

my life

Issue 16/October 2018

Cardiomyopathy^{UK}

The heart muscle charity magazine for people affected by cardiomyopathy



Contact us

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

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

MEET THE... FINANCE TEAM

Question: What do you like best about the festive period?



Andrew Kaponi

Financial Consultant for
Cardiomyopathy UK

'It's got to be the TV, food and seeing the kids' faces when they open their presents on Christmas Day!'

Chris Lynch

Finance Officer

'The thing I like best about the festive period is long walks with my dogs on a frosty morning.'



WHAT'S INSIDE

My Life Story - **Page 5**

DCM Study - **Page 8**

Ask the experts - **Page 9**

How support is at the heart of all we do - **Page 10**

September Stroll in pictures - **Page 13**



PLUS:

**DON'T GET CAUGHT
NAPPING THIS
CHRISTMAS!**



See our
2018
Christmas
cards -
Page 7





Welcome

from Alison Fielding
Chair of Cardiomyopathy UK

Every issue of My Life, the team send me a message with the broad 'theme' for its content.

This time it was 'support', but as everything we do is rooted in being supportive to you, it had me stumped on where to start.

So I am going to focus on thanking those who support us, starting with the staff.

Our team is very small for the numbers of people we help, so everyone needs to have a 'hands-on' attitude; be flexible about working hours and be part of a team committed to helping people with heart disease, rather than taking a role guaranteed to make them rich.

It is a tall task and I am very proud of the work of our staff, so I want to thank them on behalf of the trustees and patients.

Increasingly, much of our support is delivered by volunteers, so we are also grateful to the hundreds of you, who dispense caring words - on the phone, in person and on Facebook - and help others or raise much-needed funds.

Please continue to show your support to us and raise awareness by talking about your condition and sharing our posts on social media.

Between all of us, we can make a difference so fewer people will ask the question 'What?' whenever they hear the words myocarditis and cardiomyopathy.

2019 is our 30th anniversary year

Throughout 2019, we will be celebrating Cardiomyopathy UK's 30th anniversary since it was founded as the CMA in 1989 by the late Carolyn Biro

We'll be looking back at how far clinical intervention has come for people with cardiomyopathy over the past 30 years and thinking about where we'd like the charity to be in the next 30 years for future generations.

In 2019, Cardiomyopathy UK will be busy further developing our services to reach more people affected across the UK.

To celebrate this landmark year and

help fund this work, we'll be launching some exciting new fundraising opportunities to suit everyone - whether you're keen to take on a new challenge, or you prefer to get together with your friends and family.

We also want to reach out to others, who are not aware of cardiomyopathy and myocarditis and tell them about the conditions and the value of our services - more of which will be in our next edition of My Life.

If you have any ideas how we can celebrate our 30th anniversary, or are keen to get involved early on, please contact Sheila Nardone at Sheila.nardone@cardiomyopathy.org or call us on 01494 791224.



Carolyn Biro

Congratulations to raffle winner Alison



We're delighted to announce Alison Bradley, from Chester, has bagged £500 as the winner of our summer raffle.

On hearing the news, Alison said: "Having only recently been diagnosed, Cardiomyopathy UK has helped me mentally by being able to access information about

my condition and support from members locally and UK-wide.

"Knowing there are nurses available to answer questions is invaluable. Winning the raffle after only being a service user for such a short time is unbelievable.

"I think I'm going to have a little weekend away to recharge."



More footballers at high risk of dying suddenly

A new study published in the *New England Journal of Medicine* shows that the risk of young footballers suffering sudden cardiac death is at a higher rate than previously thought

A study conducted by St George's, University of London, analysed more than 11,000 players from the ages of 16-17 over a 10-year period.

Of these players, 42 had cardiac diseases that could cause sudden cardiac death - hardly any had symptoms.

Eight died during exercise - six from conditions that had gone unidentified and two, who were diagnosed with hypertrophic cardiomyopathy (HCM) and were advised against competitive sport.

Between 1997 and 2016, the footballers filled in a health questionnaire; were given a physical examination and a 12-lead ECG and echocardiograph.

Thirty out of the 42 players had surgery, or other treatment for their heart defect and were able to go back to playing football, but the other 12 stopped playing.

There have been a number of high-profile deaths in recent years, including that of Marc-Vivien Foe aged 28, as well as former England defender Ugo Ehiogu,

who died last year, aged 44.

The research was overseen by Professor Sanjay Sharma, who said: "Sudden deaths in footballers are more common than we previously believed and despite screening, cardiac conditions are still the leading cause of death in footballers.

"The most important finding in this paper is the necessity for those athletes, who are pushing their bodies to their limits every day, to be tested regularly, through to early adulthood, to pick up those conditions which develop after the teenage years.

"The death of a young athlete is highly tragic when one considers that most deaths are due to congenital electrical or structural diseases of the heart, which are detectable during life."

There has always been a debate about whether screening is proven to be successful and a previous review in the *British Medical Journal* in 2016 said its efficacy was not supported by evidence.

The independent UK National Screening Committee annually review this and has come to the same conclusion that untargeted screening is not effective.

Joel Rose, Chief Executive at Cardiomyopathy UK, said: "We don't believe in untargeted cardiovascular screening programmes.

"Screening shouldn't be a one-off occurrence, but should be a planned strategy.

"However, this study has highlighted the importance of raising awareness of those at risk from underlying conditions such as cardiomyopathy, which are more common than people realise."



