

my life

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

Issue 08 | Winter 2016

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**'Our son Elliott lived on a heart pump for a year.
Now he's cheeky like other toddlers'**

Dad Adrian talks about enjoying parenthood at last – Page 5

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 a UK landline) or email them at supportnurse@cardiomyopathy.org

- **information packs**

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

- **support volunteers**

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

- **information days**

We hold information days around the UK each year. These days provide people affected by cardiomyopathy and their families with the chance to meet others who have the condition and hear leading experts talk about the disease, developments in care and latest research. Details of this year's information days are on Pages 3 and 19.

- **support groups**

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

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

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

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



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Website cardiomyopathy.org
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Email info@cardiomyopathy.org

Like us on Facebook

facebook.com/cardiomypathyyuk

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Join our Facebook group

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facebook.com/groups/cardiomypathyyuk

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

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The future together



Chair of trustees
Alison Fielding
chair@cardiomyopathy.org

Family is our theme for this issue. While any illness hits the family and carers of a patient, inherited conditions like cardiomyopathy can pack a bigger punch as families worry about their own and their children's future health.

Our lives change in so many ways. The condition and the treatments can make us fatigued and unable to join in family events. Our incomes may go down if we can't work or cope with overtime. Holidays become more of an issue as we search out insurers and try to find suitable places which aren't too hot, too hilly or too far from hospitals.

Relationships can come under strain. My husband admits to times when he watches me to make sure I'm still breathing. When I gave up my job and the lifestyle that went with it, his life changed too.

These ripples happen to all of us and I hope that My Life and events such as our information days and national conference will help families face the future together.

Since my diagnosis of cardiomyopathy so much has changed. With improved genetic testing, better treatments and even pre-implantation genetic diagnosis for IVF, the future looks better for all the family.

Conference to help you live better with cardiomyopathy

Our first national conference for families with cardiomyopathy will include medical presentations and workshops on living with the disease

Our first national conference for families affected by cardiomyopathy is being held on Saturday, 12 November in London.

It will focus on helping people to live better with the disease, looking at both their medical and psychological needs.

It will include medical presentations about the condition, and supporting and empowering sessions. These will be around living well and focus on emotional wellbeing and developing coping strategies.

As well as expert medical speakers, people with cardiomyopathy will be sharing their personal stories and experiences of living with the disease.

There will be a variety of sessions running throughout the day, including several at the same time, to help ensure there is something for everyone. These include sessions on many types of cardiomyopathy – dilated, hypertrophic, arrhythmogenic right ventricular, peripartum (pregnancy related), restrictive and left ventricular noncompaction.

There are also talks on research, what's new in cardiomyopathy, and the genetics of cardiomyopathy and its impact.

A series of workshops will look at coping with the impact of cardiomyopathy on you and your family, supporting a young person with cardiomyopathy, exercise and lifestyle, benefits and employment rights, taking control of your care, and first aid



and CPR training. There will also be a special session for teenagers, including ten-pin bowling (see page 4).

The conference is being held from 9am to 4.30pm at the Royal National Hotel, 38-51 Bedford Way, London WC1H 0DG.

The fee is £20 per person including refreshments and lunch. For more details and to book, go to cardiomyopathy.org/cardio2016

Part of the family?



Chief executive
Joel Rose
joel.rose@cardiomyopathy.org

This family themed issue of My Life highlights how important it is to have the help and support of others.

Many people tell us that they would not be able to cope with the impact of cardiomyopathy without their friends and family.

I want to make sure the charity can be part of your extended family. We need to be able to give you the support you want, when you need it. We need to listen to what you tell us about how your cardiomyopathy affects you and stand up for you so you get the treatment you deserve.

Being part of a family means we help each other. Our national conference will be a great opportunity to hear from world-leading experts and meet each other, share experiences and support each other as one family.

New cardiomyopathy support group

New group for Surrey to hold its first meeting in Chertsey in October

A new cardiomyopathy support group has been set up in Surrey.

The group is being started by heart failure specialist nurse Tracey Bradshaw (pictured right), from St Peter's Hospital in Chertsey.

The first meeting is on Thursday 15 October, 2pm-4pm at the Post Graduate Medical Centre, St Peter's Hospital, Guildford Road, Chertsey.

The main speakers are consultant cardiologist Dr Ian Beeton, from St Peter's Hospital, who will be leading a question and answer session on cardiomyopathy, and Cardiomyopathy UK support nurse Robert Hall who will talk about Cardiomyopathy UK and its services.

Those affected by cardiomyopathy, family members and friends are welcome to attend.

Tracey said she decided to set up the group after one of her patients and his wife asked if there was some local sup-

port. She said:

"For a long time I've been involved with support groups so I understand the difference they can make. I'm hoping this group can be built on to provide the type of support group that cardiomyopathy patients and their families want and benefit from."

She said there was already a support group in the area for heart patients, but it was mostly people with coronary artery disease who attended. So she realised there was a gap in provision. She said the heart consultants at the hospital fully supported the idea of a special group for people with cardiomyopathy.

For more details about the group, email tracey.bradshaw@asph.nhs.uk



Help us develop our services for young people



Jo Franks | youth and peer support manager
Cardiomyopathy UK

Jo talks about our session for young people at our national conference and our plans to involve young people in shaping our services

Cardiomyopathy UK is looking for ways to improve its services to young people aged 12 to 17 affected by cardiomyopathy, and wants them to help shape these services.

To get the ball rolling, we are having a special session for young people at our national conference in London in November.

It will include ten-pin bowling at the All Star Lanes bowling alley in Holborn, a question and answer session on cardiomyopathy, a discussion on what's new in cardiomyopathy and a chance for young people to have their say on what services Cardiomyopathy UK should be providing for young people.

We want to provide more services to young people who have the condition and also those living with others who have it. As well as getting the chance to meet and socialise with other young people affected by cardiomyopathy, those who attend will be able to find out more about the disease, developments in treatment and latest research.

Our national conference is taking place on Saturday, 12 November, at the Royal Park Hotel, 38-51 Bedford Way, London, WC1H 0DG. Young people coming to the session can attend the conference free of charge.

We really want the help of young people to develop our youth services. We'd like to hear from you about what helps young people affected by cardiomyopathy and what isn't useful, what it's like to live day to day with the disease and how we can better support you.

If you would like to come along and share your thoughts during a morning of bowling and meet other young people then we would love to see you.

If you can't make the day but are still interested in sharing your thoughts, do drop us a line at the email address at the end of the article.

We are hoping to set up a steering group of young people aged between 12 and 25 to

help us develop our young people's work.

This is an opportunity for young people to help us shape our work and develop it in ways that are relevant to your needs.

The group would meet periodically on Saturdays to help develop our young people's strategy, ensuring we are putting young people's views at the heart of what we do. If you are interested in getting involved, we would love to hear from.

We would also like to develop young people's website content, including relevant information written by and for young people not just aimed at their parents.

We also plan to host a couple of social opportunities to meet up each year to give young people more opportunities to share their experiences and learn more about the condition.

For more information, sharing your views or to book a place at the national conference, please contact us at alison.thompson@cardiomyopathy.org



• As part of our national conference we have ten-pin bowling for young people

Jo's role to assist support services

Jo Franks, who has spent much of her career working in young people's support and education, has been appointed as our youth and peer support manager.

