

myLife

The magazine for people affected by
cardiomyopathy and myocarditis

Issue 26/Summer 2021

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"As difficult as it was at times, the restrictions did have some benefits that I'll always be grateful for"

Jenny Taylor



"It's hard to have the freedoms you love taken away, and I hope people can reflect on this last year and really appreciate what they already have"

Jess Maranzano



Cardiomyopathy^{UK}
the heart muscle charity

**Read how our community
coped during the pandemic.
Pages 21-23**

Contact us

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

Call or write to us

 75A Woodside Road
Amersham
Buckinghamshire
HP6 6AA

 01494 791 224

Helpline

0800 018 1024

(free from a UK landline)

8.30am-4.30pm, Monday-Friday

Find us online

 www.cardiomyopathy.org

 contact@cardiomyopathy.org

Live chat

www.cardiomyopathy.org

8.30am-4.30pm, Monday-Friday

Social media

 /cardiomyopathyuk

 @cardiomyopathy

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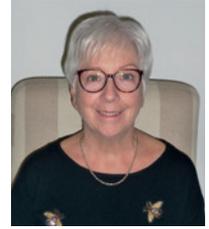
Cardiomyopathy UK is a charitable incorporated organisation (CIO) with a registered charity no 1164263

This magazine and its plastic wrapper is 100% recyclable

Front page images: Supporters Jenny Taylor (top) and Change Maker Jess Maranzano (below) with their families.

Designed by Hi Top Design

Resilience



As we look forward to COVID-19 restrictions being lifted our theme of “Resilience” gives us the opportunity to reflect on what we have been doing, and how we have managed during these extraordinary times.

Along with the challenges of managing a busy shielding household, homeschooling, achieving at least 10,000 steps each day (even if it meant marching up and down in the garden) and keeping up to date with friends, family and Cardiomyopathy UK - spending more time at home this past year gave me the opportunity to organise my time and think about what I want to do and get involved with. One of those decisions was to take on the role of Chair.

With more than 28 million people in the UK now having received the COVID-19 vaccination, we bring you the latest news and updates affecting people living with cardiomyopathy and myocarditis.

In this issue we hear from Jenny Taylor and Jess Maranzano who share their lockdown experiences during the pandemic on **pages 21-23**.

We acknowledge and applaud the achievements of two of our loyal fundraisers who used their time at home to support the charity. Katie with a very brave “head shave” on **page 18**, and John Newman who completed an amazing Land’s End to John O’Groats cycle ride **pages 15-17**. I think this beats my 10,000 steps! We welcome Charlotte Sills, to Cardiomyopathy UK; our new Head of Fundraising and Marketing.

We hope you and your family will enjoy our new children’s activity pack which features on **page 20**, and excitingly, here is a date for your diaries: our National Conference returns on the **Saturday 23rd October**.

I sincerely hope by our next publication date we will be able to see more of our loved ones and return to more of the things we’ve missed this past year.

Rita Sutton, Chair

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Land's End to John O' Groats - 15





By Joel Rose,
our Chief Executive

Our

RESILIENT

charity

It is fair to say that 2020 has been an incredibly challenging year for the charity, the people we help and for society as a whole. I am very proud of the resilience that we have shown and how we have worked together to meet the challenges that we have faced.

Thanks to the strength of our community, we have been able to continue our work and help more people than ever before at a time when they have needed us the most.

We were able to cope with a massive 300% increase in calls to our helpline and transform our support group network so we could keep providing much needed emotional support. We even

launched our new Coffee and Catch-Up group to create a much-valued opportunity for people to take a break from pandemic concerns. Remarkably, overall support group attendances was up 25% on the previous year and we were able to meet our targets for peer support work funded by the National Lottery Community Fund.

At the same time as managing the increase in demand on our helpline, we worked hard to make sure that we could meet the need to provide accurate and timely cardiomyopathy specific information about the pandemic.

"This service is vital without a pandemic but during it's been, in my opinion, another emergency service."

Service User



300%

increase in calls at the start of the pandemic



40%

increase in all calls

"It's a trusted source of information for me and I feel comforted that I have Cardiomyopathy UK in my life"

Service User



600 people joined our online conference from 20 countries



increase in online information accessed

42%



"Remembering that I am part of a valuable community is strengthening. Hearing from others is so valuable"

Service User



80% of service users are highly likely to recommend the service to others



132 support group meetings

increase in support group attendance



We worked closely with our network of clinical experts to provide regular information on our website. We also ran a series of Facebook Live Q&A sessions with Professor Perry Elliott and other experts that received a total of over 17,000 views.

When pandemic restrictions meant that we could not run our normal national conference, we adapted and moved it online so we could welcome over 600 people from 20 different countries.



17,000 views for our Facebook Q&A videos

The pandemic did not stop us from launching our Change Makers project, recruiting and training volunteers to work to improve their local cardiomyopathy services; nor did it hold up our research work or planning our Peripartum Cardiomyopathy campaign which was launched at the start of this year.