By Priya Manek
PR & Communications Manager

Television sports presenter Gabby Logan's brother collapsed and died from cardiomyopathy, aged 15, while playing football

'It didn't feel like a good start'

Attending a support group not only led to improved treatment for Peter Dunn, from Surrey, but also the opportunity to lead one himself

After being diagnosed with heart failure and dilated cardiomyopathy in 2015, Peter Dunn was badly affected by the side-effects of the high doses of his cardiac medication.

The retired criminologist felt let down by his cardiologist, who was reluctant to adjust his medication and was also frustrated by the failure of the NHS to offer any choice regarding his treatment.

Following his diagnosis, Peter attended Cardiomyopathy UK's support group in south London after trying a local NHS group in his home town of Woking.

"The NHS group had been organised by the cardiology team with whom I was in dispute, so I felt too awkward going there and left after just one meeting," he recalls.

"But when I attended the Cardiomyopathy UK south London group, I was able to speak openly about the difficult feelings engendered by my condition and by what I saw as the inflexibility of my cardiologist," he adds.

Like many, Peter believed he had a good knowledge of the condition as his brother lived with dilated cardiomyopathy for 18 years before having a heart transplant in 2014.

"I'd read about cardiomyopathy and researched it widely on the internet, but listening to other members' experiences at the support group, I soon realised my understanding of the condition was not as comprehensive as I'd thought," he admits.

Hearing other people's stories also helped Peter identify what he needed to know in order to get the best out of his own treatment.

"The other members encouraged me to continue to press for a change of cardiologist and my GP eventually agreed to transfer me to a different cardiologist; my medication was reduced, my health improved and I felt better."

Having taken early retirement from his job as a prisons inspector and with more spare time and improved energy levels as a result of his improving cardiac output, Peter applied to become a volunteer with Cardiomyopathy UK.

"I was asked to re-establish the west London support group, which had stopped meeting a year or two previously," he says. "I had benefited from attending the south London group and I was keen people in west London should have similar opportunities to gain support from a group in their area. But the first meeting of the relaunched



group in November 2017, was attended by only one person – which didn't feel like a very good start!"

Fortunately, things soon improved and there were ten people at the next meeting – some of whom had attended the old support group.

"Together, we spent time planning future speakers and talking about our experiences and concerns. It felt very positive," says Peter.

"The biggest challenge was living 30 miles away from where the group meets. Arranging speakers without being linked into local networks and even simple tasks like picking up the keys to the meeting room is more difficult than if I were local," he reveals.

When his co-leader felt she had to resign owing to a sudden bereavement, Peter needed to draw on all his social work experience to run the group single-handedly, but undeterred, he never thought of standing down and is about to notch up his first anniversary as support group leader.

Today, with the help of a new co-leader, Peter remains dedicated to helping members the best way he can.

"London is a difficult place to get around if you are unwell and cannot face a long walk to the bus stop or Tube station. At least one member struggles with buses to get to meetings and I need to find some way of helping her have a less exhausting journey to the meeting," he says.

So why does he think people living with cardiomyopathy should attend a support group?

"Speakers provide a readily available source of expert knowledge and someone who can answer members' questions," he explains.

"Many members have enthusiastically seized upon the written information resources produced by Cardiomyopathy UK, which are available at each meeting.

"It all shows the tremendous potential that support groups have for enabling everyone living with cardiomyopathy to help each other live better with the condition."

■ The west London group meets at the Ealing Friends' Meeting House on a Saturday afternoon, four times a year. Turn to Page 19 for more details of a group near you.

Harnessing the latest technology

Myocarditis is an inflammatory disease of the heart muscle, usually triggered by a recent viral infection.

It can affect anyone at any age and symptoms include chest pain mimicking a heart attack, difficulty breathing due to weakened heart muscle, and palpitations owing to electrical rhythm disturbances.

Diagnosis is challenging, with no specific blood test and taking a biopsy of the heart is definitive, but high-risk.

Whilst most patients recover, a third can go on to experience symptoms of heart failure and develop dilated cardiomyopathy for reasons that are not currently understood.

Over the past three years, funding from the Alexander Jansons Fund (AJF) has allowed the research team at the Royal Brompton to set up a prospective multi-centre observational study of patients presenting in the acute and chronic setting with myocarditis.

They have invited more than 230 patients from hospitals across north west London to undergo specialised blood tests for new biomarkers and genetic analysis, detailed questionnaires and a state-of-the-art cardiac MRI scan.

The hope is to improve our understanding of who gets myocarditis and why, and who does well and who does badly.

The research team has also collected more than 11,000 health records for patients admitted to NHS hospitals in England over the past 18 years.

The aim is to improve understanding of the epidemiological changes over time in terms of age groups affected, geographical location, seasonal variation and treatment differences.

Combined with other studies looking at the long-term effects of heart muscle scar due to myocarditis in over 400 patients, and new finger-prick bloods tests for heart muscle proteins using nanotechnology, the research team led by Dr Sanjay Prasad continues to harness the latest technological advances to drive forward our modern understanding of acute myocarditis with the aim of improving outcomes for patients.

● Find out more at www.alexanderjansonsfund.org



By Patricia Dean
AJF Fundraising
Manager

Expanding the scope of our services

Support for those with myocarditis

Since Cardiomyopathy UK incorporated the Alexander Janson's Fund (AJF) earlier this year, we have ensured that our services for people affected by myocarditis are up to date, appropriate and accurately reflect the needs of people affected by the condition.

Our team of cardiac specialist nurses, who are clinically trained to advise on the condition, attended a refresher training day at the Royal Brompton to ensure that they are abreast of any treatment and research developments.