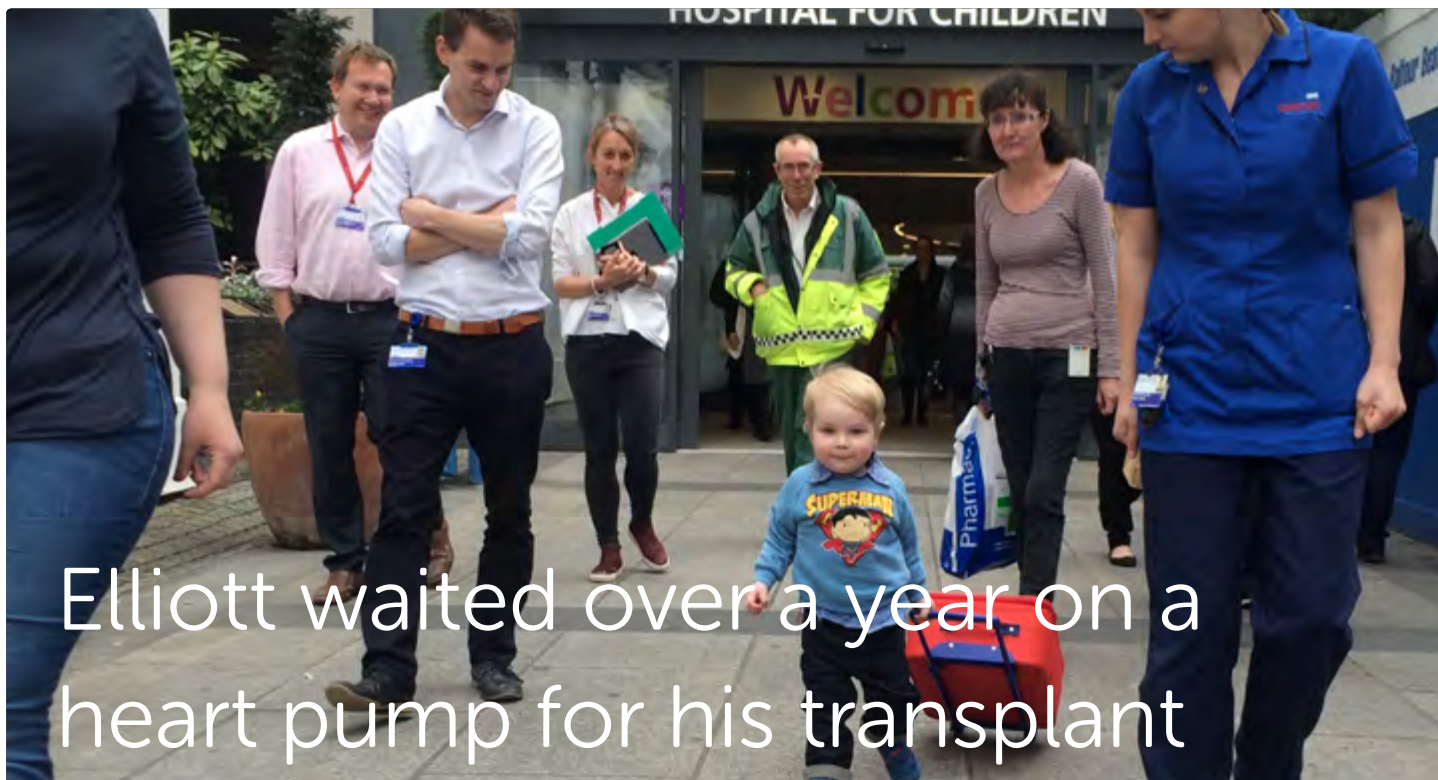


In her new role she will be:

- working with support groups and helping to set up more
- supporting and increasing our network of support volunteers
- developing our services for young people with their help

Jo, who has been a teacher, studied counselling and worked for charities including the YMCA and the British Red Cross, said: "I'm very excited about developing the charity's support services, ensuring we meet people's needs."

Working with support group leaders, Jo has already created a pack for them. She will also be recruiting and developing group leaders through training and supervision. Looking at extending support via online groups will also be important. If you would like to help lead a support group, email jo.franks@cardiomyopathy.org



Elliott waited over a year on a heart pump for his transplant

Elliott Livingstone's story

Adrian Livingstone talks about his three-year-old son being diagnosed with dilated cardiomyopathy as a baby and spending a year on a mechanical heart pump before having a heart transplant

Our son Elliott was diagnosed with dilated cardiomyopathy when he was just 12 days old. My wife Candace had a normal pregnancy and delivery, and all seemed well in the early days.

He began to get a bit puffy round the face, and at his first weigh-in he had put on quite a bit of weight. But we didn't know anything was wrong. It was when Candace was having a Skype conversation with her mum, a paediatrician in America, it was first noticed Elliott was struggling to breathe, intermittently sucking in with his breaths.

We called 111 and an ambulance was sent. We both went with him to hospital but we were told his breathing was normal for a new born baby and we were sent home.

The following morning Elliott started to turn grey and grunt when breathing. At hospital he became seriously ill and had what is called a neo-natal collapse. He was fighting for his life.

He was transferred by ambulance to the Evelina Children's Hospital in London. Doctors initially thought a virus had affected his heart. He was put on heart drugs and started to improve, but when he came off the drugs he became extremely ill again. It was then he was diagnosed with dilated cardiomyopathy. His left ventricle was so weak he could not pump blood efficiently round his body. This news left us in shock. How could this be happening?

Elliott was kept in hospital for five weeks and then allowed home on various medications and with regular hospital check-ups. He struggled with feeding, as many babies with heart conditions do, and this affected his growth. Candace had to be careful taking him out to reduce the risk of him getting an infection.

But he was very active doing everything that babies do and was walking at nine months old. Apart from one spell in hospital for bronchiolitis he was quite well.

Just before Christmas in 2014 he became ill again and was fitted with a pacemaker. At first he improved and was eating better than we had ever seen before. But then he went off his food, stopped running around and tired very quickly. Doctors told us his condition was deteriorating and he might need a heart transplant. In February

2015, when he was 16 months old, he went into Great Ormond Street Hospital (GOSH) for a heart transplant assessment. He was immediately admitted and became so ill he had to be sedated, ventilated and put on a Berlin Heart, a type of heart pump, to keep him alive while he waited for a transplant. It was all hard to take in, but we had to make the best of it. We had to stay positive.

It was quite a roller coaster to begin with, but he soon flourished on the pump. He came out of intensive care, had a sustained appetite and was up and about, managing to walk about with the pump sitting between his legs.

Elliott had a long wait on the pump for a new heart. The previous longest wait had been 276 days – Elliott had to wait 420 days. He had his transplant earlier this year. Initially there were some serious complications and it was touch and go for a few days, but then everything snowballed in a good way. Only three weeks later Elliott was ready to go home and we weren't prepared at all.

It had been more than a year since Elliott had been home and we had to prepare him. The hospital advised us to show him photos of the house and his bedroom so he was familiar with them before he got there. But he walked straight in. It took us longer to adjust to having him home.

The doctors and nurses at GOSH are very friendly and have been like our extended family, and we have good nurse support at home. Elliott is doing very well and has become cheeky. At first his play was very much about hospital life, but that has changed. He's struggling to sleep but it's nice having normal parent problems. Having a heart transplant is not a cure and comes with its own set of problems. But who knows what treatments will become available? There's always hope.

• Pictured are (front page) Elliott with mum and dad and (above) leaving GOSH after his transplant

Dad Adrian said: "When Elliott was first diagnosed with cardiomyopathy we found the Cardiomyopathy UK website. It was extremely helpful and we downloaded information about cardiomyopathy and the disease in children. We attended the charity's cardiomyopathy in children information day run with Great Ormond Street Hospital (GOSH). We met many parents in the same position as us, and listened to many informative talks. So when Elliott was admitted to GOSH the staff were familiar to us and we could relax more and feel Elliott was in good hands."