2020 was of course a very difficult year for fundraising. A large part of our income usually comes from our fundraisers running their own events and taking part in various challenges across the country. Pandemic restrictions meant that most of these fundraising activities could not take place. But our fundraisers really stepped up and we were amazed by their ingenuity and adaptability; taking on a host of online supporters from gaming competitions to virtual marathons. We were also really pleased with the response we had to our fundraising appeals and our 12 Days of Christmas Challenge.



increase in social media reach

Although the pandemic made things harder for our community fundraisers, we were able to increase the amount of support that we receive from charitable trusts such as BBC Children in Need and The National Lottery Community Fund. We were also able to increase the amount of income that we receive from companies for work we do to raise awareness, advocate for better treatment and educate clinicians. This income, along with support from the Government's COVID-19 fund, means that the charity remains in a good position for 2021.



93% of callers found their call very helpful

The remarkable resilience that the charity has shown over the past year is thanks to the efforts of our staff, supporters, volunteers, clinical advisors and the wider community. I want to thank them all for their work. It has meant that the charity has been able to support so many people and ensure that we can keep supporting anyone who needs us for years to come.

You can read our full 2020 impact report online. Visit www.cardiomyopathy.org/our-impact/our-impact

#BeatingforTwo

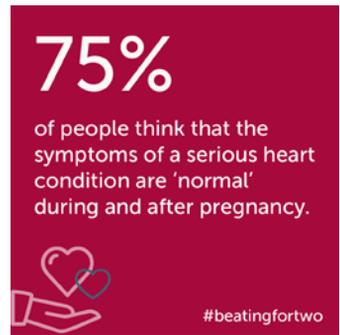
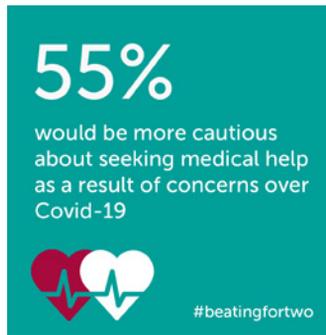
Despite COVID-19 dominating the news headlines; in January we launched our latest campaign #beatingfortwo, to raise awareness of peripartum cardiomyopathy (PPCM).

PPCM is a disease of the heart muscle that can develop during the last month of pregnancy, or the first five months after giving birth.

Cardiovascular disease is the most common cause of maternal death in the UK. PPCM accounts for 1/3 of this.



Our peripartum cardiomyopathy survey of the general public found that:



Our main aim was to inform people about this condition, and to empower them to understand and seek medical help. We produced factsheets on PPCM, and what are considered 'Normal' or 'Not Normal' symptoms for the heart during pregnancy.

We're delighted to share we received 32 items of coverage in the press including the Daily Mail, iNews, ITV Wales Lunchtime News and the Metro, reaching 5.5 million people.

Our #beatingfortwo campaign will continue throughout this year.

For more information about the campaign and to download our factsheets and resources, visit www.cardiomyopathy.org.uk/beatingfortwo

Preparing for your Virtual Appointment



By Jayne Partridge,
Cardiomyopathy
UK Support Nurse

The pandemic has changed how appointments are run with many taking place online. Nurse Jayne shares how to help you prepare for and get the most out of your appointment.

Golden 3 tips:

- 1 Have a notepad to take notes.
- 2 Write down any questions or concerns you may have about you and your needs.
- 3 Don't forget to say how you are feeling emotionally as well as physically



Top 10 tips:

1. If you are attending a virtual appointment, make sure you have access to video and are in a quiet space without interruptions.
2. Write down relevant phone numbers in case you lose connection.
3. If you can, allow time before your appointment to get organised. Have a copy of your last clinical letter and a list of your current medications; including the name, dose and how often you take them.
4. Make a note of new symptoms or change in existing symptoms, since your last appointment.
5. If you are advised to start new medication or alter the dose, find out how this will be communicated to you - for example, via a letter.
6. Write down any further tests or appointments you may need.
7. Ask your clinician to explain anything you don't understand.
8. Take your time, there's no need to rush.
9. Finish with next steps for your future care.
10. Visit Cardiomyopathy UK for further support or talk to one of our nurses on our helpline.



RESILIENCE

at the Heart of Our Community



By Ali Thompson,
Head of Services

2020 has been a year like no other in living memory, a global pandemic saw families separated, town centres deserted, and countries locked down around the world.

Given the speed with which COVID-19 spread, coupled with the lack of a cure or vaccination, nations of people were scared and experiencing a fear that they could not equate with anything they had encountered before.

Our community of service users, volunteers and staff were as affected to varying degrees of uncertainty and anxiousness. The familial aspect of the charity meant that we were able to pull together and build resilience as a means of coping with the short term and longer term challenges placed upon us by the pandemic.

