

my life

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

Issue 07 | Autumn 2016

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**'Working round my heart transplant
gave me more to focus on'**

Karen (centre right) talks about how cardiomyopathy has affected her life

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.



Contact us

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Website cardiomyopathy.org
Helpline **0800 0181 024**
(free from a UK landline)
Email info@cardiomyopathy.org

Like us on Facebook
facebook.com/cardiomypathyuk

Follow us on Twitter
[@cardiomypathy](https://twitter.com/cardiomypathy)

Join our Facebook group
(closed privacy settings)
facebook.com/groups/cardiomypathyuk

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

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Improving lives



Chair of trustees
Alison Fielding

At Cardiomyopathy UK, every trustee either has cardiomyopathy or has a family member or close friend with the condition.

We know that while cardiomyopathy is difficult enough to manage, the impact on our lives in terms of employment and money matters is often equally challenging.

So our new national conference for families in November in London will have workshops on issues as diverse as your employment rights, coping with the emotional aspects of cardiomyopathy, first aid and getting the best care from the NHS. It will also include the popular medical sessions from leading cardiomyopathy doctors. We hope people will come from all over the UK and make it our biggest event.

The charity has been rocked by the loss of a trustee's young daughter and the challenges of another trustee's granddaughter waiting for a new heart. This increases our resolve that diagnosis and care improves.

We are looking for a new trustee from either Scotland or Wales. If you think you can bring skills and passion to the board, email me on chair@cardiomyopathy.org

Sarah's our new children's nurse

Sarah is providing information and support to parents of children affected by cardiomyopathy. You can reach her through our helpline (0800 0181 024), our facebook group, or at sarah.regan@cardiomyopathy.org

Sarah Regan, a nurse with extensive experience of treating children with cardiomyopathy, has joined the charity as our first children's cardiomyopathy support nurse.

Sarah, who has spent 20 years as a children's cardiomyopathy nurse specialist at Great Ormond Street Hospital (GOSH) in London, is providing information and support to parents through our telephone helpline, our online helpdesk, our facebook group and our forum. She will also help develop our children's services, including helping at an annual event for young people.

She joins our established team of nurses who support adults with cardiomyopathy and their families, but Sarah will respond to parents of affected children who seek our help.

She will also develop cardiomyopathy information for parents and young people, including on our website, in My Life and other media, and build our links with children's cardiomyopathy teams around the country. As well as working part-time for Cardiomyopathy UK, Sarah will continue in her part-time role at GOSH.

Cardiomyopathy UK chief executive Joel Rose said: "Having Sarah on board means we can do much more for parents of young people with cardiomyopathy.

"We wanted to be sure that parents can get the support and information they



need to better understand cardiomyopathy, to support their children and feel they, as a family, can cope.

"Sarah comes with a huge amount of experience as a specialist nurse at GOSH working with young people with cardiomyopathy, and we are delighted to have her on the team."

More practical help



Chief executive
Joel Rose

In this edition we have some excellent articles on coping with cardiomyopathy at work. This subject often comes up and is one of many aspects of living with cardiomyopathy that we want to do more to help with. Dealing with these practical issues can help people feel more on top of their cardiomyopathy.

So later this year at our first national conference for families we will be running sessions to give support and advice on some of the practical and emotional aspects of living with cardiomyopathy along with the usual expert clinical information. I do hope that we can see you there.

If you have any questions about the charity and our work, call me on 01494 791224 or email me at joel.rose@cardiomyopathy.org

New style cardiomyopathy conference for affected families

Cardiomyopathy UK is launching a new-look cardiomyopathy conference in London in November

A new type of cardiomyopathy conference for families affected by the disease is being held in London in November.

The day will be a flagship event for the charity and replace the London information day, which has been held every year in September.

The conference, on Saturday, 12 November at the Royal National Hotel in Bedford Way, will not only provide families with lots of medical information but also include sessions to help people live more successfully with the disease. These sessions will look at the psychological effects of cardiomyopathy, and focus on developing coping strategies and emotional well-being.

Information manager Rona Eade said: "We want to run sessions so everyone who attends will find something of relevance and interest. Families who come will be able to meet expert speakers and ask questions, share experiences with

others affected by cardiomyopathy, and help develop a sense of community.

"We want people to leave feeling empowered, less isolated, in control of their condition and more connected to us."

The programme will include specialised sessions on more types of cardiomyopathy – not only hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy but also restrictive, peripartum and left ventricular noncompaction.

Some people with the various conditions will speak about their experiences. There will also be a session on financial issues.

A £20 per person registration fee for the conference will include a self-service lunch, and mid-morning and afternoon tea and coffee with pastries and biscuits.

For more information about the event, see cardiomyopathy.org/cardio2016 or call us on 01494 791224. You can book online or request a registration form.

Getting back to work



Robert Hall | cardiomyopathy support nurse,
Cardiomyopathy UK

Robert talks about the issues to consider when you are returning to work after a spell of ill health

Returning to work after a period of absence due to cardiomyopathy can be a daunting prospect for some.

You may have been recently diagnosed with the condition, or have been off work because of a spell of poor health.

The diagnosis itself, or the severity and type of symptoms, may make you doubt if you will ever be able to return to work. But it's important not to rush a decision.

Once you are established on the correct treatments you may feel a lot better and be keen to get back to as normal a life as possible.

Many people will be able to return to the job they have been doing. But in some cases this may not be possible. If you are an airline pilot or heavy goods vehicle driver, for example, you may not be able to continue in your current job. Other jobs may be too physically demanding for you.

So some people may need to change their career and possibly retrain. This will obviously cause major concerns about financial security, the family's future and quality of life.

Making the decision and then returning to work is a positive step and can be part of the recovery process and help you regain a level of normality.

Your cardiologist will help you decide when is the right time for you to return to work. He or she will also be able to discuss with you which parts of your job you may be able to fulfil, which parts may be difficult and whether you will need to reduce your working hours, at least initially.

It can be helpful to discuss these issues and reasonable changes to your working conditions with your employer before you return.

If you work for a large company, it may have an occupational health department and an advisor who can assist you with this. For example, there may be opportunities to change shift patterns, negotiate time off for medical appointments and change heavy manual work to lighter duties.

It may be beneficial to negotiate a phased return to work with your employer as this gives some flexibility and helps you more gently re-establish a work routine.

If your work involves driving, it is important to be sure of any driving restrictions that might be relevant. Discuss this with your cardiologist and check the DVLA website gov.uk/driving-medical-conditions

During your period of absence from work you may find differences in the structure and hierarchy. New people may have joined, familiar processes may have changed, and new procedures may have been introduced. You may also find that you are treated differently if colleagues know you have a heart problem. These issues can affect your confidence in the early stages. So it is important to take time to adjust.

How much you tell your colleagues about your cardiomyopathy is your personal decision. If you do decide to discuss it, bear in mind people's knowledge and understanding may be limited.

So talk about the things you can do as much as any negatives. People with cardiomyopathy can and do successfully return to work.

You may find that initially fatigue and your ability to concentrate prevent you from reaching your previous level of performance. But give yourself time to settle down.

Try to ensure you keep to your contracted hours and take your allotted annual leave. Maintaining a good work-life balance will be very important.

