbury, London WC1H 0DG

See back page for more details or www.cardiomyopathy.org/KMLB2017

December

Saturday 2 December

North East England Support Group

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

Jeff Knox, Heart Failure Nurse, will answer questions about cardiomyopathy.

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

Enquiries

If you have questions about

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



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



Knowing more, living better

2017 Cardiomyopathy UK National conference

Saturday 18 November 2017

Royal National Hotel, 38-51 Bedford Way, London WC1H 0DG

- Hear presentations on types of cardiomyopathy and treatment options
- Share your experiences about emotional wellbeing and lifestyle
- Meet other people with cardiomyopathy, and family, friends and carers

For more information or to book a place contact us:

email events@cardiomyopathy.org

call 01494 791 224

book online www.cardiomyopathy.org/kmlb2017