Resilience can be defined as, “the capacity to recover quickly from difficulties; toughness,” and this is what we as a charity and community developed.

Resilience can be defined as, “the capacity to recover quickly from difficulties; toughness,” and this is what we as a charity and community developed. We responded to the needs for information, reassurance and inclusion from our service users in many ways. This meant that they were supported to grow and develop their own coping strategies and understanding in response to COVID-19. Volunteers and staff gave their free time over evenings and weekends to deliver support groups, helpline support and telephone peer support. March 2020 saw the highest number of calls responded to via our helpline since the charity’s inception. More telephone peer support volunteers than ever were trained and deployed to provide one to one support to service users. We released our mandatory online training course to create more peer support volunteers to provide even more community based services for our people. Our nurse team ensured that our helpline, Facebook groups and Live Chat services were extended so that more people could be helped and supported, and several key clinicians gave their time and expertise to answer questions from our community about COVID-19 through our Facebook Live channel.

One year on, we have seen a definite growth in resilience amongst our community with people identifying that they feel better able to cope, more hopeful about the future and less anxious than at the start of the pandemic.

As with many charities within the sector, we were also negatively impacted by a loss of income due to the cancellation of major fundraising events such as the London Marathon. However, our fundraising team, volunteers, services users and staff rallied, and we were able to raise some funds through creative, home based endeavours.

The respected, high calibre of our community peer support work was further instrumental in the charity receiving urgent pandemic restricted funding from the National Lottery Community Fund who currently fund our peer support services. The pandemic enabled us to think more creatively about how we included those in our community who perhaps felt isolated or alone and we reached out to more people via our weekly Coffee and Catch up sessions and newly created Facebook chat group.

Throughout the pandemic, our Board of Trustees with our CEO were committed to our community making sure that both staff and volunteers well being was prioritised. Newly home based staff teams were supported to continue to provide the best outcomes for the charity and for our community. One year on, we have seen a definite growth in resilience amongst our community, with people identifying that they are better able to cope, are more hopeful about the future and less anxious than at the start of the pandemic.

If COVID-19 has brought about one reflection for me personally, it is just how strong Cardiomyopathy UK is and how easily we are able to adapt and change alongside our community.

The huge part our volunteers have played in bringing about this strength cannot be undervalued, and we are grateful for everyone in our community who has helped us steer through choppy seas.



Children and Cardiomyopathy

Coping Well with a Diagnosis



By Emma Greenlade,
Paediatric
Support Nurse

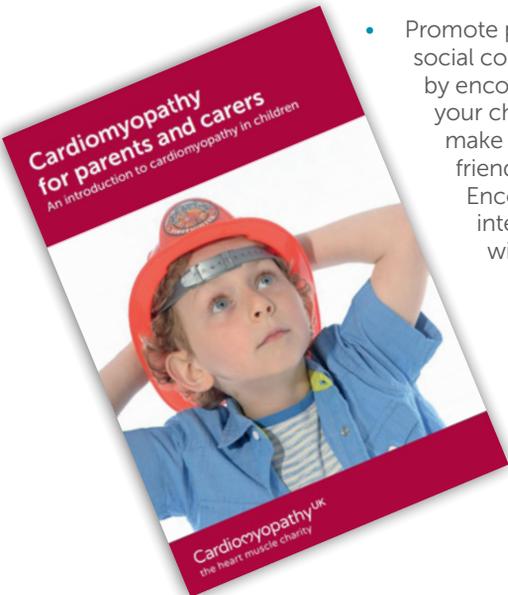
Children can be emotionally robust, and this is true when they are diagnosed with a chronic health condition such as cardiomyopathy. The following are some suggestions to help your child or young person better cope with and manage their condition.

Resilience is an important factor for those dealing with chronic illnesses and can be related to better coping by children and parents as they face significant illness-related stress.

- Encouraging your child's unique talents and interests can help boost resilience. Get involved in your child's education and activities. Encourage your child to develop skills and engage in activities and teach them how to find and use resources. Adolescents can greatly benefit from the independence to manage what's in their control.

- Promote positive social connections by encouraging your child to make and keep friends. Encourage interaction with peers.

- Provide consistent and clear expectations. Set, explain, and stick to rules and expected behaviours consistently and fairly. This fosters a sense of security and boundaries help children and young people feel secure.
- Try to reduce the sense of blame and guilt for your child. Many children feel guilty about having a chronic illness. Help them to understand that their cardiomyopathy is not their fault – and that's true for parents, too.
- Help your child label emotions in words and teach appropriate ways to express emotions, both negative and positive ones. You may not always agree with how your child is feeling, but validating feelings opens communication. Children need parents to listen.
- Increasing hope has been shown to support resilience in children. You can increase hope by trying to remain optimistic in the face of disappointment and helping your child focus on achievable goals.