An online support group aimed solely at people with myocarditis has been arranged and our support services are now fully inclusive for people living with a diagnosis of the condition.

Our helpline services have seen an increase in people contacting us for advice and support on living well with myocarditis and we have a renowned consultant cardiologist due to speak on the disease at our annual national conference this year.

To ensure that we effectively reach and support children, young people and younger adults affected by the condition, we have recently appointed a young person, who has recurring episodes of myocarditis, to the Children and Young Adults (CYP&YA) Panel.

The charity is keen to be guided by someone who has lived personal experience of the condition and who can help us translate that into the best information resources for young people.



By Ali Thompson
Head of Services



Our CYP&YA Panel



In My Heart this Christmas

This Christmas, we're asking My Life readers to make a donation in celebration of someone special.

Whether they live nearby or far away on foreign shores - or live only in your memories and your heart - your support in their honour will make a huge difference to the work we can do.

Instead of giving a present, or to remember someone special

this Christmas, donate £20 to Cardiomyopathy UK and send us a photo of your loved one(s) and we'll upload it into our Christmas website gallery.

It's a way of telling those you love how special they are, or a way to remember someone close to you this Christmas.

Please complete our form online www.cardiomyopathy.org/inmyheart,

upload the photo you'd like us to share on our 'In My Heart gallery', and then you'll be directed to make your donation.

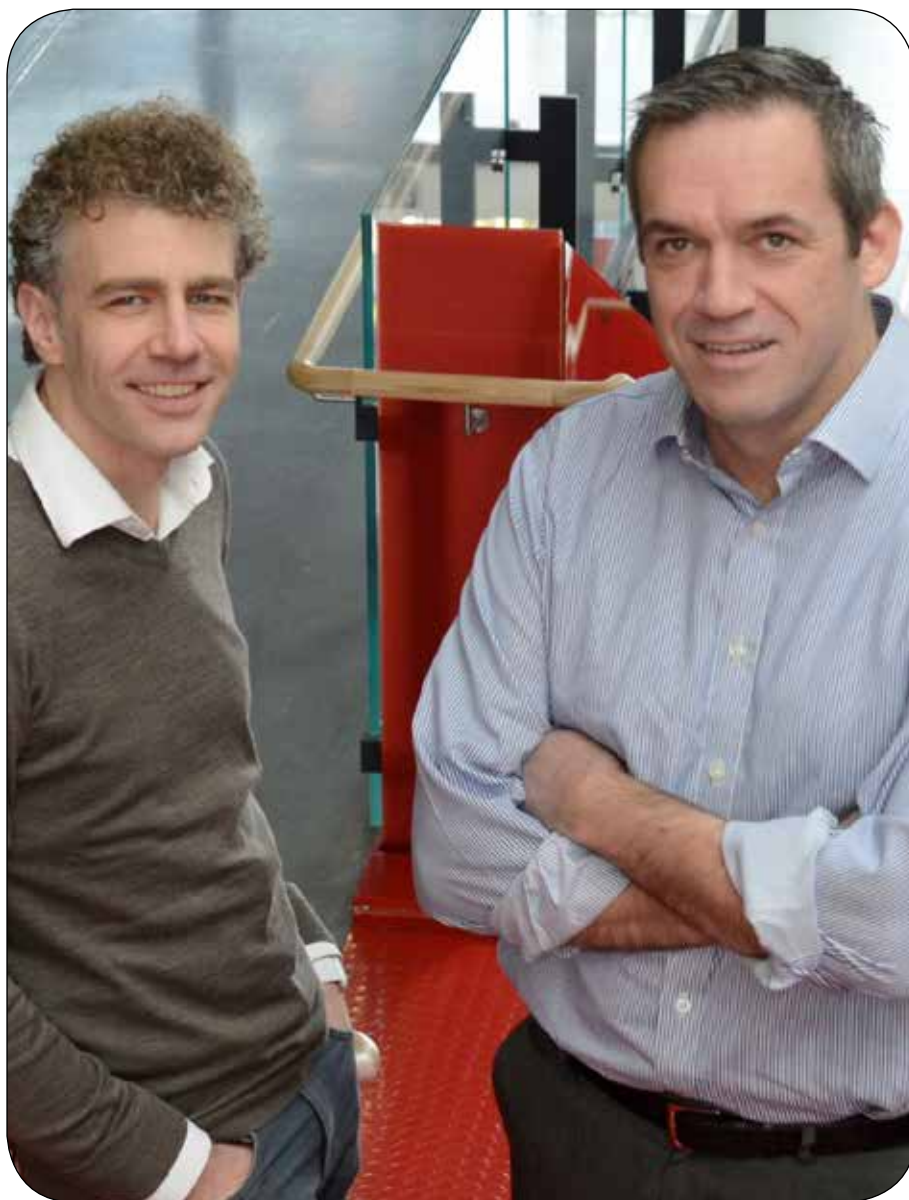
Thank you for supporting Cardiomyopathy UK this Christmas - your donation helps us change lives. [Please note all photos, including iPhone pictures, should be high resolution to display properly and be at least 5MB.](#)



Support our work and spread the cheer

Our new range of Cardiomyopathy UK Christmas cards is now available online and from our Christmas catalogue, enclosed with this edition of My Life. All proceeds from our Christmas 2018 range of cards and money wallets go toward supporting our work helping families affected by cardiomyopathy.

Every pack purchased can help make a difference to the work we do. Take a look at our festive range today and place your order in plenty of time for Christmas - there is even a free gift if you spend over £20! Visit our shop at www.cardiomyopathy.org to place your order, or request an additional Christmas catalogue, by calling 01494 791224.