Marty is just the greatest inspiration ever



Marty Bishop's story

Sarah Bishop talks about her son Marty being diagnosed with hypertrophic cardiomyopathy in the womb. Doctors initially suggested a termination but Marty is now six and doing well

In 2010 a series of pregnancy scans revealed that our unborn baby had cardiomyopathy. I remember starting to shake uncontrollably as my husband Darren asked the doctors more questions. I had nothing to say to them. What on earth do you say?

We were asked to return in a week's time for a further scan. At this appointment we were told that our baby's heart had worsened and I was offered a termination. This was unthinkable. I was 24 weeks pregnant and had had six previous miscarriages including an ectopic pregnancy.

We were told that our baby would be unlikely to survive to the end of the pregnancy and almost certainly would not survive birth. We were given the contact details for Cardiomyopathy UK.

We googled and googled, and cried and cried until it felt like we could do neither anymore. I rang Cardiomyopathy UK and spoke to a nurse there at the time called Gill Rogers. Gill became my life line. We had weekly conversations. She was kind and so caring and really understood what cardiomyopathy was. She sent some cardiomyopathy leaflets and books in the post. I began to understand more and more and, with more understanding, came a very welcoming and important degree of comfort.

We decided to find the best doctors with the most expertise in the country (or even in another country) and found Dr Gurleen Sharland, a fetal cardiology consultant at the Evelina London Children's Hospital (over 200 miles away). Our GP, who was particularly supportive, referred me to Dr Sharland, who saw us without delay.

Dr Sharland was worth every mile. She scanned our baby son (now named Marty) and told us she could see hypertrophic cardiomyopathy and noncompaction (the left ventricle appears to be spongy and noncompacted) but was confident that we could safely get him to birth. We visited her three times until she said she was happy for Marty to be born a week early close to where we lived.

We were booked in and invited to look around the special care baby unit where he was expected to stay. That was quite a difficult visit. Marty was born weighing 8lbs 10oz. He was breathing for himself and we had a very brief cuddle before the special care team

took him into their care. We waited for four hours with no idea what was happening to Marty. My gynaecologist came along, went to special care to find out more, returned with a wheelchair some 20 minutes later and told me to hop into it. We found Marty in a plastic crib with no tubes, and no breathing or feeding apparatus. He was in his own baby grow but had on a hospital hat and tiny gloves.

We were told Marty was fine and told to pick him up and cuddle him. I cried but it was more like hysteria. The nurses had to reassure everyone in the ward they were tears of joy not devastation.

We took Marty home and were asked to return in 11 weeks for more tests. He was well during this period and everything felt wonderful. We were unsure why we had been told he was unlikely to survive to this point but didn't let it concern us. We were so pleased to have this gorgeous little chap. However, at the tests we were told his heart was still showing serious hypertrophic cardiomyopathy and noncompaction. The world came crashing down once again.

Days later we had a telephone call from a nurse specialist at Great Ormond Street Children's Hospital (GOSH). The nurse, Sarah Regan, who now also works part-time for Cardiomyopathy UK, asked if we would consider taking Marty to GOSH. Ten days later we had our first visit to that wonderful hospital.

At first I told Darren that I couldn't possibly go in. This was somewhere you saw on the television, a place for very poorly children. This couldn't possibly be the right place for us. I was overcome with fear. We were greeted with kindness and understanding, and nurses and consultants who were intrigued by Marty and wanted to help.

Following tests they did an awful lot of explaining to us. They said Marty also had a hole in his heart but his heart function was good.

Marty is now six years old, a beautiful, funny, quirky little character who is adored. He has had numerous visits to GOSH but each time doctors have been more pleased with him. The hole in his heart rectified itself and the thickening of his left ventricle has now improved to the edge of normal limits.

Marty still has noncompaction and the valve on the left side of his heart is mildly malformed. But he looks well and enjoys life to the full. He is aware of his story and has been thrilled to be in the media on several occasions. His classmates call him 'famous Marty'.

As a family we have found comfort and self-help in fundraising and running Marty's Penny Bank. From this cause we have raised £1,000 for GOSH, £600 for Genetic Disorders UK, and nearly £20,000 for Cardiomyopathy UK. Cardiomyopathy is now a huge part of our lives. It's ok though. We have been taught more love, hope and faith, and Marty is the greatest inspiration ever.

- Marty is pictured above with mum Sarah and dad Darren



Ade Ashaye's story

Ade was diagnosed with hypertrophic cardiomyopathy as a baby. He has missed a lot of school and so is having an extra year in sixth form before taking his A Levels. He hopes to get into a leading university to study accountancy and finance

When I was born at St George's Hospital, London, doctors realised I had a heart problem so they transferred me to the Royal Brompton Hospital where I was diagnosed with hypertrophic cardiomyopathy.

My mum didn't know much about the condition so she contacted Cardiomyopathy UK. She spoke to one of our heart nurses, Robert Hall, and began supporting the charity. Robert visited me at my primary school and he helped at a day to raise awareness of cardiomyopathy and this was covered in my local newspaper, the Guardian in Merton.

When I was about seven my mum attended an information day where she met Dr Maite Tome, a consultant at Great Ormond Street Hospital (GOSH) who was guest speaker and soon my care was transferred to GOSH.

As a child I didn't know much about my condition. I just knew what my parents and doctors told me. I didn't know what medication I was taking and the reason why I had to take it. My stubborn childlike self didn't listen to the doctors' instructions. They talked to me about pacing myself when doing sports so not to put a strain on my heart. Yet, I would always push myself more than I could handle especially when it came to playing football.

With every visit to the hospital I had to have an ECG, an echo scan and the one I hated the most, the 24 hour tape. The sticky sticker that was attached to my body was what I hated the most. Occasionally I would take an exercise test to see how much strain my heart could handle and how I was reacting to the medication.

As I got older I became more nervous about going to hospital even though the doctors and nurses at GOSH, especially Sarah Regan (who also now works part-time for Cardiomyopathy UK) were really helpful and kind. They encouraged me to ask any questions I had about my condition and helped me to deal with it. Consequently I am now more interested in my health and my care.

All my hospital appointments, my condition and the side effects of my beta-blockers, including tiredness and fatigue, have affected my school work. But my school, Harry's Academy in Merton, has been really supportive. I was very happy with my GCSE exam results and have been studying maths, computer science and business at A Level. I now hope to go to a good university next year.

More recently I have been prescribed the anti-arrhythmic drug disopyramide to help reduce my palpitations and chest pain. When I was 17 I had to be transferred to an adult clinic but am still able to see Dr Tome, who is now at St George's Hospital. It was a very easy, stress-free transition thanks to the nurses at GOSH.

• Ade is pictured above with his mum Ufuoma

More IVF help for families

Families affected by cardiomyopathy due to changes on the MYH7 gene are now eligible for IVF treatment to ensure their babies are not affected.

The Human Fertilisation and Embryology Authority (HFEA) has licensed pre-implantation genetic diagnosis (PGD) for families who have dilated cardiomyopathy co-existing with left ventricular noncompaction, caused by a mutation in the MYH7 gene.

PGD is a technique that enables people with a specific inherited condition in their family to avoid passing it on to their children. It involves checking the genes of embryos created through IVF. Then only those embryos without the gene mutation are implanted in the mother's womb.

Genes causing various types of cardiomyopathy now have a special licence.