Helpline

0800 018 1024

*(free from a UK landline)
8.30am-4.30pm, Monday-Friday*

You can get a copy of the booklet on our website here:

www.cardiomyopathy.org/booklets/

Practicing Mindfulness



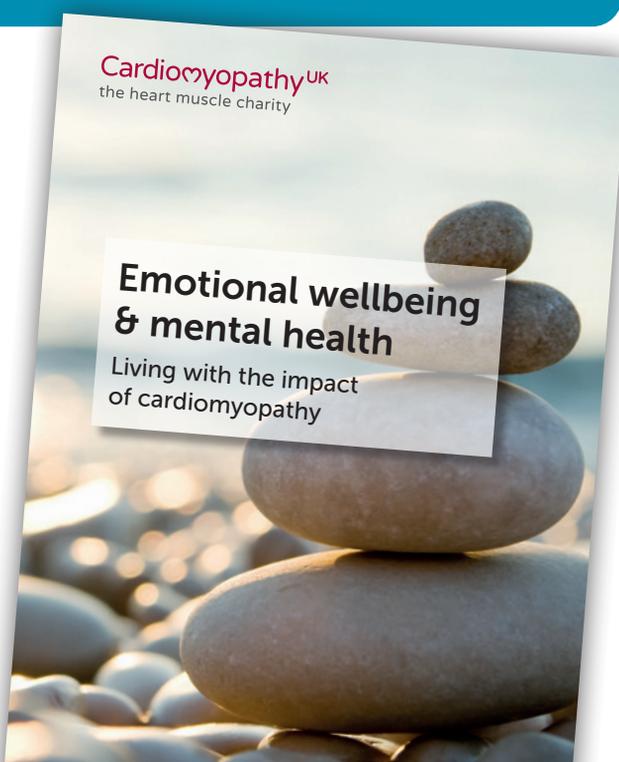
By Jayne Partridge,
Cardiomyopathy
UK Support Nurse

Question

Since my diagnosis of cardiomyopathy I feel uncertain about the future, I feel my world has changed, I want to try and focus in the here and now and worry less about the future.

Mindfulness can help people to calm and focus the mind, it can also help people develop ways to deal with stressful thoughts and feelings. Mindfulness is a technique you can learn which involves making a special effort to notice what's happening in the present moment (in your mind, body and surroundings) – without judging anything. It can help you to become more self-aware, feel calmer & less stressed, feel more able to choose how to respond to your thoughts and feelings, cope with difficult thoughts and feelings and be kinder to yourself.

Mindfulness can help to manage some types of anxiety, depression and feeling stressed.



Further information about mindfulness can be found in our Emotional wellbeing & mental health booklet which can be downloaded www.cardiomyopathy.org/emotional-health/emotional-wellbeing-and-mental-health-1

Cardiomyopathy

Change Makers



By Natalia Bartolome-Diez,
Policy and Advocacy Manager

We are really pleased to share our new, patient centred, Change Agenda.

This Change Agenda is for all who care about cardiomyopathy. It highlights what people affected by cardiomyopathy want at all stages of their healthcare pathway, to improve the care they receive and enable them to live well with their condition.

Read our full Change Agenda on our website:

www.cardiomyopathy.org/volunteering/cardiomyopathy-change-makers-



The Change Agenda is for all who care about cardiomyopathy. It highlights what people affected by cardiomyopathy want at all stages of their healthcare pathway, to improve the care they receive and enable them to live well with their condition.



Early detection and diagnosis

Many cardiomyopathy patients have struggled to receive an appropriate diagnosis, spending too long in primary care being treated inappropriately. Once diagnosed, many feel isolated, without opportunity to ask questions or with the necessary information to understand and manage their condition. Cardiomyopathy UK's support at the point of diagnosis has been a lifeline for many.

People affected by Cardiomyopathy want...

1. GP's to ask, and have on record, a detailed family cardiac and medical history, for potential cardiomyopathy symptoms to be identified in this context.
2. The use of a NT ProBNP blood test where the possibility of heart failure symptoms are apparent, and with guideline referral times to secondary care met when results dictate.
3. The referral process for diagnostic tests in hospital, through whichever point of entry, to be effective and timely.
4. To be seen by and cared for by a cardiologist, and if in hospital on a cardiology ward.
5. The cardiology team to deliver a specific cardiomyopathy diagnosis, where this is the cause of symptoms. This should be delivered in a sensitive manner, with the opportunity for further explanation available and a point of contact agreed.
6. The cardiology team to signpost newly diagnosed patients to Cardiomyopathy UK.

Improving specialist treatment

Once diagnosed, a cardiomyopathy patient can still struggle to get the specialist treatment and emotional and wellbeing support that they require. Patients often feel 'lost' in the system, confused about what is likely to happen next and how to access additional support.

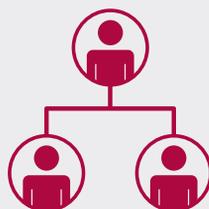
People affected by Cardiomyopathy want...