Dr James Ware, left, and Professor Stuart Cook

Largest ever study of DCM

Stuart Cook, Professor of Clinical and Molecular Cardiology at Imperial College London, is leading a £2million study of dilated cardiomyopathy

Dilated cardiomyopathy affects up to one in 250 people in the UK and remains the primary condition for heart transplantation, despite the use of medications and advanced device therapies.

Over the past six years, Professor Stuart Cook and Dr James Ware, (pictured above), have worked with a

large international team funded by a \$6,000,000 grant from the Fondation Leducq and grants from the BHF and Wellcome Trust, to better understand the way that changes in DNA - sometimes referred to as genetic variants or mutations - can predispose somebody to develop DCM.

families, with the child of an affected parent typically having a 50/50 chance of inheriting the gene defect.

What has become clear during these studies is that a genetic defect alone is often not sufficient to cause DCM, especially if the defect is in the titin gene.

This gene makes the biggest protein in the human body, found in all muscle cells, and variation in titin is the commonest genetic cause of DCM - affecting up to one in five people with DCM.

Working with cardiology colleagues at six hospital Trusts across the UK, the team will invite patients with DCM to take part in a study that combines cutting-edge heart imaging with DNA sequencing to better understand this complex disease.

Patients agreeing to take part in the study will undergo blood testing, DNA sequencing and cardiac MRI scanning of the heart with regular follow-up to see how they are getting on.

The overall goal is to recruit at least 2,000 patients with DCM. This is a big target.

Mutations

To help achieve this ambitious goal, Dr Ware is exploring new ways to help reach as many patients as possible using new technologies, like social media, phone apps, and a direct-to-patient approach.

Their vision is that all patients, no matter where they live, or which hospital they attend, should have the opportunity to participate in research if they choose to.

This is a new and exciting way for patients to be involved in research programmes, but comes with challenges too, which are currently being worked out.

Ultimately, the team hopes to better understand how DNA mutations lead to DCM, to find new treatments, and to develop refined approaches to inform individuals with mutations what they can do to best manage their condition: what to do, what to avoid and what to expect.

The team are also working with scientists, who will test the effects of various mutations in the laboratory and try to work out new ways of preventing heart failure and cardiac arrhythmias in DCM.

■ Read more research news online at: www.cardiomyopathy.org



Head of Services Ali Thompson and Support Nurses Robert Hall, Jayne Partridge and Emma Greenslade answer your questions

Q: I have noticed that since I was diagnosed with my heart condition, I have lost all of my confidence. How can I help myself feel more confident?

Support Nurse Jayne says: Sometimes when you have been diagnosed with a heart condition, you might notice that you feel emotional and find understanding complex medical information difficult, which can affect your confidence.

Learning as much as you can about your condition and sharing your experiences can help to improve your confidence levels.

Cardiomyopathy UK has lots of information about cardiomyopathy and provides help for you to talk about your concerns and feelings, which can help.

We run support groups, factual information, peer support, information days and telephone helpline support.

If you are worried about how you are feeling, you can also speak to your GP for advice.

Q: How do I organise a care plan to support my son at his new school?

Support Nurse Emma says: School is a welcome refuge from the world of hospitals and illness, offering normality and a chance to be just like everyone else.

However, school staff may be anxious about taking on the responsibility of supporting a pupil with a risk of a sudden cardiac death. For this reason, identifying your son's day-to-day care needs and anticipating and managing potential risks are key factors to ensuring success.

Schools will already have protocols for supporting pupils with health needs, but a child or young person with cardiomyopathy will require an individual health care plan, (HCP),

written jointly by family, student, school and health care professionals.

The HCP must be reviewed regularly as needs will change and should address:

- A travel plan to provide help with transport.
- Extra support for when moving between classrooms, eating, or with personal hygiene.
- Arrangements for extra equipment, (e.g. oxygen storage) and the person(s) responsible identified.
- The administration and secure storage of any medication. HCPs should provide school staff with written guidelines for this and training to ensure responsibilities are clear.
- Emergency guidelines.
- A name and contact number of an appropriate health care professional, (ie: cardiac nurse specialist), for the school to liaise with regarding any health concerns at school.

Q: I was diagnosed with dilated cardiomyopathy three years ago and have been taking the usual drugs since that time.

I feel well and my recent echocardiogram showed my heart has returned to normal. Does this mean I no longer have cardiomyopathy and can I stop taking the drugs?

Support Nurse Robert says: Dilated cardiomyopathy is unfortunately not a curable condition, however, the drug therapies now available are very effective in controlling the symptoms of the condition and improving the function of the heart. The improvement you've seen is likely to be due to treatment.

Stopping the drugs risks reversing these improvements.

There has been some recent pilot research at the Brompton Hospital into the effect of stopping the drugs and we are awaiting the publication of the results.



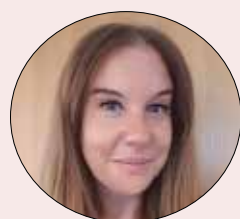
If you have questions you would like the team to answer, email them to: contact@cardiomyopathy.org



Sharing

Cardiomyopathy within the third s practice and inn other charities an heart conditions.

Since its ince registered with th 1990), the charity within the sector service users are local and nation



By Ali Thompson
Head of Services

At the heart of the car

Working tirelessly to support people of all ages

We believe everyone affected by cardiomyopathy can learn how to manage their condition and live well thanks to the accurate, relevant and timely support we offer

For the past three decades, Cardiomyopathy UK has been refining our services and developing our support methods ensuring anyone affected by a diagnosis of cardiomyopathy or myocarditis has access to timely, factual and appropriate support.