For more details about PGD, see cardiomyopathy.org/genetics-of-cardiomyopathy/intro

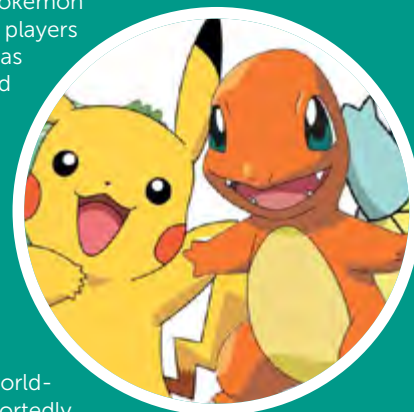


Pokémon Go welcomed

The new app Pokémon Go, which gets players on the move, has been welcomed by some cardiologists in America.

The mobile app, which was released in July, has already been downloaded more than 15 million times world-wide and is reportedly on more than 10% of all Android phones.

"There's already clear evidence that people are walking more each day while using it," Dr Wei Peng told the American Heart Association's online news pages.



Keep up-to-date with the news

For more news stories about cardiomyopathy treatments and latest research, see cardiomyopathy.org/news

Coping with a diagnosis of



Sarah Regan | Cardiomyopathy UK children's support nurse

Sarah talks about the difficulties families face when a child is diagnosed with cardiomyopathy and what can help

When you are first given a diagnosis of cardiomyopathy in your child the immediate days that follow can be overwhelming and it can be extremely difficult and confusing to work out what comes next.

There are many practical and helpful ways parents can come to terms with the diagnosis and devise a plan of action that is helpful to them.

Receiving news about any diagnosis is difficult, and your life has changed from that moment. The feelings and emotions that families experience at the time of diagnosis are likely to change over time and you may not experience all these emotions. There is no right or wrong way to feel, and some days your emotions will go up and down and other days it will feel easier.

Shock is one of the most common feelings experienced and is a very normal reaction. Naturally you will feel worried and anxious as you come to terms with the diagnosis and what it means for your child. Fear and denial is another common emotion and this can affect decision making, particularly if families are making decisions about surgery or emergency procedures.

It is normal to feel angry too. You may feel angry at the hospital staff for putting your child through tests and treatment, especially tests such as blood tests that can be distressing for your child.

Parents and carers can also react differently and have different ways of coping with their children's diagnoses. Some parents want to talk about the situation, while others may want to largely ignore it and carry on with normal family life.

Many parents need to grieve for what they thought was their child's future. It's not that they can't help their child have that future but the journey will be different.

You can contact our children's support nurse Sarah Regan through our helpline 0800 0181 024 (free from a landline), our facebook group or email sarah.regan@cardiomyopathy.org

It is also very natural to feel sad and hopeless. All of these emotions impact on us physically too. Parents often report feeling exhausted but finding it difficult to sleep, feeling nauseous and having a very poor appetite.

It is extremely important that parents try to look after themselves physically and emotionally too. When children are in hospital, parents are encouraged to eat well too (not always possible with hospital food!) and do something for themselves including physical exercise or meeting a friend. Having some time to yourself can be valuable in helping you to cope.

Some parents cope better by looking at and exploring all the research and information available to them. There is a lot of information on the internet but not all of it is reliable. So it is best to talk to your medical team about where to look.

The best advice is to use a website by a recognised organisation, such as Cardiomyopathy UK. Remember that every case is different. You may read about a child in a similar situation to yours, but they may have a completely different experience.

When you receive the diagnosis, you may not take everything in and you may feel you haven't asked sufficient questions. But you can ask to see or speak again to the specialist doctors and nurses.

It can really help to have someone with you at appointments who can help you to remember all the information. You can write down questions you want to ask in advance. This can help you get the most out of your consultation. Remember there is no such thing as a silly question.

There are many people who can help you deal with difficult emotions and feelings. Some people find it easier to talk to people they know while others may find it easier to talk to their GP, health

We have parents of children with cardiomyopathy who offer support to other parents over the telephone or by email. For their details, contact us on 0800 0181 024 or email supportnurse@cardiomyopathy.org

cardiomyopathy in a child

visitor, specialist nurse or consultant.

The team at your child's hospital, including the specialist doctors and nurses, can also offer practical and psychological support. Practical support may involve seeing a family support worker and social worker for support and help with claiming fare reimbursement, disability living allowance and making decisions about returning to work depending on financial support.

Psychologists work closely with children with life-long conditions and their families helping them to adjust to their new situation and to improve their quality of life. They also help families develop strategies for coping with distress arising from pain or uncomfortable medical procedures.

Family and friends often want to give their support but are frequently unsure of how to and don't want to interfere. It helps to keep your family and friends informed so that they can understand what is happening. Family and friends may worry if they are reacting the right way. They may not understand the diagnosis or behave in the way you expect them to. This can often feel overwhelming. So there may be a family friend or relative who is happy to be responsible for keeping everyone up-to-date.

Many families find it helpful to have assistance with school runs and looking after other children, particularly when parents are trying to keep siblings' lives as normal as possible. Giving lifts to and from appointments and cooking dinner for a family can make a



Hearty, our children's guide to cardiomyopathy, is designed for children aged six to eight with the condition and their siblings and friends. For a copy, contact us

huge difference. When children are admitted to hospital for an extended stay and a relative or family friend is able to visit them often in hospital or stay for a time, it can allow parents valuable respite and the opportunity to go home.

Most children's wards and intensive care units do not have strict visiting times. Remember it is important to ask your family and friends for support. They are often waiting for you to ask!

For more information about cardiomyopathy in children, get in touch and ask for our children's booklets or see cardiomyopathy.org/cardiomyopathy-in-children/cic

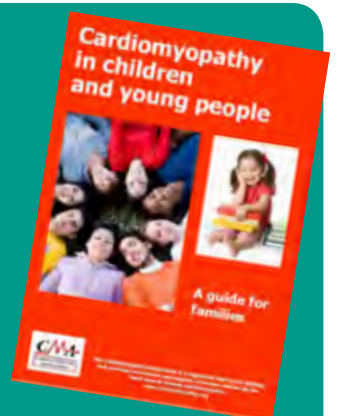
Help us update our children's booklet

We are planning to update our booklet on cardiomyopathy in children and young people and we'd like families to help.

The booklet is designed for parents and carers of affected youngsters under the age of 18, and for older children to read themselves. So we're looking for people from those groups to tell us what they think about the content to help us with the updated version.

Information manager Rona Eade said: "We want to ensure the booklet covers the most relevant topics, that we understand what information you were given at the time (and what you needed) and we cover some of the commonly asked questions (and questions that people were reluctant to ask)."

To help, please complete our online survey going live on Monday, 10 October at cardiomyopathy.org/cyp-survey. If you'd prefer a copy in the post, call the office on 01494 791224.



Very few children with cardiomyopathy die suddenly, say researchers



Researchers have been looking into the risks of young children dying suddenly from cardiomyopathy.

Though the disease can be serious in young children and difficult to treat, during a median follow-up of 12 years the team found only one in 20 had died suddenly, the researchers reported in the *Journal of the American College of Cardiology*.

A total of 289 children aged under ten were enrolled in the National Australian Childhood Cardiomyopathy Study. The on-going study is assessing all children diagnosed in the country with cardiomyopathy from 1987 to 1996.

Each child was categorised as having dilated cardiomyopathy, hypertrophic cardiomyopathy, restrictive cardiomyopathy or left ventricular noncompaction.

In the 12 year follow-up, 5.5 per cent of the children died suddenly, and risk varied depending on the type of cardiomyopathy.

Those with noncompaction were most at risk followed by those with restrictive cardiomyopathy. Young people with hypertrophic and dilated cardiomyopathy were at lower risk.

The researchers said risk factors also included older age at diagnosis, a family history of cardiomyopathy and severity of left ventricle dysfunction.