7. Mutually agreed 'Care Plans' encompassing their immediate and wider treatment plan, and indicating additional support arrangements, including devices. They want to be able to take these away and for them to be updated as required.
8. When newly diagnosed or actively symptomatic, Specialist Heart Nurses should explain and maintain care plans, as well as educate and enable patients to effectively self-monitor vital signs and symptoms.
9. Access to an integrated package of care appropriate to the needs of patients, covering the following areas: emotional and mental health support, sexual health and family planning clinics, prescription of tailored exercise, information on welfare rights and nutritional support.

The **top 3 improvements** to care and treatment that people want are:



quicker diagnosis, more emotional support and more practical support.



37%

37% had not been offered genetic testing for their condition.

17%



17% weren't informed by a health professional that their condition may be genetic.

Accessing genetic and family testing

Cardiomyopathy is often an inherited condition. However, awareness of the genetic nature of the condition and access to appropriate screening or genetic testing, including for their immediate family varies considerably between regions and UK nations.

People affected by Cardiomyopathy want...

10. All patients diagnosed with cardiomyopathy to be considered for genetic assessment and to understand the implications, with every hospital having this ability, or a clear and timely process of referral to an existing Inherited Cardiac Conditions clinic.
11. Genetic test results to be delivered, with all the implications explained, family testing initiated where indicated, and a point of contact established to address future concerns.

Ongoing care and support

Good quality services help individuals to understand their diagnosis, cope with the potential changes they need to make in their lives and support patients in doing so.

People affected by Cardiomyopathy want...

12. Access to cardiac rehabilitation services when prescribed, and for these to be personalised to individual needs.
13. Those with complex cross speciality needs arising from their cardiomyopathy to be cared for in a coordinated and multidisciplinary way.
14. Patients with negative genetic test results to be actively considered for further testing as new gene panels are identified.
15. An established point of contact for concerns outside regular reviews, including risk and symptom assessment.
16. Advanced/advancing heart failure patients, caused by cardiomyopathy, to be carefully monitored and supported, to enable referral to a Transplant Centre for assessment and on-going care at the earliest opportunity. This support should include:
 - Assistance with frailty, including support to access disabled parking badge, occupational therapist support within the home and 'pre-hab exercise programmes', where available.
 - Palliative care with an advanced care package to run ahead of and in parallel with route into transplant.
 - Referral for end-of-life provision for those patients judged unsuitable for transplant of Left Ventricular Assist Device.



Our Change Makers

What next?

Our Change Maker volunteers will work with the NHS alongside clinicians, commissioners and professional organisations to begin to implementing our priorities.

If you are interested in becoming a Change Maker, please get in contact with Natalia:
natalia.bartolome-diez@cardiomyopathy.org

John Newman

Fundraising story

Land's End to John O' Groats

"I was diagnosed with Dilated Cardiomyopathy in 2010. It was a shock to the whole family, but following my nephew and father's diagnosis between 2003 and 2010, not a total surprise.

I feel very well in myself and I know the signs of any symptoms to look out for.

In August 2019 I came across a manuscript that my Great, Great Grandfather Édgar John Wainwright had written of his Land's End to John O'Groats cycle ride in the 1930's. I issued this challenge to the rest of the family; and me, my partner Enrique and cousins Simon and Robert took on the socially distanced epic cycle ride in August 2020.

We covered 1021 miles and climbed 74,215 feet over 13 days as part of a team. I raised money for Cardiomyopathy UK.

Day 0: Penzance

I am nervously excited today about starting the tour tomorrow from Land's End. Our route begins in Cornwall which just scares the life out of me after driving through this morning.

The height of those hills is admirable, in a car. Cycling, we must be mad.

WHOSE IDEA WAS THIS!!

Day 1: Land's End to Lostwithiel: 67 miles, 6078 ft.

I am totally overwhelmed by the support and generosity of my friends and family. It really makes a difference cycling for a worthy cause rather than just to get painful legs!

I am so committed that the bike rests in the room with us tonight.



Day 2: Lostwithiel to Tiverton via Dartmoor. 78 miles, 8769 ft.

Today we finish Cornwall and are doing the epic climb up Dartmoor, which no doubt will break us at moments!

I'm hoping to lift my head up more today to take in the scenery. Yesterday I missed the Eden project because I was concentrating on the road!

Day 3: Tiverton to Bristol via Cheddar Gorge. 83 miles, 5079 ft.

An easy day today- I learnt that these lovely Lycra jerseys we are wearing come with a snack tray attached!

Our support team John and Anne are doing a sterling job at the stops.

Day 4: Bristol to Ironbridge Gorge. 103 miles, 6534 ft.

Great views, beautiful rural buildings and a signpost that reminded us what exactly we are doing. I'm upbeat but knackered; I think we were on the bikes at 7.45am this morning and finished at 6.30pm.

Day 5: Telford to Gradbach Mill. 69 miles, 5834ft ascent

We've totalled over 29,000 feet so far- the height of Everest!