If you continue to struggle, have an open and honest discussion with your employer. You may need to discuss reducing your hours. In these circumstances you may be eligible for benefits support. See entitledto.co.uk and cardiomyopathy.org/finances/benefits

Further advice can be obtained from citizensadvice.org.uk


For details about employment law, see Pages 8-9.

Reasonable adjustments help

Occupational health advisor and support volunteer Elaine Boaler says:



Reasonable adjustments in your working role can include major and minor changes to working practices (temporary or permanent) and can be of significant benefit, enabling people with cardiomyopathy to remain in work and their employers to benefit from their contribution. See Robert's main article (left) for examples. Discussing your situation with your employer can provide the opportunity for occupational health advice and a fair and supportive medical assessment. If you feel you are being discriminated against at work talk to your manager or human resources representative. Ask about referral to the occupational health department if there is one. An occupational health advisor or physician would be able to advise the employer. You could also find information and support from your trade union if you have one.

A portrait of Anne-Marie Cole, a woman with long, wavy reddish-brown hair and bangs, smiling warmly at the camera. She is wearing a dark blue top. The background is a soft, out-of-focus grey.

Anne-Marie is also a support volunteer for Cardiomyopathy UK

I'm really glad I pursued a career in nursing, but it's been a challenge

Anne-Marie Cole's story

Anne-Marie, who has hypertrophic cardiomyopathy and is a support volunteer, has become a children's nurse, even though a doctor told her it would be too demanding for her.

I was diagnosed with hypertrophic cardiomyopathy (HCM) when I was two but only fully understood what the condition was when I was 14 and needed to have an internal defibrillator (ICD) fitted.

I spent my childhood under the care of Great Ormond Street Hospital for Children in London and I soon came to realise I wanted to be a children's nurse.

One day, during my teens, I mentioned at my outpatients' appointment that I wanted to go to university to study nursing and I wanted to become a cardiac clinical nurse specialist.

I was told it wasn't advisable as it was a highly demanding job. The hours were really long, I would be on my feet all day, and I wouldn't be able to hold the job down for long. However, after much consideration I still went ahead with the plan.

I got a place on a nursing course at Sheffield Hallam University. During my first hospital placement, I was exhausted after every shift. I was not used to 12 hours of work at a time, but I soon got used to it and it became the norm.

Trying to study as well as doing my work placements was hard at times, especially when it came to writing my dissertation. There were countless times when I wanted to throw my laptop out of the window, but I got through it with help from family and friends.

After three years at Sheffield Hallam, I was a fully qualified paediatric nurse. In my first role at a paediatric hospital in Brighton, I worked in the high dependency unit. Even though it was a highly demanding job, I could always take all of my breaks and I never suffered from any symptoms.

However, during this time my ICD battery warning alarm went off. I was nervous about everyone hearing it but luckily it was so noisy on the ward only I could hear it. I told my ward manager that I had a cardiac condition and had to have my ICD changed. Everyone was very supportive and gave me all the time off that I needed and then allocated me the easiest workload when I got back.

Things soon changed when I changed jobs to a day care surgery unit. I began to get a lot of extra heart beats (ectopic beats) and

was admitted to Pembury Hospital for the night. I struggled to walk down the road without getting short of breath and was extremely tired. Even though I now had a shorter working week than I was used to – only three 12.5 hour days plus one four hour shift each week – I wanted to be able to do the job to the best of my ability.

Two months in I had to have my beta-blockers increased. For a time I was having some irregular heart rhythms and spells of feeling dizzy. One of the sisters there knew about my condition and my ICD and was extremely supportive if I had any problems.

One weekend I was continuously having ectopics and feeling weak and lightheaded. I went in on the Monday and told my ward manager that I wasn't sure how long I was going to last but I wanted to stay. She listened to me, felt my pulse and told me to go home and come back the next morning when it was only a half day shift.

After being at the day care unit for just under a year I wanted a new challenge. So I got a job on a cardiac and respiratory children's ward in London. I didn't realise how busy that environment would be. I found it extremely exhausting and even now two years on I come home shattered. The nursing staff at the occupational health department have been amazing. Soon after I started I had to have a month off for personal reasons. They asked me if I would prefer not to work night shifts and just do day shifts, but I said no.

Some days I find myself struggling. I work 12.5 hour days with only a 45 minute lunch break and sometimes it's too busy to take that. I commute by train, leaving my flat at 5.45am and getting home at 10pm.

Recently my beta-blockers have been reduced as I am more active. This has meant I'm less tired. I have the normal symptoms of HCM but luckily my medications are managing them at the moment. I know when it's time to stop and take it easy, but having this condition allows me to relate more to the children I look after.

I'm now a band five staff nurse and hope soon to apply for my band 6 in charge role. My occupational health team are always there if I need anything. I have only ever been to them once – for an unrelated reason – in my current role, but they always ask how I'm doing and whether any additional adjustments are needed.

I'm really glad I pursued my career in nursing. There has been a lot of happy, sad and challenging times but I could never think of doing anything else.



Karen Flavell's story

Karen, who had a heart transplant two years ago because of her hypertrophic cardiomyopathy, says she plans to honour her donor by leading life to the full.

I had symptoms of hypertrophic cardiomyopathy (HCM) at 16, but was given a clean bill of health.

I was finally told I had HCM, very casually, when I was pregnant with our first daughter Katie but wasn't told it was genetic. I had our second child Hayley two years later.

It was only when several members of our extended family died suddenly, including a cousin who was only 24, that I discovered it was genetic. I contacted Cardiomyopathy UK and it was wonderful to talk to someone who understood my concerns and issues for the first time.

Over the next few years I was very lucky to be referred to London to Professor William McKenna's clinic at St George's Hospital and the girls to Great Ormond Street Hospital. I was given medication for the first time.

I was busy running toddler groups. I then volunteered in school and joined the PTA, becoming treasurer and organising events.

In 2001 I had my first internal defibrillator (ICD) fitted which gave me more confidence. So I enrolled on an IT course and went to college to train as a higher education teacher. I qualified as an IT tutor, a job that fitted around the girls' school day. The job gave me a focus away from home and was a distraction from my health.

Unfortunately travelling between venues and carrying a box full of work made me struggle with breathlessness. My medical care was transferred to Professor Perry Elliot's excellent team at the Heart Hospital (now Barts). He explained that, unusually for an HCM patient, my heart was deteriorating and I might need a transplant.

In 2008 I got a job with Wolverhampton City Council's education department for 25 hours a week in term time. It was mainly desk work but involved some school visits. My colleagues were very understanding and made adjustments for me when necessary.

As my condition became more unpredictable, I adapted my lifestyle so I could rest when necessary. I was given an office on the ground floor, more flexible hours and a disabled car parking space.

The girls were growing up and going away to university. So I felt it was extremely important that I continued to work. It was also my motivation to get up in the morning. At work I could be useful

whereas at home I would be sitting around thinking about all the jobs I should be doing without the energy to do them.

By the end of 2012 my biventricular ICD and medication were no longer effective and I was referred to Papworth Hospital for a transplant assessment. Throughout 2013 I was at risk of redundancy. Like many other councils, Wolverhampton was making job cuts. My colleagues and I started to discuss how we could continue peer mentoring and personal development training in schools. This was an exciting time and took my mind off the pending transplant.