The researchers concluded that larger childhood studies of individual cardiomyopathy types might be helpful for identifying children most at risk.

The study, which is continuing to follow the children into adulthood, is supported by the Royal Children's Hospital Research Foundation, the National Heart Foundation of Australia, the Australia and New Zealand Children's Heart Research Centre and Heartkids Australia.

Gene for severe children's disease?

An international team of geneticists say they have found a gene mutation that leads to severe hypertrophic and dilated cardiomyopathy in children.

It is hoped the discovery will lead to better screening for cardiomyopathy in affected children.

A study of the DNA of children who were seriously ill with early onset disease showed a mutation from both parents in the gene alpha-kinase3, which plays an important role in the early differentiation of heart muscle cells. All the children in the small study showed severe hypertrophic or dilated cardiomyopathy in the womb, at birth or in early childhood.

Twenty per cent of family members also showed signs of milder hypertrophic cardiomyopathy.

The results of the study were presented to the annual conference of the



European Society of Human Genetics by Dr Johanna Herkert, a clinical geneticist at the University Medical Centre of Groningen, the Netherlands.



For more details see cardiomyopathy.org/gene-mutation

Alternative way of fitting heart device in children

Doctors in America say that an alternative way of fitting children and young people with internal defibrillators (ICDs) is effective.

They say that fitting the device in the membrane sac around the heart, usually via a small incision in the side of the chest between the ribs, is less invasive.

It is particularly suitable in young children and those worried about scarring from the wound.

This procedure is called epicardial ICD placement. It differs from the usual method which sees the device, which can shock the heart into a normal rhythm, fitted into the front chest wall with leads going into the heart.

The research team, from the Mayo Clinic in Minnesota and led by Dr Andrew Schneider, said that young patients tended to have higher rates of ICD lead fracture and were more at risk of other related problems.

But fitting the ICD in the inner layer of the heart sac had the potential to avoid the usual complications. The researchers concluded that epicardial placement was an acceptable alternative to the traditional transvenous placement.



For more details see cardiomyopathy.org/child-heart-device

More support for post mortem gene testing

The use of genetic testing in post mortems substantially increases the identification of possible causes of sudden death from heart problems in children and young people, say researchers.

The study, reported in the *New England Journal of Medicine*, looked at 490 deaths of those aged one to 35 in Australia and New Zealand between 2010 and 2012. The cause was unexplained in four in ten of the cases.

In those that a cause had not been identified despite detailed tests, heart genes were studied to see if known gene mutations could be found.

A relevant mutation was found in 31 of 113 cases (27%) in which genetic testing was done. During follow-up,

inherited heart diseases were identified in 13% of the families. The European Society of Cardiology has already recommended that detailed genetic testing should be a fundamental component of the post mortem examination.

Researchers also noted there were 1.3 cases of sudden death per 100,000 people aged one to 35. More than seven in ten involved males. Those aged 31 to 35 were most at risk.

The most common explained causes were coronary artery disease (24%) and inherited cardiomyopathies (16%).



For more details see cardiomyopathy.org/post-mortem-tests

Q&A

Professor Perry Elliott, from the inherited heart disease team at Barts Heart Centre, London, answers your questions



Q: I've seen a study that suggests that drinking caffeinated drinks such as coffee, tea and chocolate doesn't have any effect on your heart rate. Is this true for people with heart diseases like cardiomyopathy?

A: Unless you drink vast quantities of caffeine or similar stimulants it is probably true to say that these substances do not substantially alter heart rates. However, they can sometimes trigger heart rhythm disturbances and so it is wise to avoid excessive consumption.

Q: I have dilated cardiomyopathy and will be going to a Disney park soon. Is it safe for me to go on all the theme park rides and roller coasters?

A: Many theme parks advise against going on their more dramatic rides if you have a heart condition, and it is certainly prudent to seek advice before doing so. The major issues to consider are the severity of your heart condition in relation to symptoms, history of heart rhythm problems and degree of cardiac dysfunction. If your condition is mild, your symptoms well controlled and there is no reason to believe that you are at increased risk of dangerous heart rhythms, then it may be possible to go on some theme park rides but always seek advice from your cardiac specialist who knows your condition.

Q: My cardiomyopathy is caused by Fabry disease. To what extent can enzyme replacement therapy with Replagal reduce heart mass and other related side effects?

A: Fabry disease (or Anderson-Fabry) is a rare genetic condition that causes deficiency in an important enzyme in the body that breaks down particular types of fats. It often causes thickening of the heart muscle and can cause problems with the heart rhythm and valves. There

are two licensed enzyme replacement therapies available in the UK which have been shown to help different aspects of the disease, in particular symptoms of pain in the limbs and progressive kidney damage. The evidence of benefit in the heart is less certain, but several studies suggest that enzyme treatment can, if started before severe damage to the heart has occurred, slow development of hypertrophy. Complete reversal of hypertrophy is very unlikely in most people.

Q: Is there any benefit in taking vitamin D if you have dilated cardiomyopathy?

A: In experimental models vitamin D has a number of effects that could theoretically be of value in people with heart muscle problems. In addition, many people with heart failure have a high prevalence of vitamin D deficiency that in some studies has been associated with increased mortality. However, it does not follow necessarily that replacement improves prognosis. A recent trial (VINDICATE (Vitamin D treating patients with Chronic heart failure) in patients with symptomatic heart failure has recently examined this question. After a year of vitamin D supplementation exercise tolerance was unchanged but there was a small increase in left ventricular function. However, the significance of this finding is not clear and, for the moment, more evidence is required before vitamin D supplements can be used as a treatment for cardiomyopathy.

Q: Why do I get breathless if I have water retention?

A: Fluid retention in someone with impaired heart function causes an increase in back pressure from the heart to the small blood vessels in the lungs. This results in increased stiffness and sometimes

accumulation of fluid in the airspaces of the lungs and a sense of breathlessness.

Q: I have had hypertrophic cardiomyopathy for many years and am now in my 60s. As I become older it seems to cause me more breathlessness. Is this usual and what should I do?

A: Symptoms can change over the years for many reasons. It may be that your condition has deteriorated or changed in some way. For example, the heart pump may stiffen with age or there may be obstruction to the outflow from the heart. It is also possible that there is a treatable complication such as a change in heart rhythm or indeed an unrelated condition such as lung disease or anaemia. If your symptoms have changed you should get your heart checked by your heart specialist.

Q: How important is it for people with cardiomyopathy to try to keep their weight in check?

A: Being overweight will increase the likelihood of symptoms in people with cardiomyopathy. It is also important for general health reasons to have a healthy diet and body weight.

If you have a question you would like Prof Perry Elliott to answer in My Life, please send it to Sarah Dennis at sarah.dennis@cardiomyopathy.org

New rules on medical devices designed to speed up approvals

European cardiologists have welcomed plans for new rules on medical devices, such as pacemakers and internal defibrillators.



The new regulations are designed to allow patients to benefit from advanced technology sooner, while still insuring devices are safe.

The European Council said the regulations, which still need to be formally approved, will increase scrutiny of devices before they enter the market, enhance surveillance once they are being used, improve the availability of clinical data through a central database, and require devices to have unique identification numbers so they can be traced through the supply chain.

The European Society of Cardiologists (ESC), which represents around 95,000 cardiology specialists, says the rules will, for the first time, guarantee transparency for regulatory processes, and clinical information submitted by manufacturers will be made available to doctors and patients alike.

Professor Fausto Pinto, president of the ESC, said: "This legislation, once passed, will herald a new era for active engagement by scientific, engineering, and clinical experts in writing specific standards for the clinical evaluation of medical devices, and in contributing to improved monitoring of their performance."