The charity works tirelessly to support our people - from the end of a phone to the rooms of Parliament.

Alongside our cardiac nurse helpline and national network of support groups and information days, we provide support to people who need welfare rights advice; to children and young people and to volunteers and clinical professionals.

Our information resources cover a vast range of topics that are of benefit to people with the condition and to those who support them, including the Equality Act; emotional wellbeing; support for carers and exercise.

Each resource the charity publishes is clinically checked by the appropriate authority before release and annually thereafter, to guarantee that all the information provided by

Cardiomyopathy UK is always correct. Our support groups, online groups and closed Facebook groups enable service users to talk confidentially about their physical health and emotional wellbeing with like-minded people, as well as having the opportunity to speak with our nurse and welfare adviser team and hear from recognised speakers.

The annual information days that the charity delivers are of particular benefit to people who are newly diagnosed, as they afford them the chance to ask questions that their own clinician might not have the time to discuss in detail with them at appointments.

Diverse

The days also reassure people that they are not alone and that there are others within their local area who are living with cardiomyopathy and myocarditis.

The helpline, which is often considered the frontline service has developed hugely over the years.

We now offer paediatric support; a greater variety of peer support volunteers and welfare advice. This is because the charity acknowledges how diverse the needs of our people have evolved over the years and to meet those needs effectively and holistically, we have adapted the helpline service.

Government unveils its plans for Max's Law

The Government has announced the introduction of a new 'soft' opt-out system for organ donation in England, in order to tackle the shortage of donors.

The new system is expected to come into force by 2020.

Cardiomyopathy is the leading cause of heart transplants in the UK and hundreds of lives could be saved each year, by many receiving the life-saving transplants they need.

Individuals will be able to record their preferences on a new NHS app launched later this year, or via a helpline and website.

The new proposal, which will be known as Max's Law, will ensure the wishes of the majority of people are better represented.

Currently, there is real shortage of organ donors in the UK, with only one in three people on the donor register. Right now, there are more than 6,000 people on the NHS waiting list for a transplant.

There are also around 300 people waiting for a new heart and most of these people will have cardiomyopathy.

The announcement follows a consultation, in which the Government sought views from members of the public about organ donation, receiving a record 17,000 responses.

Cardiomyopathy UK Chief Executive Joel Rose said: "Organ donation saves lives.

"The change to presumed consent is important, but will not solve the problem on its own.

"There must be no let-up in efforts to encourage people to actively sign up and make their wishes known to their loved ones and we need to make sure our organ donation and transplant service is well funded and fit for purpose."

Under the proposals, children under 18; individuals who lack the mental capacity to understand the changes and people, who have not lived in England for at least 12 months before their death, will be excluded from the plans.



Simon Dyson proudly supports Cardiomyopathy UK

Making headlines

Our PR and Communications Manager Priya Manek worked with Cardiomyopathy UK ambassador Simon Dyson to place an exclusive interview in the Daily Express.

The article, published in August, told how as a teenager, the sportsman was a promising footballer on the books of York City and Scarborough FC and the early indication was that he would follow in his uncle Terry's footballing footsteps.

However, Simon was encouraged to take up golf by his brother, Nick, and by the age of 16, had achieved a scratch rating.

In 2009, a routine test revealed Simon had hypertrophic cardiomyopathy (HCM), but he refused to let his diagnosis hold him back and went on to enjoy a flourishing golf career.

"I'd prefer to manage my condition naturally, if possible," he told the newspaper. "If I can keep myself healthy, fit and active, I hope it will mean I don't need to take medication or have operations.

"I can still play golf, but I can't train with the intensity I used to. The important thing now is I am here for my family and I can see my daughters grow up."

Simon, 40, who is an ambassador for our charity, said: "I'm delighted to be supporting Cardiomyopathy UK. This cause is very close to my heart, having being diagnosed out of the blue, which has changed my life.

"I want to help raise awareness for Cardiomyopathy UK, which is a lifeline for those affected by the condition and their families."

The article highlighted our 2017 campaign, Know Your Heart Story, which urged affected families to have regular heart checks and genetic testing to find those at risk and save lives.

"I want to make people more aware of cardiomyopathy," explained Simon. "If people know about the condition, they can get checked out and it could maybe save their life."



September Stroll 2018

We're absolutely delighted that so many of our supporters took to their local countryside to be part of the biggest ever fundraising walk for cardiomyopathy.

From Perthshire to Brighton, a total of 14 September Strolls took place last month, including members of our superstar support groups in Sussex, London, Bristol, and Cheshire & Merseyside.

We also enjoyed a sunny Saturday morning walk around the beautiful Chess Valley, close to the Cardiomyopathy UK office, when we donned our walking boots for a three-mile ramble, supported by Chesham mayor Jane MacBean to wave us off.

Businesses around Buckinghamshire kindly donated prizes to our tombola stall on Chesham high street, which was a big hit in raising funds and local awareness for our cause.



Keep on strolling

Thanks to everyone who organised or took part in a September Stroll this year and we look forward to seeing even more strollers in 2019 to celebrate our 30th anniversary!

Takotsubo can cause as much damage as a heart attack

It is thought at least 3,000 adults in the UK suffer from Takotsubo cardiomyopathy - but the true number may be even higher

Takotsubo (TS) is one of the rarer forms of cardiomyopathy which causes the heart muscle to contract abnormally - suddenly ballooning out of shape causing symptoms similar to a heart attack.