At my third transplant assessment I was strongly advised to go on the waiting list. But I first went to see Katie, who was in France, and we had a wonderful time. I joined the list on my return in April 2014.

The same month I left work and set up WiderLearning Ltd with my colleague Paul. He was fully aware of my health issues but we both felt a new venture was the right thing for us and we expected I'd be waiting around 12 to 18 months for a transplant. The new office had a lift and a disabled parking space and I has the flexibility to work from home.

Although I was working the same hours there was less stress and I could work around the bad days. All was going well. Then in May I got the call from Papworth. The operation took all day; it was a very stressful day for everyone (except me!). After three days in intensive care I was up and about.

With modern technology and hospital Wi-Fi, I could finish off some work loose ends and was reading my work emails to keep up-to-date. This gave me something else to concentrate on.

I continued to improve and was discharged after only two and a half weeks with a very large bag of tablets and a list of instructions. The care and support I received from staff was fabulous. I'm convinced continuing to work contributed to a speedier recovery.

As well as walking round the garden until I had the confidence to go out, I continued to use an exercise bike. I started to do the company accounts at home. I worked from home for the rest of the summer, gradually building up my hours at work during the autumn.

My family and friends have given me the support and confidence to continue to work. I am fitter and exercising more than I have ever been able to do. I still ride my exercise bike and walk, but I also go to a keep fit class, play badminton and have started ballroom dancing with my husband Mark.

I feel extremely lucky to have been given the 'gift of life'. So I intend to honour my donor by leading life to the full. I think of my donor and their family every day and I will never be able to express how grateful I am to them.

• Karen is on the front page with (from left) Katie, Mark and Hayley



Colin McVittie's story

Colin, who was diagnosed with cardiomyopathy 11 years ago, works as a sales agent and also has his own light haulage business. He says his jobs give him time to reflect on life while being productive.

When I was diagnosed in 2005 with hypertrophic cardiomyopathy (HCM) I was self-employed as a sales agent selling service related chemicals to the motor trade. This was a successful venture that enabled me to work flexible hours and be in control of my life. I had had symptoms well before that and had designed a lifestyle I could manage, or so I thought.

Soon after my mother was diagnosed with cancer and passed away. I lost my business as the main supplier had sold out and the new people had different ideas. I split with a long term partner at about the same time and had to sell my house, being left with next to nothing. This was a tough period.

I decided to buy a franchise with the little money I had left but their promises weren't met and that venture failed very quickly. So I tried to set up as a sales agent again. My HCM symptoms weren't too bad so I carried on, managing myself carefully. However, I just couldn't settle with the right company and products. My father was diagnosed with dementia and he also passed away. This left me in a position where I wasn't in the frame of mind to do sales.

So one day I got out my heavy goods (HGV) licence from my RAF days. When I went for my medical the doctor asked why I wanted to go driving. I shared my story and he told me of someone who had done the same. Until that moment I was wondering if I was doing the right thing. Now I knew that I was. I registered with a local agency and started doing a few van deliveries moving up onto the larger trucks quickly.

During the next 12 months the DVLA was deciding whether I was fit to drive larger trucks, with its final decision being not. This was yet again a bit of a kicking but I cannot say that I was surprised.

So I decided to set up as a sales trainer. But in the meantime I met a guy who owned a garage makeover company. I got on very well with him and became a sales agent for his company Garagetek. He supplies the leads and I see garage conversions through to completion. It's a job I enjoy with little pressure.

This wasn't keeping me busy enough, though. So last year I bought a van and set up in light haulage. I select the loads I take and where I go. It suits me as I can take days off when I want and select my own hours.

In October I had one of my heart valves replaced which meant taking a few months off but I went back the odd day and was selective about what I did. Now I'm a lot better than I've been in years so don't need to be as selective. Self employment suits me. My boss is very flexible and understands! That is difficult to find in the normal work place.

Support volunteers

Anne-Marie Cole and Colin McVittie are among Cardiomyopathy UK's support volunteers who provide one-to-one support to others with cardiomyopathy.

There are more than 60 people on our support volunteer network.

They include people with different types of cardiomyopathy who have had different treatments.

Partners of affected people and parents of affected children are also on the network. To speak to a support volunteer, call

Anne Foster on 01494

791224 or email her at

anne.foster@cardiomyopathy.org



Support groups

Colin McVittie also runs our Kent Cardiomyopathy Support Group, one of a series of groups around the country supporting families affected by cardiomyopathy. Colin's group

meets periodically on Saturday mornings

at the Mercure Maidstone Great Danes Hotel at Hollingbourne near Maidstone.

We have support groups around the country run by people affected by the condition.

To find out more see cardiomyopathy.org/shared-experiences/support-groups



Personal experiences

People giving their experiences of cardiomyopathy will be a focus of our new style cardiomyopathy

conference in November.

Supporters who have had the condition for many years, including trustee Tina Amiss

(pictured), will also talk about what matters to them.

For more details of the conference, see Page 3



Working rights for people



Ivor Adair | Cardiomyopathy UK trustee and principal lawyer at Slater & Gordon (UK) LLP

Ivor talks about the Equality Act 2010 and how it can help workers with cardiomyopathy

A great many people living with cardiomyopathy are also working. Difficulties over sickness leave, performance issues and requests for adjustments to procedures or job roles can arise and can be stressful.

Many people with cardiomyopathy may well have valuable rights and important protections in equality law.

The Equality Act 2010 prohibits different forms of disability discrimination in the workplace and puts employers under a duty to make reasonable adjustments for disabled employees and job applicants who are placed at a substantial disadvantage because of their disabilities.

The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. It sets out the different ways in which it is unlawful to treat someone

Disability

In many cases there will be little doubt that a person suffering from cardiomyopathy is disabled.

But in other cases the issue may not be so clear cut and some employers will simply refuse to accept the employee or job applicant is disabled (even in the course of an employment tribunal claim against them). In these cases the person suffering from cardiomyopathy will have the burden of proving they are disabled.

The applicable test is not associated with an assessment of disability benefits or an issue of capability for the purposes of a health insurance policy. The relevant definition is set out in section six of the Equality Act.

This provides:

"A person (P) has a disability if P has a physical or mental impairment, and the impairment has a substantial and long-term adverse effect on his ability to carry out normal day-to-day activities".

Where the "physical impairment" is cardiomyopathy, there may be

considerable focus on whether the symptoms present a substantial adverse effect on the individual's ability to carry out "normal day-to-day activities".

So what are normal day-to-day activities? There is guidance to the Equality Act which states:

"In general, day-to-day activities are things people do on a regular or daily basis, and examples include shopping, reading and writing, having a conversation or using the telephone, watching television, getting washed and dressed, preparing and eating food, carrying out household tasks, walking and travelling by various forms of transport, and taking part in social activities."

Helpfully the courts have determined that some work related activities can be normal day-to-day activities, such as standing for long periods or lifting heavy goods.

So where the normal things a person does in their life or even professional life is adversely impacted by the condition to a more than trivial degree, is it possible that they may be disabled.