More information

If you want to know more about cardiomyopathy, ask for one of our cardiomyopathy booklets, produced with support from the British Heart Foundation.

We also have a booklet about living with cardiomyopathy. For copies email anne.foster@cardiomyopathy.org, call us on 01494 791224 or see cardiomyopathy.org



How our information days help

Families affected by cardiomyopathy have been telling us in a survey how they benefitted from attending one of our cardiomyopathy information days held this year.

Almost two thirds of those who came to one of our special days took part in the survey. Most had had cardiomyopathy for less than five years, with many being diagnosed for only a year or less.

More than six in ten said they felt better able to be involved in their care and manage their health afterwards.

More than six in ten people came with 'a little' understanding of the disease and 98% said they left with more knowledge.

Cardiomyopathy UK has been holding information days for more than 12 years as part of its work to improve understanding of the condition and help people take a full part in their own care, including having a good working relationship with their medical teams.

The days also allow affected people to meet others in a similar situation to share experiences and help reduce their feelings of isolation.

More than six in ten of people who responded to the survey had the condition, while the others were family and friends.

Nearly half (49%) said attending an information day had helped how they felt about their condition.

Nine in ten said they had learnt something that would make a difference to them.

A total of 99% gave positive comments about the day, including enjoying the knowledge and approach of the expert speakers and talking to and hearing from affected people.

Almost three quarters (73%) would attend another Cardiomyopathy UK event.

Information manager Rona Eade said: "Specific feedback, particularly around what people enjoyed and suggestions for improvement, will help to improve the information days in 2017. So we will look at adding sessions specifically for partners and structured sessions for sharing experiences and hearing personal stories."



More than six in ten said they felt better able to be involved in their care and manage their health after attending an information day

More than six in ten people came with 'a little' understanding of the disease and 98% said they left with more knowledge

Nearly half (49%) said attending an information day had helped how they felt about their condition

Nine in ten said they had learnt something that would make a difference to them

Our information days for 2017

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

- Nottingham – 18 March
- Wrexham – 1 April
- Ipswich – 22 April

- Edinburgh – 13 May
- Bradford – 3 June
- Southampton – 24 June

More details, including the venues, will be announced shortly. For more details, see cardiomyopathy.org/expert-advice/home

Who gets a heart — does allocation need changing?

People with hypertrophic and dilated cardiomyopathy survive better than others on heart transplant waiting lists in America, say a group of researchers.

But those with restrictive cardiomyopathy were among people who did less well. So they should have greater priority for new hearts, recommended the researchers in the American College of Cardiology's journal *Heart Failure*.

They suggested the allocation system should be revised to reflect the differences in survival.

The researchers looked at data from more than 30,000 American people waiting for a transplant between 2004 and 2014. During follow-up of under four years nearly 5,000 patients had died.

The statistics showed those most at risk of dying while they waited were people with restrictive cardiomyopathy, a previous heart transplant and those born with

problems in the heart's structure.

Those with the lowest risk were people with dilated cardiomyopathy, hypertrophic cardiomyopathy, coronary artery disease and valve disease.

The study was led by Dr Eileen Hsich, an associate director of the heart transplant programme at the Cleveland Clinic.

Gender also played a role. Women with restrictive cardiomyopathy were at significantly lower risk of dying on the waiting list than men with the same disease, but at higher risk if they had coronary artery disease.

The current heart transplant allocation system is based on severity of disease. Dr Hsich said further research was needed to better define the risk factors.



For more details, see cardiomyopathy.org/transplant-list

Commonly used drugs may worsen heart failure

Commonly used medications and nutritional supplements may cause or worsen heart failure, says the American Heart Association in its first scientific statement on the issue.

The statement provides comprehensive information about drugs and "natural" remedies that may have serious unintended consequences for people with heart failure.

Heart failure patients, particularly older ones, may have five or more separate medical conditions and take seven or more prescription medications daily, often prescribed by different healthcare providers. Since many of the drugs heart failure patients are taking are prescribed for other conditions, it is crucial but

difficult for doctors to reconcile whether a medication is interacting with heart failure drugs or making heart failure worse," said Professor Robert Page, chair of the writing committee for the new statement.

Anti-inflammatory drugs, such as ibuprofen, were among the medications that can adversely affect heart failure.

Professor Page said patients should be asked during every visit about all prescription and over-the-counter medications they're taking, as well as nutritional supplements and herbs.



For more details, see cardiomyopathy.org/drugs-worsen-heart

What increases takotsubo cardiomyopathy risk?

Researchers say that people who develop takotsubo cardiomyopathy may have had higher levels of psychological distress, including illness-related anxiety.

Takotsubo cardiomyopathy (TTC) is thought to be largely a transient condition caused by emotional triggers such as bereavement, a serious accident or some other very stressful event. It can lead to heart failure and symptoms that mimic a heart attack.

With appropriate care, those affected will often make a full recovery, though some people will have lasting problems and need on-going care.

Takotsubo means octopus pot in Japanese, and the shape of the heart in TTC is said to look like such a pot.

The Dutch researchers, led by Dr L Smeijers from Tilburg University, said that little was known about the psychological background to developing the condition. So they wanted to find out more.

The team studied 56 people with the condition. The results showed they had higher levels of depressive symptoms and illness-related anxiety compared to those who were healthy.

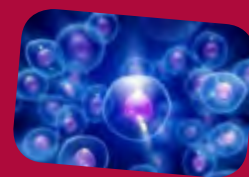
But they did not display significantly increased levels of perceived stress or general anxiety. They also showed lower levels of openness with others.



For more details, see cardiomyopathy.org/takotsubo-risk

Stem cells may help hearts

People with heart disease may be able to benefit from stem cell treatment in the future, a new small study has suggested.



Stem cells are building blocks of basic tissue.

As they grow they become more specialised and develop into specific types of tissue, for example bone cells, nerve cells or heart muscle cells.

Stem cells have already been used to prevent or treat diseases, such as leukaemia and lymphoma. But now a new study has suggested that heart tissue damaged by a heart attack can be regenerated through a stem cell treatment injected into the heart during surgery.

The study, published in the *Journal of Cardiovascular Translational Research*, followed 11 patients who, during bypass surgery, had stem cells injected into their hearts near the site of tissue scars caused by heart attacks.

The trial reported a 40% reduction in the size of scarred tissue after two years. The scarring was previously thought to be permanent and irreversible.

Angina drug for HCM?

A biotechnology company working on drugs for hypertrophic cardiomyopathy (HCM) is to begin further trials of the drug perhexiline.

The drug was developed in the 1970s to treat angina but its popularity waned because of side-effects in some patients.

Heart Metabolics, which has its headquarters in Dublin, says it will be using the drug to treat 33 people with HCM and moderate-to-severe heart failure with preserved left ventricular function.

In an earlier study, the company reported statistically significant improvements in exercise capacity, energy and quality of life.

"We expect the new study will once again demonstrate the compound's ability to safely improve the functional status of patients with HCM, and help identify optimal dosing levels," said William Daly, president and chief executive officer of Heart Metabolics.

Cardiomyopathy UK support nurse Robert Hall said: "Previous studies have been undertaken to look at the effectiveness of perhexiline in adjusting the heart's metabolism. It will be interesting to see the results of this study, particularly focussing on hypertrophic cardiomyopathy."

Drugs to treat genetic cause of disease?

A drug being developed to treat the underlying genetic cause of hypertrophic cardiomyopathy (HCM) appeared to be safe and effective in initial trials. So phase 2 trials will now go ahead, says its maker MyoKardia.