The condition was first identified in Japan in the 1990s and is called Takotsubo - the Japanese word for an octopus pot - because the heart's appearance resembles this shape.

The condition is commonly triggered by elation or shock and occurs when the stress of the event causes the heart muscle to become weak. Until now, it was thought the damage was temporary and would eventually heal with time.

Takotsubo is commonly treated with beta-blockers, ACE inhibitors and diuretics, but currently, there are no formal recommendations to guide treatment.

Joel Rose, Chief Executive at Cardiomyopathy UK said:

"It does seem that some people are more prone to Takotsubo cardiomyopathy than others and that emotional stress can be one of the triggers that can cause the heart muscle to become stunned and weakened. Until now, it was thought damage was temporary, but this research shows there are long-lasting consequences that we need to find solutions for."

Researchers from the University of Aberdeen followed 37 Takotsubo patients for an average of two years.

Using exercise testing and cardiac MRI scans, the team

'Takotsubo is more common than we originally thought'



found that patients' heart function was often affected long after an event.

Worryingly, they also found patients had ongoing symptoms of heart failure, similar to patients who have suffered a heart attack.

The researchers said patients should be offered the same drugs as those whose hearts have been damaged by a heart attack.

Dr Dana Dawson, lead researcher at the University of Aberdeen, said: "It is becoming increasingly recognised that Takotsubo is more common than we originally thought."

"This is the longest follow-up study looking at the aftermath of Takotsubo and clearly shows permanent ill-effects on the hearts in some of those who suffer from it."

"These patients are also unable to perform physical exercise and fatigue more easily. Our research shows that Takotsubo needs to be treated with the same urgency as any other heart problem and that patients may need ongoing treatment for these long-term effects. Our next goal will be to identify suitable treatments."

Living with stress: Don't keep it to yourself

Having heart problems or watching those you care about cope with a heart problem can be stressful.

Talking to someone and expressing your feelings can often help reduce stressful feelings, but sometimes it can be difficult to ask for help.

Cardiomyopathy UK has a dedicated helpline with trained nurses, who are there to listen, advise and support you.

Peer support is also available to you through our helpline, where we can try and arrange for you to speak one-to-one with someone with a similar heart condition, who understands how it feels. This is an opportunity to identify

practical ways to cope with your symptoms and feelings.

There are also Cardiomyopathy UK support groups, which are often run by people with a similar heart condition to you.

They provide the chance to make new friends and share experiences, which may help reduce your stress.

If you would like to obtain our information booklet about coping with stress, you can request a copy or download - 'An introduction to emotional health and wellbeing' either via our website, or helpline, on 0800



018 1024.

You can also get information about dealing with stress from MIND at mind.org.uk

If you think that stress is affecting your health, or feel that you may have a mental health condition, make an appointment to see

your GP to talk about this.

By Jayne Partidge
Cardiomyopathy UK Support Nurse

How did you become a clinical psychologist?

I first became interested in psychology because I experienced my own problems in early adolescence.

I had poor experience of mental health services, but thought I might be able to learn more and so I did a psychology degree and went on to do my postgraduate training in clinical psychology. I then worked as a clinician, researcher and trainer, before roles in NHS mental health services at local, regional and national levels.

How did you feel after you were diagnosed with HCM in 2011?

I was surprised, but not shocked - perhaps because I was relatively symptom-free at the time and had not previously linked cardiomyopathy to sudden cardiac deaths in two members of my family. Also, getting my diagnosis in my 60s probably meant it had less impact on me than it might have on a younger person, or someone who had family members who might also be affected

How much does cardiomyopathy affect a person's emotional wellbeing?

From surveys undertaken by Cardiomyopathy UK in 2016, we know more than 50% of people living with cardiomyopathy report it has an impact on their emotional well-being a lot of the time, with only 8% saying it had no impact.

The way this affects people varies considerably, but we know depression and anxiety can occur in around a third of those affected. The survey also showed how cardiomyopathy can have a significant impact on the lives of the individual's family, friends and carers.

Why is it difficult for people to discuss their emotions with others?

People tend to be cautious talking about how they are affected, because they may see this as a sign of weakness rather than something that's a very understandable response to living with a condition that is potentially life-threatening. Many are also reluctant to talk to their family or friends about the emotional impact because they don't want to worry them more and the same applies to family members not feeling able to discuss this with the person with the condition.

Unfortunately, this can create a situation where the issues are impacting on everyone, but no one feels able to raise the subject.

People feel they shouldn't raise emotional issues with doctors or other health professionals, as they assume they are only there to help with the physical aspects of their condition.

Our survey also found most patients had never been

asked about the emotional impact of their condition by any professional, either in cardiology or primary care.

This may be because cardiology professionals are reluctant to raise emotional impact for fear it will open up issues they aren't in a position to deal with in the limited time they have and cannot readily access psychological support for their patients

Cardiomyopathy UK tries to help both patients and professionals recognise this doesn't need to be a "no-go area" and that by discussing emotional impact, we can bring about significant improvement to the lives of patients and families

How would you encourage people to talk about the emotional impact of cardiomyopathy?

I think it helps to think of 'doing unto yourself as you would do unto others'. Most of us hope our friends would be willing to share their concerns if feeling anxious or depressed because they had found out they had a serious health problem. I would also encourage people to speak with their health professionals as they might be able to signpost them towards other forms of support.

How can Cardiomyopathy UK help?

One of the most important things Cardiomyopathy UK can do is to help all of those living with the condition understand what this means for us as individuals and also, for our families and others who care for us.