I need a covid mask with mesh, just to keep the flies out!

I HAVE SWALLOWED AT LEAST FOUR TODAY.



Day 6: Gradbach Mill to Skipton, North Yorkshire. 79.95miles, 6886ft.

A fantastic day cycling around the outskirts of Greater Manchester and seeing all the Mill towns. The scenery and the overall amazing experience is starting to sink in; we are on our way to John O'Groats!

Lots of things ache more towards the end of the day. My palms of my hands from holding on and braking, to losing strength to turn the shower tap on.



Day 7: Skipton to Haltwhistle. 95miles, 8096ft.

A misty start in Skipton but the weather soon cleared with bright blue skies and sunshine all day.

We cycled through the beautiful Yorkshire Dales and up Fleet Moss. We hit the Cumbrian border, with the Pennines on our right-hand side and the Lake District on our left.

We travelled through lots of farmland and rolling hills, but it can be a lonely place. Playing little mind games with yourself helps- particularly when it came to the afternoon's monster climb at Hartside.

It was cold and we struggled against quite a northerly breeze. We hit the 1900 ft summit really fed up, but after two hours we arrived to a warm welcome and socially distanced support.

Day 8: Haltwhistle to Peebles – 80 or so miles, 6070ft.

We've now covered 680 miles and travelled for 7 straight days on our bikes!

There were a few climbs today which Enrique and I took steadily and we managed to come in only an hour later than the first group. We said farewell to our fantastic support team John and Ann and welcomed Nigel and Catriona.

I'm enjoying myself, but it is tiring and wearing.

MY BODY IS ACHING.

Day 9: Peebles to Perth. 66 miles, 3515 ft.

Queensferry was our one and only stop today so lunch was a little earlier. I think that set the tone for a bit of an 'eating day'. When we arrived in Perth we tried a couple of the local delicacies- a battered Mars Bar and a battered pizza slice. Both were delicious but didn't spoil our appetite for Macaroni Cheese and Creme Brûlée about an hour later.

I think there is a general agreement in our group that we want to get it done now after so many days peddling.

Day 10: Perth to Ballater via The Spittle of Glenshee. 66 miles, 3988ft.

The Spittal of Glenshee is an epic and stunning landscape: the hills and mountains were covered in pink flowers and green forest.

No tricky bits, no potholes, sheep or vehicles- I did a maximum of 44mph at one point!

Day 11: Ballater to Strathpeffer tackling the formidable Lecht. 94 miles, 6650ft.

We left Ballater after a night of thunderstorms (most of which I managed to sleep through), and luckily had beautiful sunshine all day. This made climbing the Lecht even harder than it was going to be. The climb in several parts was intense and I didn't stay on the bike much. It was all I could do to push the bike up the mountain (and probably quicker).

We were rewarded with spectacular views of the mountains, heather and grassland. We continued along through Inverness and onto Strathpeffer, enjoying the calmness of the shore side drive. It was early evening and the sun bathed us in golden light. Magical.

Day 12: Strathpeffer to Bettyhill. 87 miles, 3823ft.

Our second to last day started a little on the dull side and I found it difficult to really get going at first. Was it the weather or was I just feeling the toll of 11 consecutive days on the saddle?

It was chilly and rather damp but the view looking down onto the stunning Dornoch Firth was amazing.

Day 13: Bettyhill to John O'Groats. 50miles, 2893ft.

The final day. Would I actually make it? How was it all going to feel at the end of our journey?

Everyone had waited for us to ride the last two miles together. It felt a real honour to lead the team down the remaining roads with views of the Orkney Islands straight ahead.

IT FEELS AMAZING, but at the same time I'm sad to say goodbye to a great group of people who have travelled together over the last two weeks."



Our Incredible Fundraisers

Katie's New Look



In March, Katie bravely shaved her luscious locks to raise funds. Katie raised an incredible £420 and is rocking her new look. Katie said, "the reason I decided to fundraise for

Cardiomyopathy UK is because my mum has dilated cardiomyopathy.

In 2016, she was rushed to hospital with endocarditis (and later Sepsis) resulting in a 12 and a half hour operation that saved her life. As a family, we felt very supported by Cardiomyopathy UK and continue to feel supported".



Libby's 30-Day Challenge

We're in awe of Libby, who managed to stay away from chocolate through the whole of March for her 30-Day Challenge. With a fundraising target of £100, Libby completed her challenge on March 31st (with a big bar of chocolate we hope!).

Libby says, "I have been dreaming a lot recently about getting back to a sunny beach!

What better way to get 'beach ready' whilst simultaneously raising funds for Cardiomyopathy UK, than with a 30 day home challenge to give up chocolate!"



Angela's Birthday Fundraiser



Angela celebrated her lockdown birthday this year by setting up a Facebook fundraising page and asking for donations from

loved ones with whom she could not celebrate with in person. Angela fundraises in memory of her beautiful daughter Carly and raised a fantastic £375 through her birthday celebrations.