The oral drug, MYK-461, is designed to reduce excessive heart muscle contraction that occurs in HCM.

Dr Tassos Gianakakos, chief executive officer of MyoKardia, said that by targeting an underlying molecular defect causing HCM, it was hoped the treatment could restore normal heart muscle contraction and relaxation, and reduce or prevent disease progression.

Earlier this year the drug won special support in America, being granted orphan drug designation by the Food and Drug Administration. This designation, which supports the development of medicines in underserved or rare disorders, gives the company various financial benefits.

The company says it also aims to start trials next year of a drug to help reduce heart contraction problems in dilated cardiomyopathy (DCM). This drug is currently called MYK-491.

MyoKardia concentrates its work on heart disease and says it is hoping to generate a pipeline of therapies for the treatment of the two most common forms of inherited cardiomyopathy — HCM and DCM.



For more news about cardiomyopathy go to cardiomyopathy.org/new-hcm-drug

Improved ways to interpret gene tests

A study, led by experts from the University of Oxford and the Royal Brompton Hospital, has discovered better ways to interpret the significance of gene mutations in people with cardiomyopathy.

Researchers, including Professor Hugh Watkins, compared genetic data from nearly 8,000 cardiomyopathy patients with more than 60,000 samples from the general population.

Variants in genes that are typically associated with dilated cardiomyopathy (DCM), hypertrophic cardiomyopathy (HCM) and arrhythmogenic right ventricular cardiomyopathy (ARVC), were looked at.

The results, published in the journal *Genetics in Medicine*, found that rare variants in some of these genes were not any more common in the cardiomyopathy patients than the general population and so unlikely to be disease-causing.

Only eight out of 48 genes previously implicated in DCM, and two thirds of genes regularly screened for HCM, were found to be much more common among the cardiomyopathy patients. They are more likely to be disease-causing and so most relevant for genetic testing.

Cardiomyopathy UK support nurse Robert Hall said: "Doctors will be more confident about dismissing some genetic findings and be able to focus more on what gene mutations clearly cause cardiomyopathy."



For more news about cardiomyopathy go to cardiomyopathy.org/improved-gene-test

Update on our work



Chief executive
Joel Rose

In February we reported on some of the great things that we had achieved together in 2015. Nine months on and it's time for another update, particularly as so much has been going on and so much has been achieved already.

One of the things that I am especially proud of is how we have been able to influence the NHS and politicians. We have done this by using the feedback you have given us in surveys, evaluation forms and in meetings to clearly demonstrate that people with cardiomyopathy are not getting the help they need. When we talk to politicians and the NHS we are your voice. The more people who help us by sharing their experiences, the louder we can be.



I am also proud that we have been able to do this work while at the same time continuing to improve doctors' understanding of cardiomyopathy, and provide fantastic support through our helpline, information days and resources.

When we set our plans for the year we always ask ourselves whether what we do will help people with cardiomyopathy feel better able to cope or whether it will save lives. We set ourselves objectives and measure ourselves against them because we know that the work that we do is so important and that we have a duty to use the income we receive in the most effective way.

This is our commitment to you. As we do not receive any funding from the government, it is a commitment we can only meet because of the fantastic support you give us through sharing your experiences, volunteering, and funding our work.

We have some big plans for the year ahead. We want to extend our support group network, make it easier for people to access our helpline, and work with doctors and nurses so that they are better equipped to help people cope with the physical and emotional impact of cardiomyopathy. These are the things that you have told us are important to you. I want to make sure that we can deliver them.

So if you don't already, please do consider supporting us. Whether it is fundraising, volunteering, making a donation or sharing your experiences, your support will change lives.



cardiomyopathy.org/support-us

What you've helped us achieve so far

We've done so much already this year to support people affected by cardiomyopathy and help educate and inform doctors and nurses. We've grown as a charity, with new staff and volunteers joining the team – allowing us to do more than ever before. None of this would be possible without your support. Every year hundreds of you get involved; donating, fundraising and volunteering – and every single one of you makes a difference.



Providing direct support

Our nurse helpline

Our nurse helpline offers the chance for people affected by cardiomyopathy to get personal support and advice from a trained nurse. Our nurses have helped over 1,000 people so far in 2016.

Online support

Our website is a vital source of information and support for people affected by cardiomyopathy – this year we've already had over 125,000 users. Our Facebook group and online forum are a safe place for people to discuss their condition – this year they grew to a combined 4,500 active users.

Information days

This year nearly 300 people attended our five cardiomyopathy information days held in Bristol, Belfast, Glasgow, Manchester and Newcastle. 99% of the feedback rated our information days positively.

Accessible information

We work hard to provide accessible information for everyone who needs it. This year we've created a simple 'What is cardiomyopathy?' fact sheet and an online glossary for many of the terms associated with the disease.



Educating doctors and nurses

As well as our patient focussed information days, we run annual conferences for medical professionals. We want doctors to be better able to spot and diagnose cardiomyopathy, and to support their patients in the most appropriate way.

We are in regular contact with over 2,200 doctors and nurses and around 150 attended our conference earlier this year. We've also developed resources for healthcare professionals – including a simple checklist for GPs to help with cardiomyopathy diagnosis.

Contributing to research

As well as promoting opportunities to take part in research trials, we've also been busy undertaking our own research. Over the summer we sent out a survey to help us get a better understanding of how cardiomyopathy impacts on mental wellbeing.

Later this year we will be presenting the findings when we bring together leading cardiologists and mental health experts to identify how we can help more people cope with the impact of cardiomyopathy and what the NHS can do to help.



Campaigning for change

With your help we were able to make sure that the thoughts and concerns of people with cardiomyopathy were heard by politicians and policy makers. The fantastic response to our survey on diagnosis and treatment meant that we had the evidence we needed to prove that things need to change.

We continue to work with other charities to make the case for improvements in care, and made a significant contribution to the recent All Party Parliamentary Group on Heart Failure enquiry and report.

Find out how you can support our work - cardiomyopathy.org/support-us



'Tis the season

Our brand new range of Cardiomyopathy UK Christmas cards and gifts is here! Available both online and via our catalogue our seasonal range is out now.

Each pack of cards sold helps us be there for the people that need us and there's even a free gift if you spend over £20. So why not have a look today?

Visit our shop at
cardiomyopathy.org/christmas
 Or request a catalogue on
 01494 791224



Armchair fundraising

With Christmas almost upon us and gifts to be bought, did you know you can shop online and raise funds for Cardiomyopathy UK without it costing you an extra penny? In fact there are many ways you can support our work, all from the comfort of your favourite chair.



Raise funds for us when you shop online

Give as you Live lets you raise funds for us when you shop online, at no extra cost to you. Every time you shop at many favourite online stores they make a small donation to us. With over 4,000 shops participating from M&S to Amazon, it's a really easy and quick way to raise funds.



Sell your way to success with ebay

Fundraise for us when you sell an item on ebay. When you list your item you can donate some or all of your profits to us once it's sold. You can even add Gift Aid and, as a bonus from ebay, whatever you donate to us will be waived against your next listing – so donate 50% to us and ebay will knock 50% off your fees. Brilliant!



Find out more about armchair fundraising on our website at cardiomyopathy.org/armchair

#teamcardio highlights

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

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

Snowdon climb



Emyr and his daughter Gwennan scaled Mount Snowdon in May in honour of her grandfather who has dilated cardiomyopathy. They had lovely weather and raised a brilliant £500

Fundraiser Florence



Our youngest fundraiser to date, eight-month-old Florence, was helping to celebrate her family and friends completing the ten mile KM challenge walk in June – raising a fantastic £2,300.