Expert legal advice is required to make a clear assessment however and very often medical evidence is required from a cardiologist who has been carefully instructed to address the various aspects of the legal test and the patient's condition and circumstances.

For some people seriously affected by cardiomyopathy, there will be little doubt they are disabled under the act, but in other cases it is not so clear.

Types of discrimination

Under the Equality Act it is unlawful for an employer to do the following:

- Directly discriminate by treating a job applicant or employee less favourably because of disability
- Discriminate by treating a job applicant or employee unfavourably



with a heart condition

because of something arising in consequence of their disability without objective justification. Something which arises in consequence of a cardiomyopathy disability could be the need to take regular hospital visits, take rest breaks or be on extended sickness absence for a period. Dismissing someone for these reasons can give rise to claims

- Indirectly discriminate by applying a provision, criterion or practice that disadvantages job applicants or employees with a shared disability without objectively justifying that treatment
- Fail to comply with a duty to make reasonable adjustments where a disabled job applicant or employee is placed at a substantial disadvantage. This often arises in the context of an employee on long term sickness absence or where there are issues with changes to duties or when returning to work from a period of sickness. It is important to be able to demonstrate that the employer knew or ought to have known both that the employee was disabled and that his disability was liable to disadvantage him substantially. So in some cases there can be serious disadvantages to not being very clear and open about the impact of the condition and any treatment or medication
- Subject a job applicant or employee to harassment related to disability
- Victimise a job applicant or employee because they have made or intend to make a disability discrimination complaint
- Ask job applicants pre-employment health questions other than for certain prescribed reasons. Such questions will not be prohibited where the questions are necessary for the purpose of, for example: establishing if the applicant will be able to comply with a requirement to undergo an assessment or establishing if a duty

For more details
about the Equality Act
see
[gov.uk/guidance/
equality-act-2010-
guidance](http://gov.uk/guidance/equality-act-2010-guidance)

to make reasonable adjustments is (or will be) imposed in relation to the applicant in connection with a requirement to undergo an assessment, or establishing if the applicant will be able to carry out a function that is intrinsic to the work concerned or monitoring diversity.

If there is a breach of the Equality Act the employee or applicant may bring a claim in the employment tribunal seeking a declaration of discrimination and compensation to include losses for injury to feelings and financial losses.

There are very strict time limits for doing so. However, in general, this is three months less one day from the act complained of plus a mandatory ACAS (the Advisory, Conciliation and Arbitration Service) early conciliation process.

Very often the issue of time limits is complex and it is important to promptly take specialist legal advice.



Further information

- Ivor will be talking about employment rights and how equality law can help people with cardiomyopathy at our national cardiomyopathy conference in London on Saturday, 12 November.

He'll be presenting a workshop on financial issues, including state benefits, with independent financial adviser Bill Bartholomew and welfare rights specialist Osian Evans, both supporters of the charity. We are often asked about these topics by families affected by cardiomyopathy.

For more information about the conference, see Page 3 or go to cardiomyopathy.org/cardio2016

- ACAS is dedicated to preventing and resolving employment disputes. It provides free and impartial information and advice to employers and employees. See acas.org.uk or call 0300 123 1100.

Most people with heart failure return to work



The younger you are, the more likely you are to return to work after first being in hospital with heart failure, a new study has suggested.

The study from Denmark looked at almost 12,000 people under 60 who were in work when they were admitted to hospital.

More than eight in ten of those aged 18 to 30 re-entered the workforce within a year, whereas only 64 per cent of the 51-60 age group did.

Overall a quarter did not return to work in the first year.

The figures were reported at the European Society of Cardiology Heart Failure Conference.

Lead author Dr Rasmus Rørth, from the Rigshospitalet-Copenhagen University Hospital, said the research showed a lot about heart failure patients' quality of life and ability to get on with life.

"It would be nice if we could now find a way to get more back to work, for example with workday flexibility," he said.

The study looked at people with heart failure who were in hospital between 1997 and 2012. A year after leaving hospital more than 11,000 were alive.

A total of 8,040 had gone back to their jobs, 2,981 had not and 54 had emigrated. More of those who returned to work were men, and more had a higher education.

Dr Rørth said some of the findings weren't surprising because other health problems occur less in younger patients, and having a higher education often resulted in a job being less physically demanding.

"Returning to work is important financially, as a marker of functional status, and for self-esteem in patients with chronic illness," said the researchers in their poster presentation at the congress.

He added that inability to return to work should perhaps be included as an additional quality measure in the care of heart failure.

He said plans to delve deeper into the data could see if people who returned to work were healthier and less likely to be depressed than those who don't.

Research to study effects of heart failure drug withdrawal

Researchers are looking for a group of people with dilated cardiomyopathy whose heart function has now recovered to normal.

They are seeking 50 volunteers who are still on their recommended heart medicines (such as beta-blockers, ACE inhibitors and water pills) and would be interested in taking part in a trial at the Royal Brompton Hospital in London.

The research team wants to explore whether it is safe to stop heart failure medications in people who have recovered heart function. If the medicines can be stopped without the problem coming back, this suggests that the heart problem may have abated.

'In this study, the volunteers will have their heart medicines gradually withdrawn in a structured, and closely supervised way', said clinical research fellow Dr Brian Halliday. "We will use MRI heart scans, exercise tests and blood tests to assess heart function. If there are any early signs of a reduction in heart function, medication will be restarted immediately," he said.

The volunteers will be closely monitored by a team of doctors and nurses over six months. Initially only half of the volunteers will have their medication withdrawn. The other half will remain on their usual treatment. After six months, if withdrawal of treatment has been successful, this half of patients will also be given the opportunity to undergo therapy withdrawal.

Chief investigator Dr Sanjay Prasad, a consultant cardiologist, said: "When patients recover their heart function they often ask if they can stop taking their medications. Currently there is little research for

doctors to base their answer on and no consensus about the best approach. Patients, therefore, often get a variety of answers from different doctors. Some doctors stop treatment as soon as there is recovery, while others advise their patients to continue on medication for many years. We hope our study will answer this important question.

"We will go on to study factors that predict sustained heart function recovery including a person's genetic make-up and specialised measurements from the MRI scans. If the study demonstrates that it is safe and feasible for many patients to stop medication, we will go on to perform a larger study looking at the risks and benefits of withdrawing heart failure medications in the long term".

The study has ethics and Medicines and Healthcare Products Regulatory Agency (MHRA) approval. The MHRA is the government agency responsible for ensuring that medicines and medical devices work, and are acceptably safe. The study is also supported by the British Heart Foundation.

If you would like to know more about the study, email b.halliday@rbht.nhs.uk or call him on 0207 3528121 ext 2928.

To be eligible

- Heart function must have been previously reduced. Left ventricular ejection fraction (LVEF) – a measure of the heart's pumping power – must have been less than 40% and the heart enlarged
- Heart function must now have returned to normal: LVEF greater than 50% with a normal sized heart
- Volunteers must still be on treatment for their (recovered) cardiomyopathy

Gilbert's special award

Long time supporter Gilbert Wheeler (pictured right) has won a special award for working with health organisations to promote cardiomyopathy patient involvement and empowerment.