This is so important when it comes to psychological support, because it isn't an area that most cardiology services currently address.

We are all different - so some people may want simply to read the booklets Cardiomyopathy UK has produced on this, or the articles published in My Life.

Some may prefer to discuss these issues

personally on our Helpline or Live Chat services, while others may prefer to talk with those living with similar conditions at one of our support groups. Whichever approach they use, people will find their concerns are understood by others - many of whom may have experienced similar difficulties and who will be happy to listen and share thoughts on what might be helpful.

What do you enjoy about**being a Cardiomyopathy UK trustee?**

I have been a trustee with quite a few charities, but what stands out for me are the qualities and commitment of my colleagues on the Cardiomyopathy UK board.

They all bring different knowledge and skills from varied professional backgrounds and each has personal experience of the impact of cardiomyopathy on their own lives, or on those close to them.

They understand the issues more clearly and are more passionate about ensuring Cardiomyopathy UK can help all those who could benefit from our services.



'We are all so different'

Cardiomyopathy UK Trustee Dr Ian McPherson, OBE, has a particular interest in improving support for the psychological needs of people living with cardiomyopathy



All is not lost

much  loved

Cardiomyopathy^{UK}
the heart muscle charity

Pay tribute to someone special

Remember the life of someone special with our free tribute service from Much Loved.

With a Much Loved online tribute page, you can share photos and stories, light digital candles on anniversaries and special occasions, as well as make donations directly to Cardiomyopathy UK in memory of a loved one.

It's easy to share your page with family, friends, and work colleagues and since launching the service, more than 40 of our supporter families have created a tribute space.

To find out more, go to www.cardiomyopathy.muchloved.org, or contact our Community Fundraiser, Christie Jones on 01494 791224 or christie.jones@cardiomyopathy.org

A diagnosis of cardiomyopathy can often engender a sense of loss and grief

By Ali Thompson
Head of Services

Loss is a word that has many connotations, particularly for someone living with a life-limiting condition and for those who are supporting them.

The word loss is often automatically associated with death; but while this is true, there are other types of losses that people can experience, which are not related to the death of someone close. These types of losses are known as 'secondary losses'.

It is largely accepted by psychiatrists and health care professionals that a secondary, or non-death loss, can cause a person to grieve and feel that sense of loss keenly.

People living with cardiomyopathy tells us that they feel a sense of loss; that they have been bereft of something post-diagnosis and as their health declines.

People can feel that they have lost their health, their independence, finances (if employment comes to an end due to the person's inability to work) and even their sense of self and what it means to be them.

A diagnosis of cardiomyopathy can mean that a person can no longer partake of hobbies they previously enjoyed; their career might alter or change entirely; relationships and the person's "normal" can be redefined and this can cause a sense of loss followed by grief.

Some people tell us that they

experienced a loss of identity when they became a patient and felt that their individuality had been supplanted by a generic moniker.

It is not unreasonable for a person to reflect on their life pre-diagnosis and compare it to how they are feeling and living now. This itself can cause symptoms typical of grief. Indeed, the psychiatrist George Engel defined grief as "...a departure from the (stable) state of health and well-being".

It is important to remember that secondary losses are legitimate and the grief experienced is very real.

Grief is a natural process that we will all experience at some time and a very normal reaction when someone feels something has been lost to them.

Grief can manifest in various ways: a sense of shock or numbness at point of diagnosis; a feeling of sorrow and despair, or even anger towards how life has changed, or will change.

It can also cause physical symptoms such as lethargy, palpitations, change in appetite and headaches. Allowing yourself time to grieve and recognising that living with cardiomyopathy will require adjustments - both emotionally and physically - will help.

Talking to someone you trust and seeking support for how you are feeling is essential to address issues of anxiety and to assuage any ideas of guilt or poor self-worth. Living with loss in a proactive, but gentle way, can help you reinvest in life and feel better able to cope with your condition.

Bournemouth Half Marathon 2018



It wasn't just the sun that shone brightly for the 2018 Bournemouth Half Marathon this October.

Twenty of our incredible runners, cruised their way along the coastal route and made their way across the finish line, making #teamcardio proud.

Seventeen were from the Glenmoor and Winton Academies in Bournemouth, running in memory of their colleague Dan Ferris and to support colleague Leon Lima, whose son Luka has the condition.



Great North Run 2018

This September, 23 of our incredible #teamcardio runners took to the streets of Newcastle with 57,000 other runners for the Great North Run 2018. We want to thank each and every one of our amazing runners

for taking on 13.1 miles for Cardiomyopathy UK - their support has been amazing and we're so grateful, especially to Jon Purvis, who stopped running halfway round the course to save another runner's

life, by giving CPR.

The atmosphere and support - from not only runners, but spectators - was some of the best we've seen.

Here's to next year's Great North Run 2019!



Get your Santa hat on and join thousands of Father Christmases, who are getting into the festive spirit early this December, for London's iconic Santa in the City 2018. This fantastic route takes you along a 5km route along The Thames, enjoying the world famous view of Tower Bridge. The route then takes you along the historic south embankment, past Shakespeare's Globe Theatre and some of London's oldest pubs and the Borough Market area.

Santa in the City

Location – London

Date – 6 December, 2018

London Marathon 2019 ballot runners

Were you one of the lucky ones to get a 2019 London Marathon place? If you've got a ballot place, we'd love you to run for #teamcardio. We will give you all the help and support you need, including a training day with our professional marathon coach and a post-race reception with a massage. Sign up today!



Are you up for a challenge?