Stuart Milton - Car Wash

"After my good friend Ian passed from COVID I wanted to do something positive for myself and his family and friends. He and his family have been supported by Cardiomyopathy UK and it was his chosen charity. This felt like a good way to honour our friend.

Ian would have loved for everyone to know how appreciative he was for the help, support and advice they provided us with when his daughter Lucy was diagnosed with dilated cardiomyopathy and SVT back in 2001. He would feel he was paying something back to them and that's why it was his and our chosen charity."



If you are interested in fundraising with us, email:

fundraising@cardiomyopathy.org

Welcome to Charlotte

Last month, we welcomed Charlotte Sills to the team as our Head of Fundraising & Marketing.

I'm delighted to join the Cardiomyopathy UK team. I'm excited to develop how we engage with the wonderful people who use and support our services, and to create fantastic fundraising experiences.

I'm looking forward to getting to know our supporters, hearing their stories and hopefully later this year, meet some of our Cardiomyopathy UK family at our events.



If you'd like to get involved with us, I'd love to hear from you.

charlotte.sills@cardiomyopathy.org

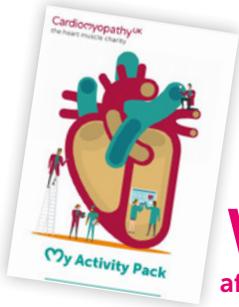
Cardiff Half Marathon

Sunday 3 October 2021

Fundraising
Target
£250

To register contact: fundraising@cardiomyopathy.org





Our Services for Children

We are delighted to announce the publication of our latest resource, aimed at children affected by cardiomyopathy who are in hospital.



By Sade McCarthy, Youth Support Manager

Our activity pack has been developed to enable children to understand a little better their surroundings and encourage them to talk to someone they trust about how they are feeling.

It is hoped that those clinicians supporting affected children in hospital download or order these packs. We believe they will make a positive difference to children who are admitted to hospital and who are likely to be frightened, feel isolated from their family and friends and need a resource such as this.

We hope the pack will provide reassurance to the child about their condition, as well as give information about what to expect during their stay in hospital.

Get your activity pack here: www.cardiomyopathy.org/bbc-children-in-need-in-hospital-activity-pack/bbc-children-in-need-activity-pack-

Hard copies are available to order via our resource information page.



This pack is one of its kind in the UK for children living with a diagnosis of cardiomyopathy and has been made possible by a grant from BBC Children in Need.

We have space for new panel members aged 14-18. If you are interested, contact sade.mccarthy@cardiomyopathy.org

Our Youth Panel members have been taking over Instagram!

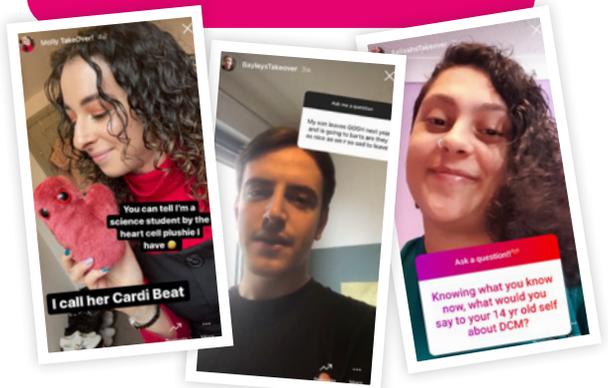
Here are just some of the topics and personal experiences they've shared:

- What it's like having a heart condition
- Taking medication
- How their condition impacts their mental health
- Genetic testing and regular check ups
- Moving from Childrens' Services to Adult Services
- How to get involved in our Youth Panel.

They hope to do more in the future, so watch this space. Plus you can now follow the charity on Tiktok.

 @cardiomyopathyuk

@cardiomyopathyuk **TikTok**



Jenny Taylor

As a family we have coped quite well during the pandemic in the grand scheme of things and luckily we've managed to stay safe.

My story

I was 5 months pregnant when lockdown was first announced and was told to shield. I have dilated cardiomyopathy and had always been told my heart may not cope with pregnancy so it was deemed very high risk.

When I was younger, I was told that having a baby would be too risky for me. I always wanted children so I found this really difficult to accept. After meeting my husband Mark, my dream came true as I had the honour of becoming Nate's bonus mum. My life was truly blessed.

As time went on, my heart function improved slightly and medical understanding and technology developed to a point where I was told a pregnancy would be very risky but could be managed. My husband and I decided that due to the risks we would only attempt a pregnancy once. We found out we were expecting a baby girl.



Our family is very close and I still find it so hard not seeing them. Zoom and phone calls are great but nothing beats a hug and a cup of tea with family and friends. I can't wait for the day that is allowed again.