Gilbert, who has hypertrophic cardiomyopathy and has run our Wiltshire Cardiomyopathy Support Group, accepted the prize for his work with Cardiomyopathy UK.

The award was given at a three-day British Cardiovascular Society conference where he spoke about living with cardiomyopathy.

He was presented with a trophy and £300 bursary for patient and clinician partnership in memory of David Geldard MBE, a former president of the UK Cardiovascular Care Partnership (CCP).



Q&A

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



Q: I've seen that the new heart failure drug Entresto has been approved by NICE for some patients with heart failure. How do I get it prescribed for me?

A: Entresto is a new drug that combines an existing drug – valsartan (an angiotensin receptor blocker) – with sacubitril (a neutral endopeptidase-inhibitor). In a recent study (PARADIGM-HF) the impact of the drug on death and hospital admission was compared to enalapril in patients with advanced heart failure. The main result was a reduction in death from a cardiovascular cause or a heart failure hospital admission from 27% to 22%. Entresto is now recommended by the European Society of Cardiology and NICE for use in people with severe symptomatic heart failure. It is important to realise, however, that ACE inhibitors alone or in combination with beta-blockers and spironolactone are extremely effective in reducing mortality and in improving symptoms, and remain the first line therapy for most people with heart failure. If you would like to know whether it is likely you could benefit from a change in treatment, I strongly advise a discussion with your heart specialist first.

Q: How much, if at all, does having a positive attitude to your cardiomyopathy and life help your prognosis?

A: Many people with chronic medical conditions understandably experience depression and anxiety. Evidence that they have a poorer prognosis than individuals who are not clinically depressed is relatively weak. Nevertheless, with respect to one's general approach to life, a positive attitude is likely to mean that you adapt to your condition more rapidly and effectively, and that you will be able to take a more active role in the long-term management of your cardiomyopathy.

Q: I have hypertrophic cardiomyopathy with obstruction. I've been reading a lot about the septal alcohol ablation versus myectomy debate for treating it. I'm 30. Would you recommend a septal ablation for me or a myectomy? I'm less keen on having the latter.

A: Many people with hypertrophic cardiomyopathy develop symptoms due to obstruction of the outflow from the main pumping chamber of the heart (left ventricle). This is caused by contact between the inlet valve of the left ventricle – the mitral valve – and the wall between the left and right ventricles (the septum). Most people with obstruction can be managed using medication, but a few require interventions that reduce the thickness of the septum. The surgical method (myectomy) has been used for decades and in experienced centres it has a low operative risk and good long-term outcomes. The major alternative is alcohol ablation in which alcohol is injected through a catheter inserted into the heart from an artery in the leg or arm in a similar way to a coronary angiogram. While there continues to be some debate about the relative risks and benefits of the two techniques, the key point is that individual patients need to be carefully assessed by expert teams as some people are unsuitable for one or other technique. In some individuals, surgery is clearly more effective, in spite of its greater risk.

Q: I have dilated cardiomyopathy (DCM) and have seen that metabolic modulators like trimetazidine may help. Why is this, and should I be on one?

A: Several studies have suggested that the heart's ability to generate and use the energy required for normal pumping action is impaired in DCM. Trimetazidine is a drug used to treat angina that works by

improving the energy balance within the heart muscle cells. Trials are underway with this and similar drugs to determine whether they improve symptoms and function of heart muscle.

Q: Four years ago my husband's GP picked up that he had a heart murmur. After tests, our local hospital said they thought he had hypertrophic cardiomyopathy (HCM) and suggested he had further tests. We then moved and our regional hospital did lots more tests and confirmed he had the disease. They said our family should be tested. They were but were all given the all clear at that time. Now we have moved again and our local hospital says they think he has furred up arteries and never had HCM. What are we to think and what do you recommend we do?

A: Whenever there are conflicting diagnoses, it is important to understand the reasons behind different interpretations of the same clinical information. Coronary disease (furred up arteries) and HCM can co-exist and the diagnoses are not mutually exclusive. I suggest that you make further enquiries about the basis of the original diagnosis of HCM and ask your specialist to explain why they no longer think this is correct.

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 standard of care for people with chronic heart failure

NICE has updated its quality standard for treating people with long-standing (chronic) heart failure, including those with cardiomyopathy.

For the first time the standard includes the need for heart care teams to see patients again within two weeks of having their drug treatment changed, and better access for patients to cardiac rehabilitation both inside and outside working hours.



The standard, which covers the assessment, diagnosis and care of chronic heart failure (CHF) in adults, outlines high priority areas for better patient care in the NHS.

NICE, the National Institute for Health and Care Excellence, says that CHF medication can cause significant side effects, including dehydration, low blood pressure, a low heart rate and kidney problems. Some drugs may initially make heart failure symptoms worse. So when the dose or type of medication is changed, the person should have a review within two weeks. The appointment could also include a review of the effectiveness of the medication and whether any further changes or referral to other members of the care team are needed.

On cardiac rehabilitation, which can improve how well people do both clinically and in their quality of life, it must be offered at suitable times and at home, in the community or in a hospital.

Another five quality statements have been updated. These comprise:

- those with suspected CHF and referred for diagnosis have an echo and specialist assessment
- those with suspected CHF and either a previous heart attack or very high levels of serum natriuretic peptides have an echo and specialist assessment within two weeks
- those with CHF due to left ventricular systolic dysfunction are started on low dose ACE inhibitor and beta-blocker medications that are gradually increased until the optimal tolerated doses are reached
- those with stable CHF have a review of their condition at least every six months.

For details, see [nice.org.uk/guidance/QS9/chapter/qs9](https://www.nice.org.uk/guidance/QS9/chapter/qs9)

Ventricular tachycardia



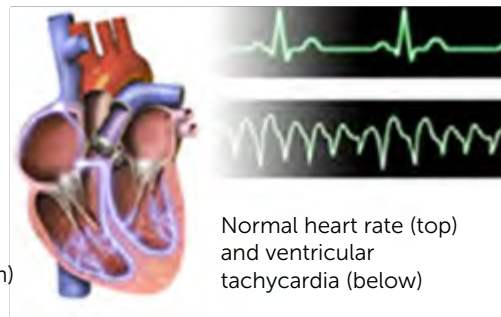
Robert Hall | cardiomyopathy support nurse, Cardiomyopathy UK

Our My Life series of articles on the heart rhythm problems that can occur in cardiomyopathy this time focusses on ventricular tachycardia

Ventricular tachycardia, sometimes known as VT, is a fast arrhythmia (heart rhythm) caused by abnormal electrical activity in the ventricles, the lower heart chambers.

The abnormal impulses arise from areas in the ventricle walls and interrupt the heart's normal conduction system. The exact definition is of a heart rate of over 100 beats per minute, with at least three abnormal beats in a row.

In some cases, and if the rhythm abnormality is left untreated, it could lead to ventricular fibrillation. This is where the electrical activity of the heart is chaotic and there is no effective pumping action, and therefore no output of blood. This is a cardiac arrest needing the person to be resuscitated.



Normal heart rate (top) and ventricular tachycardia (below)

Cardiomyopathy is one of the most common causes

Ventricular tachycardia will generally occur as a result of another condition, though sometimes the cause may not be known. The most common causes are cardiomyopathy and other inherited heart conditions, myocardial infarction (heart attack), or it may be associated with symptoms of heart failure.