Email fundraising@cardiomyopathy.org or call 01494 791224 for details

Vitality Big Half 2019

New to the 2019 #teamcardio calendar is London's Vitality Big Half Marathon (13.1 miles). Join 20,000 runners for this fantastic one-day festival, which aims to be truly global and uniquely local in a celebration of all the cultural diversity of the great city of London. Their vision is to create a sports event for all Londoners and inspire entries from participants from all backgrounds so the event mirrors London's multi-cultural population.

Location – London

Date -10 March, 2019

Pledge – £350



Check off your bucket list with #teamcardio global adventures

Take your fundraising on a journey next year with Cardiomyopathy UK. Whether it's skydiving, trekking the highest mountain in Africa, or cycling from London to Paris, we have plenty of events available to help you make 2019 a year to remember. Simply complete our overseas event form and share your challenge and we will send you a fundraising pack and anything you need for the big trip. So start ticking off your bucket list today and join us for a unforgettable adventure.

Here to support you - anytime, anywhere

Our online support groups are an easy way for you and your family to get in touch with others affected by cardiomyopathy, giving you the chance to share experiences and tips on living with the condition, writes Jo Franks, Support Group Manager

In the past year, we have launched a number of online support groups for different groups of people.

While an online group in no way replaces the benefits of being part of a face-to-face group, we feel they are important in increasing accessibility to the range of support services we are able to offer.

We now have 30 support groups spread across England, Wales and Scotland, but there are still large parts of the country where there are currently no support groups.



How do online support groups work?

Online support groups are hosted by Jo Franks, our Support Group Manager, (left), or one of our support nurses.

The sessions take place in real time and work like a webinar or a Skype session. People book a

place in advance and are sent a link by email.

On the day, participants click on the link to access the session. You can choose whether you want to be visible via webcam or not; you can talk on the sessions if your computer has a microphone, or you can type questions or responses in the chat box. Alternatively, you can dial in via your phone. Our support nurse will give a short presentation on a cardiomyopathy topic and then Jo will host a discussion, where participants are encouraged to share their experiences and ask questions.

What technology do I need?

You can join an online session from your computer, laptop, iPad or by phone. If you have a webcam and a microphone, others will be able to see and hear you.

What do I do if I have problems accessing the session?

Call the office and Jo or Arvin will be able to help you. However, our experience is that people find it very straightforward to use.

How do I book onto an online group?

All sessions are free of charge, but you will need to book to secure your place. If you are interested in joining a session,

go to the support group section of our website, find the relevant online support group and click on the red button 'Book Your Place', then fill in your details to register.

You will then receive an email confirmation asking you to fill in our support group registration form online.

A week before, you will receive an email explaining how to access the session.

What online support groups are there?

ARVC; Supporters and Carers; DCM; HCM; Takotsubo and Myocarditis. If you are interested in a particular topic, please get in touch, we love hearing your ideas.

Dates for your diary

November

Birmingham - Saturday, 3rd November, 2pm to 4pm
Shyema Alkhalaf, pharmacist: Cardiac drugs

Oxford (NEW) - Wednesday, 7th November, 7pm to 9pm
Emma Greenslade, support nurse: An overview of Cardiomyopathy

Cheshire and Merseyside - Thursday, 8th November, 7pm to 9pm
Discussion led by Rebecca King, arrhythmia nurse

ARVC - North London - Saturday, 10th November, 2pm to 4pm
Tootie Bueser, cardiac genetic nurse: Making the most of your hospital appointment

York - Saturday, 10th November tbc

Bridgend - Saturday, 10th November, 2pm to 4pm
Kate Francis, pharmacist: Cardiac drugs

Online Parents and Carers - 14th November, 12 to 1pm

West London - 17th November, 2.30pm to 4.30pm Topic tbc

Leicester - 21st November, 7pm to 9pm
Jayne Partridge, support nurse: An overview of Cardiomyopathy

Manchester - 21st November 7pm to 9pm
Cardiac physios

North East England - 24th November
Janette Frank, Patient Advice and Liaison Service

Leeds - 24th November, 2pm to 4pm Topic tbc

Exeter - 27th November, 7pm to 9pm
Robert Hall, support nurse: Overview of Cardiomyopathy

December

Hampshire Fareham, Portsmouth and Gosport - 1st December, 1pm to 3pm
CPR with the Red Cross

Sussex - 1st December, 3pm to 5pm Topic tbc

January 2019

Brigend - 12th January
Topic tbc

West Scotland - 27th January
Topic tbc

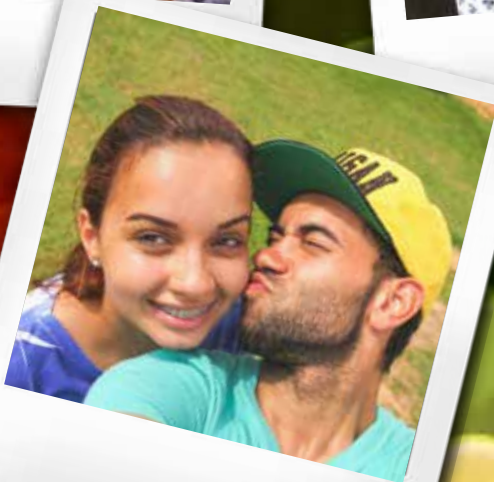
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DETAILS**

Call 01494 791224
Email contact@cardiomyopathy.org or
visit www.cardiomyopathy.org

In My Heart this Christmas

Celebrate someone special

Instead of a present, or to remember someone close to your heart, donate to our In My Heart campaign this year



www.cardiomyopathy.org/inmyheart