Thank you to everyone who took part

Wing walk



Taking to the skies in August, Mandi Bird pushed herself to the limit and took on a wing walk. Reaching speeds of 130mph, it was an experience of a lifetime. We are very impressed Mandi. Thank you!

Golf tournament



The OzCup, an annual golf tournament in memory of Marc Osborne, took place in July. The organisers, pictured with Marc's parents Dave and Ann, raised an incredible £2,500 for our work

Spartan sprinter



Eva Finlayson got muddy for #teamcardio in July! She completed a Spartan sprint race in Edinburgh for Cardiomyopathy UK and enjoyed every second, raising a brilliant £300 for her hard work

Time for tea



Becki Hobden and her family organised Tina's Afternoon Tea in memory of Becki's sister-in-law Tina Wheelhouse. The day was a great success, raising an incredible £2,800. Thank you to all involved



Santa Dash - 4 December

Santa Dash

Do you believe in Santa?

Get into the festive spirit in style and join 4,000 other Santas in this year's Santa Dash. With 5K or 10K options you can walk, jog or run the route. You're even given a free Santa costume on the day! Open to ages 8+.

Location - London

When - 4 December

Distance - 5K or 10K

To register or get more information, please visit:
cardiomyopathy.org/santa-dash



Skydiving day - 25 March

Skydiving day

Take on the ultimate adrenaline challenge

If you're looking for a challenge that'll push you to your limits, there aren't many better than a tandem skydive. Jumping from 10,000ft and at speeds of up to 120mph, you can reach for the clouds for #teamcardio. Our annual skydiving day is on Saturday 25 March in Salisbury, so come and jump with us. Wherever you jump, if you raise £450 you get to jump for FREE!

Location - Salisbury

When - 25 March 2017

To register or get more information, please visit:
cardiomyopathy.org/sky-diving



Ultra challenge series

Ultra-challenge series

Walk, jog or run

This group of five unique ultra-distance events offer something different, with distances from 25K up to 100K. You set your pace and we'll give you support all the way to help you achieve your goal. Choose your challenge today; whether it be taking on the South Coast Way or marching along the stunning Cotswold Way, there's something for everyone.

To register or get more information, please visit:
cardiomyopathy.org/ultra-challenge



Silverstone - 12 March

Silverstone half marathon

A half marathon like no other

This unique half marathon is back again for 2017. On Sunday 12 March take to the tarmac in your trainers instead of on wheels and experience the world famous Silverstone track for yourself. Come and be part of #teamcardio.

Location - Silverstone

When - 12 March 2017

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



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!

London Marathon

23 April 2017



Did you enter the ballot for the London Marathon 2017? If you were lucky enough to get a place, we'd love you to run for us on 23 April and be part of #teamcardio. To apply for one of our charity places, please visit our website. There's still time!

To register or get more information, please visit:

cardiomyopathy.org/london-marathon

Ride London

28-30 July 2017



The famous 100 mile cycle from the Queen Elizabeth Olympic Park, through the closed roads of London and into the Surrey Hills will test any cyclist. Next year will be the fifth Prudential Ride London, a world-class festival of cycling attracting the biggest names in the sport. Come and join the hundreds of people taking on the route on 28 – 30 July and ride for #teamcardio.

To register or get more information, please visit:

cardiomyopathy.org/ride-london

Dates for your diary

October

Saturday 8 October, 3pm-5 pm

North London Support Group

Finchley Memorial Hospital, Granville Road, London N12 0JE.

Percy Watungwa, clinical lead of the heart failure service, St Pancras Hospital, will host a discussion on cardiomyopathy and heart failure, and common symptoms of heart failure and their management. For details contact Jane Barnett on 0208 343 1940 or email jane@email58.co.uk

Thursday 15 October, 2pm-4pm

Surrey Support Group

First meeting of this new group at the Post Graduate Medical Centre, St Peter's Hospital, Guildford Road, Chertsey KT16 0PZ

Main speakers consultant cardiologist Dr Ian Beeton, St Peter's Hospital, and Cardiomyopathy UK support nurse Robert Hall. For details contact Tracey Bradshaw, email tracey.bradshaw@asph.nhs.uk

Thursday 20 October, 7pm

South London Support Group

Crypt Meeting Room, St John's Church, Waterloo Road, London, SE1 8TY. Speaker to be announced. For more details see enquiries panel below

Saturday 22 October, 2pm-5pm

Wiltshire Support Group

Sarum College, 19 The Close, Salisbury SP1 2EE

Main speakers Cardiomyopathy UK support nurse Robert Hall and Lucy Ryan, who had a heart transplant as a child 23 years ago. For details, Gilbert Wheeler on 07484 606811 or wheelers11@live.com

Saturday 22 October, 2pm-4pm

Cheshire and Merseyside Support Group

Outpatient Department, Liverpool Heart

and Chest Hospital, Thomas Drive, Liverpool L14 3PE

The hospital's patient and family experience safeguarding lead nurse Joanne Shaw and support group member Sylvia Walker on her role with the Broad Green Heart Support Network.

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

Tuesday 25 October, 2pm

Cornwall Support Group

Inn for All Seasons, Treleigh, Redruth TR16 4AP

The speaker is Jo Davies, clinical nurse specialist (team lead) from the heart function service at Royal Cornwall Hospitals Trust.

For more details contact Eric on 01736 351439

Saturday 29 October, 9.30am

Kent Support Group

Mercure Great Danes Hotel, Ashford Road, Hollingbourne, nr Maidstone, ME17 1RE

Dr Matthew Daniels, principal investigator at the BHF Oxbridge Centre of Regenerative Medicine at Oxford University, on gene therapy and Cardiomyopathy UK support nurse Robert Hall on treatment developments in cardiomyopathy. For details, contact Colin McVittie, 07973 412775 or email cardiomyopathykent@gmail.com

November

Saturday 12 November 9am-4.30pm

Cardiomyopathy conference

Royal National Hotel, Bedford Way, Russell Square, London WC1H 0DG

Expert speakers on cardiomyopathy and living well with the condition.

For more details see Page 3 or cardiomyopathy.org/cardio2016

Sunday 20 November, 12-3pm

West Scotland Support Group

Boardroom, Glasgow Royal Infirmary. Speaker to be confirmed. For more details contact Bob McConnachie on 07710 789581 or email mess@talk21.com

Saturday 26 November, 2pm-4pm

North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle. Pharmacist Eimear Maloy will be talking about medicines and cardiomyopathy. For details contact Cathy Stark, 0191 276 6399 or Susan Saunders, suze.saunders@btinternet.com

December

Saturday, 10 December

ARVC Support Group

Time and place to be confirmed. For more details, see enquiries panel below

Sunday 18 December, 2pm

Cheshire and Merseyside Support Group

Mince pies and mulled wine at 8 Kenwick Close, Ellesmere Port, CH66 2HY. For details, Julie Rees on 07949 241026 or julierees65@aol.co.uk

Tuesday 20 December, noon

Cornwall Support Group

Christmas lunch at the Inn for All Seasons, Treleigh, Redruth TR16 4AP. Places need to be booked.

For more details contact Eric on 01736 351439

Enquiries



If you have questions about

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

please phone us on **01494 791224**, email info@cardiomyopathy.org or visit our website at cardiomyopathy.org

Tell us

your story

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

If you would like to share your story with other people who are affected by cardiomyopathy, contact My Life editor Sarah Dennis at sarah.dennis@cardiomyopathy.org or telephone **01494 791224**.



Knowing more, living better

2016 Cardiomyopathy UK National conference

Saturday 12 November 2016

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

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