Symptoms include dizziness and fainting

When ventricular tachycardia occurs many people will be aware of the palpitations and will experience symptoms caused by the reduced output of blood from the heart, such as dizziness, light-headedness and syncope. Some may also experience chest pains and a general feeling of anxiety.

Urgent treatment needed

Obviously ventricular tachycardia is an arrhythmia that requires urgent therapy. The initial treatment will be the emergency response, where it may be necessary to provide a shock to the patient's chest using a defibrillator.

To prevent further episodes drugs, such as amiodarone, may be prescribed and, in some cases, it may be possible to destroy the area in the heart muscle responsible for causing the abnormal impulses, by using a radio frequency ablation procedure.

Treating underlying conditions, such as heart failure, using ACE inhibitors and beta blockers, is also important.

NICE guidelines, published in 2014, recommend the use of an implantable cardioverter defibrillator (ICD) as a further treatment option in patients who have had a serious ventricular arrhythmia.

Where the heart is not pumping effectively the ICD may also be used in conjunction with resynchronisation therapy, using a combined ICD and biventricular pacemaker.

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](https://www.cardiomyopathy.org)



Gene therapy for heart failure on the horizon?

A potential gene therapy for treating long-standing (chronic) heart failure may soon start human trials.

Gene therapy is a largely experimental technique that uses genes to treat or prevent disease.

It can involve replacing a faulty gene with a healthy one, knocking out a faulty gene's ability to cause disease, and introducing a new gene into the body to help fight a disease.

Heart failure is when the heart cannot pump enough blood round the body to meet its needs, causing symptoms such as breathlessness and fatigue. It can affect people with cardiomyopathy.

The new treatment, carfostin, is an experimental treatment from NanoCor Therapeutics. It has recently been accepted by the US Food and Drug Administration as an investigational new drug. The company says this is an

important milestone, and it intends to start a phase one trial later this year in people with advanced chronic heart failure.

Carfostin is an intracellular protein therapy, delivering a therapeutic gene. It is hoped it will not only improve the heart's ability to contract but will also help reduce the heart's enlargement to a more normal size.

Dr Roger Hajjar, NanoCor scientific co-founder and director of the cardiovascular research centre at Icahn School of Medicine in New York, said: "Gene therapy is a viable option for the treatment of chronic heart failure, and our proprietary technology platform allows for targeted and minimally-invasive delivery of the therapeutic to the heart."



For more details see cardiomyopathy.org/gene-therapy

Children need better anaemia treatments

Further studies are needed to find better anaemia treatments for children with heart failure, researchers have concluded.

One in five children with acute heart failure has low iron in the body leading to a deficiency of red cells or haemoglobin in the blood. And this is associated with them doing less well, said researcher Dr Jason Goldberg, from Baylor College of Medicine in America.

Anaemia is widespread in adults with heart failure but the prevalence in children was previously unknown, Dr Goldberg told a conference on paediatric heart disease.

In the country's first national evaluation of anaemia in children with heart failure, his team analysed the records of almost 3,000

children (51 % boys) on a children's health database who were admitted to hospital between 2004 and 2013 with acute heart failure and dilated cardiomyopathy.

When the team looked at trends in anaemia treatment, they found that packed red blood cell transfusion and iron therapy had no appreciable effect on outcomes.

The research did not include children with infectious or inflammatory causes of heart failure, those who had had heart surgery, or those with hypertrophic or restrictive cardiomyopathy.



For more details, see cardiomyopathy.org/anaemia-treatments

Hypertrophic cardiomyopathy stable for many

Some people with hypertrophic cardiomyopathy (HCM) have obstruction to blood flow out of their hearts – while others don't.

Now a new study has shown that most people without the obstruction do not develop severe heart failure and are likely to live as long as the general population.

Contributing to the low mortality was the effectiveness of internal defibrillators (ICDs) and the fairly accurate ways doctors now work out which patients would benefit from them.

The research, led by Dr Martin Maron from the Hypertrophic Cardiomyopathy Centre at Tufts Medical Centre in Boston, is published in the Journal of the American College of Cardiology.

In a related editorial, Professor Perry Elliott, from the Barts Heart Centre in London, said: "The low mortality in this study can be seen as a testament to the beneficial effect of targeted therapy, specifically ICDs, heart transplantation and stroke prevention. However, the low annual death rate should not mask the fact that sudden cardiac death and progressive heart failure do remain a significant problem for some patients."

During the study, 90% of those with nonobstructive HCM remained in the lowest class of heart failure.



For more news about cardiomyopathy, see cardiomyopathy.org/news

Do heart checks save young athletes?

Heart checks should not be done on young athletes because there is no proof they save lives, suggests an analysis published in the British Medical Journal (BMJ).

The findings, researchers say, show that the harm outweighs any benefits, and there is no robust evidence to show it prevents deaths.

The study, from the Belgian Health Care Knowledge Centre, estimated that around 0.001% of young athletes die suddenly from a cardiac arrest every year, often caused by an underlying heart condition, such as cardiomyopathy.

For more details, see cardiomyopathy.org/heart-checks



Promising results for new heart pump

Many people with severe heart failure who receive a new advanced heart pump continue to survive a year on, says a new study.

The HeartMate 3 left ventricular assist device, from Thoratec/St Jude, won European CE Mark approval in October after a study showed more than nine in ten patients had survived to the six month stage. Now eight in ten are still living after a year.

The study of 50 patients included those waiting for a transplant and those receiving the pump as a treatment (called destination therapy). Three in four of the patients remained on heart support. In the UK, the devices are only approved on the NHS for those waiting for a transplant.

For details, see cardiomyopathy.org/heart-pump

Keep up-to-date with the news on our website

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



More families apply for IVF help



Picture courtesy of Guy's Hospital embryologists

Still more families affected by cardiomyopathy may soon benefit from special IVF treatment to help ensure their babies are not affected.

The Human Fertilisation and Embryology Authority (HFEA) has already granted licences to help some families with hypertrophic, dilated and arrhythmogenic right ventricular cardiomyopathy.

Now it is looking at whether to license pre-implantation genetic diagnosis (PGD) for two more sets of families – those affected by the MYH7 gene that causes dilated cardiomyopathy with left ventricular non-compaction and those with Danon disease, which can lead to both hypertrophic and dilated cardiomyopathy.

PGD is designed to give families affected by a serious disease the chance to go through IVF and PGD if they know the gene mutation in their family causing the disease.

The HFEA has already licensed PGD for dilated cardiomyopathy families affected by mutations on the Troponin T2 gene and in the Lamin A/C gene. There are also licences for hypertrophic cardiomyopathy caused by mutations on the MYBPC3 gene, and for families affected by arrhythmogenic right ventricular cardiomyopathy.

Cardiomyopathy UK and the Genetic Alliance UK, a charity representing over 150 patient organisations for those with genetic conditions, make submissions to the HFEA in favour of new PGD licences for families with gene mutations causing cardiomyopathy.

For more about the genetics of cardiomyopathy, see opposite page and cardiomyopathy.org/genetics-of-cardiomyopathy/intro

You can have a say on the granting of these licences by emailing pgd@hfea.gov.uk

What is PGD?

PGD 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.

Pregnancy cardiomyopathy genetic too

An international study involving heart experts in London has found that pregnancy related cardiomyopathy often has a genetic cause.

The condition, called peripartum cardiomyopathy (PPCM), affects women late in pregnancy or shortly after birth. It can cause breathlessness and palpitations and can be life-threatening.

Until recently, there has been no clear explanation why some women develop PPCM. Risk factors, such as high blood pressure and pre-eclampsia, do not explain most cases.

The researchers, looking at whether gene mutations for dilated cardiomyopathy (DCM) might play a part in PPCM, identified a sequence of gene variants in women with the condition, including in the TTN gene which is responsible for making the largest human protein.

Researchers at the Royal Brompton Hospital compared the prevalence of variants in 43 genes in 172 women with PPCM. Around 15 per cent carried variants that disrupted important heart genes. This was similar to the patients with DCM (17 per cent). In particular, 10 per cent of women with PPCM had mutations of the TTN gene, compared with just 1.4 per cent of the control group.

The researchers concluded that the results have implications for the way the condition is treated and may mean that relatives of PPCM patients should be offered the same genetic screening as families of patients with DCM.

James Ware, a consultant cardiologist at the hospital said: "Our findings explain a significant number of PPCM cases."



For more news about cardiomyopathy go to cardiomyopathy.org/news

Treatment appears safe for young

A type of treatment used in hypertrophic cardiomyopathy may be safer for younger and middle-aged people than previously thought, says a new study.

In the past young people with the condition and severe obstruction to blood flow out of the heart have usually been given a type of open heart surgery called a myectomy. In this procedure a small piece of thickened heart wall is surgically removed, allowing the blood flow to improve and symptoms, including breathlessness and fainting, to subside.

In older people a procedure called a septal alcohol ablation has been favoured. This involves injecting alcohol into the affected area of the heart via a vein, usually at the top of the leg. The alcohol then makes the nearby heart muscle cells slowly die, relieving the obstruction. Patients usually recover more quickly.

In the study, researchers from the Netherlands found that the ablation reduced symptoms similarly in young and elderly patients, and younger patients had a lower risk of developing electrical disturbances. Long term survival was good and the risk of cardiac arrest was low in both young and elderly patients, and comparable to HCM patients who did not have obstruction.

The team said ablation was not fraught with the high risk initially thought, potentially opening up the treatment to younger people and centres without myectomy expertise."



For more details, go to cardiomyopathy.org/procedure-safer

Genetic testing and cardiomyopathy



Judith Edhouse | genetic counsellor
Leeds Teaching Hospitals NHS Trust

Cardiomyopathy is often inherited and, in the majority of cases, each child of an affected parent has a 50:50 chance of inheriting it. Here Judith explains how genetics and testing work

I expect that some of you reading this article have been through genetic testing for cardiomyopathy. Most people will have heard of genes, as they are on the news fairly frequently these days. So what exactly is a gene?

Our genes are our internal instruction manual. They tell our body how we are going to develop and function. I think of them as a blueprint or a recipe book, which the body can read and then go and make the product.

Genes are made of DNA (which stands for deoxyribonucleic acid). Each gene consists of a long string of letters, which code for proteins. These proteins are the building blocks of our body, and they make up the physical parts we have – for example our heart muscles.

We have about 24,000 genes in each cell of our body. This may seem a lot, but it's far less than we originally thought we might have. If we really want to feel inferior, a rice plant has double the number of genes that we do. But the clever things about genes is that they can be read in different ways. So each one might be able to instruct for more than one job.

So, where do these thousands of genes come from? We don't create our own genes. They come from our parents, who got them from their parents and so on back through the generations.

Half of our genes come from our mother and half from our father. When we have children we only pass on half of ours because our partner provides the other half. This means we have a pair (two copies) of nearly every gene.

Now that scientists have decoded the entire human genome (all of our genes), we are starting to work out what job (or jobs) each gene has.

We have identified a number of genes which work together to build up the heart muscle correctly, and when someone has a cardiomyopathy, it is often because one of these genes isn't functioning properly.

This is caused by a spelling mistake, or alteration in the code, which means the body cannot read the gene, and therefore cannot make the protein.

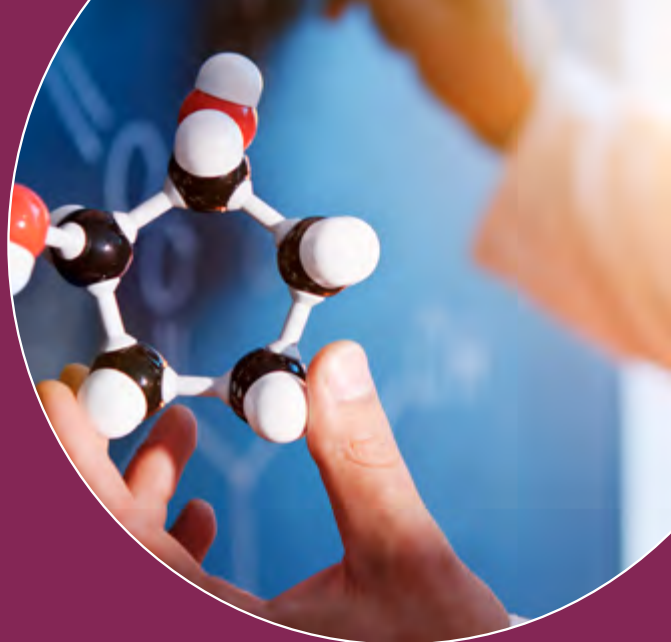
In order to make the protein, genes are read in triplets of letters. Each triplet codes for a small bit of the protein. To take an example of how a spelling alteration can change the way an entire gene works, we need an example of triplet words such as: the big dog ran for the bus

There are a number of ways we can disrupt this. If we delete (or add) a letter, the whole triplet reading frame shifts and makes no sense.

For example, delete the letter 'i' from 'big':

The bgd ogr anf ort heb us.

Or suppose we substitute the letter 'd' in 'dog' for the letter f:



The big fog ran for the bus.

Even a tiny change could disrupt the entire protein.

Another example would be to imagine I have a recipe for a jam sandwich, but someone has substituted jam for ham – it's only a one letter change, but a big difference to the outcome.

We also get normal variation within genes, and this is why we aren't all identical. Variations don't always stop the gene from working. So not all spelling alterations cause a problem.

It's the laboratories' job to work out what is and what isn't linked to the cardiomyopathy. Additionally some families may have more than one gene alteration causing the condition.

If we do find a gene alteration, then this is just the beginning. It may then allow other relatives to think about being tested (called predictive testing). Although with most inherited cardiomyopathies a child with an affected parent has a 50:50 chance of inheriting it, some forms of cardiomyopathy are inherited in different ways.

There are many considerations to discuss when opting for genetic testing, which can be done with a blood test or sometimes a saliva test. It is also important to think about the implications for other family members.

As our knowledge and technology increases, we may be able to get a better understanding of how our genes and proteins interact with each other, and what causes the variability between different people with the same condition.

Genetic counselling and testing are often available on the NHS, but this will partly depend on the diagnosis, family history and testing guidelines.

Testing and counselling is also available privately, including through Gene Health UK (genehealthuk.com).



Join our September Stroll



Get your walking boots on this autumn and walk, hike or trek your way around a September Stroll for Cardiomyopathy UK.

Our September Stroll takes place every year and we encourage all of our supporters to take part, show their support and raise funds and awareness. Invite your family and friends and organise your own local event, or join our very own #teamcardio walk in the Chilterns in Oxfordshire.

Visit our website for more information, resources and details of our Chilterns walk – cardiomyopathy.org/sep-stroll



2016 London Marathon: 26 miles, 47 runners, £100,000!

This year we had a record London Marathon team, with 47 runners taking on the 26.2 mile course on Sunday 24 April for #teamcardio. All the members of our fantastic team put in a huge amount of effort, not only with their training – clocking up between 20 and 40 miles a week for six months – but they also raised an incredible £100,000 by the end of April.

Our runners travelled far and wide to be in London for race day, each with their own story and reason to support Cardiomyopathy UK. Lisa Dyson and Julie Robinson travelled from Leeds to race their way around the capital, and Conor Nestor jetted over from Ireland with his family to join #teamcardio. A special mention goes to our first finisher on the day, Simon Shaw, who completed his 26.2 miles in an astounding 2 hours 59 minutes.

Thank you so much to all of our amazing #teamcardio runners and everyone who supported them in this incredible challenge – you did it!



#teamcardio highlights

Thank you so much to all our fantastic #teamcardio fundraisers. Our work would not be possible without you!

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

Super siblings



Siblings Ed and Alice took on their own Superhero Runs in London's Regents Park on Sunday 15 May. Ed tackled the 10km and Alice took on the 5km courses. Alice's husband has cardiomyopathy

Fundraising far and wide



Jess Walker and Bethan Smith took on a Jailbreak challenge – aiming to get as far away from Leeds University as possible in 48 hours. Jess, whose family have been closely affected by hypertrophic cardiomyopathy, and Bethan got to Milan – nearly 1,000 miles away – raising £689 in the process

Serving up success



Supporter Vanessa Owen hosted a tennis event in East Anglia in June in honour of her son who has cardiomyopathy. With a members' tournament and auction in the evening, the event was a huge success
Image credit: Stuart Beard

A night to remember



Graham Wilkinson from Leicestershire hosted a music night in memory of his son Tom on 23 April, which would have been his 21st birthday. Tom died in 2013 and his family and friends wanted to remember him and help support our work. The evening raised an incredible £1,500

Fantastic Fan2sia



Supporter Sarah Lofthouse Bishop held a Fan2sia theatre night in Leeds. Children from her Little Cherries theatre group performed songs from musicals, raising over £600. Sarah's son Marty has cardiomyopathy

Charity club



Colin Hammond has nominated Cardiomyopathy UK as his golf club's captain's charity. The club will be supporting our work all this year. His first event was a charity cup day in April which raised over £400



Spartan & Tough Mudder

Overcoming obstacles

We've got places in the Spartan Races and Tough Mudder in 2016

If running isn't challenging enough, add in some obstacles and test your mental and physical fitness along the way in these fantastic events:

Tough Mudder: The big one. Designed by the British Special Forces, this challenge will test your mental and physical fitness in running, walking, crawling and swimming your way round a 12 mile obstacle course. There are various dates and locations to choose from.

cardiomyopathy.org/obstacle/tough-mudder

Spartan Races: Challenging sprint obstacle trail races, with three levels of obstacles to choose from. Events take place between April and October all over the UK.

cardiomyopathy.org/spartan-race



Royal Parks — 9 October

Royal Parks half marathon

Run a half marathon through the capital and then enjoy a food festival

With its picturesque 13.1 mile course running through four of London's Royal Parks, this half marathon is one of a kind.

As well as the many runners taking part, thousands of spectators are also welcome to join in a food and fitness festival, cheer on their friends and family and share the experience.

Location - London
When - 9 October
Distance - Half marathon

To register or get more information please visit:

cardiomyopathy.org/royal-parks



Birmingham — 16 October

Great Birmingham run

Experience running through Birmingham city centre in this popular half marathon

Starting in the heart of Birmingham and continuing to wind its way through the city centre, this route will have you passing famous sights such as Edgbaston Cricket Ground.

Live music from bands around the course as well as the thousands of people cheering will motivate you all the way round.

Location - Birmingham
When - 16 October
Distance - Half marathon

To register or get more information please visit:

cardiomyopathy.org/great-brum

Great South Run

23 October



Experience the iconic sights of Portsmouth while making your way round this flat and fast 10 mile course. You will be taken through the dockyard which is home to HMS Victory, past the Spinnaker Tower and finish on the seafront with views across to the Isle of Wight.

To register or get more information please visit:

cardiomyopathy.org/great-south-run



Skydive for FREE!



Experience the ultimate adrenaline adventure and take on a skydive for Cardiomyopathy UK. This is a truly unforgettable way to fundraise. Attached to a professional instructor, you'll be given all the training you need on the day. We work with 14 skydive sites across the UK and, if you raise a minimum of £450, you get to jump for free!

To register or get more information please visit:

cardiomyopathy.org/skydive

GET INVOLVED

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



Dates for your diary

July

Saturday 9 July, 3pm - 5pm

North London Support Group

Finchley Memorial Hospital, Granville Rd, London N12 0JE

Cardiomyopathy support nurse Robert Hall on the psychological effects of cardiomyopathy

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

Saturday 30 July, 2pm - 4pm

Cheshire and Merseyside Support Group

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

Cardiomyopathy support nurse Robert Hall on the charity's helpline service and an update on new treatments.

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

August

Tuesday 30 August, 2pm

Cornwall Support Group

Inn for All Seasons, Treleigh, Redruth TR16 4AP

Speaker is Cardiomyopathy UK support nurse Robert Hall on the the psychological effects of cardiomyopathy

For more details contact Eric on 01736 351439

Wednesday 31 August, 7pm

West London Support Group

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

For details contact Willson Hau on 07777633398 or email him at willsonhau@gmail.com

September

Thursday 1 September, 7-9pm

Cheshire and Merseyside Support Group

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

Speaking will be Dr Thomas Giles, a consultant cardiologist from Royal Liverpool Hospitals Trust, on living with cardiomyopathy, and Sarah Quinlan, from the Countess of Chester Hospital Trust, on stress management and relaxation techniques

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

Saturday 3 September, 2pm

North East England Support Group

Function Room 137, Education Centre, Freeman Hospital, Newcastle

Speaker is cardiac rehabilitation co-ordinator Linda Llewellyn on rehabilitation and exercise

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

Sunday 11 September, 12-3pm

West Scotland Support Group

Boardroom, Glasgow Royal Infirmary from 12-3pm

Speaker to be confirmed. For more details contact Bob McConnachie on 07710 789581 or email mess@talk21.co.uk

October

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 - 4pm

Cheshire and Merseyside Support Group

Outpatient Department, Liverpool Heart and Chest Hospital, Thomas Drive, 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

November

Saturday 12 November

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

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**.



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