Before lockdown we learnt that our landlord intended to sell our house. In February we found our new home but it needed a full renovation. We were confident we could get it all done before the baby came though, we still had 5 months to go after all! Everything came to a halt by April. Homeschooling was a big adjustment I don't think any parents were ready for!

My husband Mark was furloughed and I was granted leave due to my pregnancy risk so we spent great quality time at home with our first child (my step-son), Nate and our dog Ted. Sadly we lost Ted aged 3 due to epilepsy and I'll always be grateful for that time we had together as a family in his last few months.

I think the reason I managed to maintain my heart function throughout my pregnancy was because I didn't have the stressors of normal day-to-day life. I was forced to rest and take things easy, which I definitely would not have done otherwise. I also think my recovery from the c-section was better because I was forced to get on without my husband and had a new baby to look after.

The restrictions were devastating at times - this was the only pregnancy I'd ever have and it was so risky and I wasn't able to have the physical support of my mum, dad and sisters. My sister had planned a baby shower for me which was delayed and ultimately cancelled.





My family had to see the developing baby bump through windows and doorstep visits, and they missed out on feeling the baby kick and grow. This was my parents' first biological grandchild and my Nan's first biological great grandchild and they were very upset not to be a part of it all.

Our family is very close and I still find it so hard not seeing them. Zoom and phone calls are great but nothing beats a hug and a cup of tea with family and friends. I can't wait for the day that is allowed again.

At each scan appointment, I would pass a sea of expectant fathers all waiting outside the hospital for their partners. It was heartbreaking.

There were no pregnancy classes to go to and all my appointments had to be attended alone. This was particularly difficult during consultations with my cardiac team as my husband and family were anxious to know my heart was coping well.

At one point I had to be rushed over to the hospital because I couldn't feel the baby move. All was fine but whilst there all I could think about was the prospect of being told something was wrong, without my husband by my side. It was incredibly scary.

Although I had a planned c-section Mark wasn't allowed to accompany me into the hospital for the birth. He was asked to wait in the car for 3 hours until I was gowned up and walking into the operating theatre. He was then allowed to stay with us in

recovery and ICU until we moved onto a general ward. I know Mark found it very hard to go home without us.

Incredibly, Emily was born at 38 weeks weighing 6lb 10oz, without any issues.

Although we were able to form a support bubble with my mum and dad, the weighing clinics were closed and we could only speak to the health visitor on the phone.



Emily is almost 8 months old now and she still hasn't been able to meet some family members.

My mum made her a photo book with everyone's picture in it so she would recognise their faces. It's her favourite book!



As difficult as it was at times, the restrictions did have some benefits that I'll always be grateful for. We were given precious time as a family to play board games, make cakes, binge watch Game of Thrones and go on walks. We have lots of happy memories together from that time. I appreciate my family more and am grateful to all those who helped keep us safe.



Jess Maranzano



Jess Maranzano first experienced symptoms of cardiomyopathy 9 years ago. She has since been diagnosed with arrhythmogenic cardiomyopathy, and is a Change Maker (see page 12-14 for details).

When COVID hit the UK, I was just about to return to work as a nurse after having been off for several months following a shock from my S-ICD.

I was then in hospital for 3 weeks and had my S-ICD changed to a transvenous ICD so I could be paced and have the appropriate medication.

The day after the high list criteria was revealed was my 'return-to-work' meeting with occupational health. I was told whilst I may be physically fit to return to work; I was high risk so should shield with a view to working remotely.

I am a pre-assessment senior staff nurse and I assess patients ahead of their cancer surgery to ensure they are fit and well to proceed. I never thought I could work from home, but within a couple of weeks the way we worked as a unit changed completely.

I was working remotely whilst my husband was live teaching secondary school maths full time and home schooling three out of our four children. To make matters more complicated, our daughter was advised to shield too, so we chose not to use the key worker places at school.

The new routine took a bit of getting used to. My husband would be on duty with the kids when I was working to prevent interruptions. It was challenging but between us we managed somehow. We would get out in the garden, take part in the Joe Wicks work out videos and go out for family walks when we could.

We lost our childcare during this period and were unable to have grandparents help so it was challenging to say the least- especially when hospital appointments occurred. I had made lots of plans for 2020 to make up for the rough couple of years we had. Sadly COVID came along and took away these opportunities, so my lockdown has felt a bit longer still!

We purchased a projector and have started Saturday family film nights where we all sit together and get the popcorn out and watch a film together. This is now the highlight of the kids' week and we have kept it going.

I don't really need a reminder of how precious life is or how short it can be. I felt I had my wake up call after my diagnosis and defibrillator shock.

We lost a friend to COVID and working in the NHS and seeing what my colleagues have gone through has been heart breaking.



It's hard to have the freedoms you love taken away, and I hope people can reflect on this last year and really appreciate what they already have- and perhaps may have always taken for granted.



This pandemic has changed life so much for everyone, but hopefully it has made people more aware of how tough it can be living with uncertainty and restrictions on their lives: something people with cardiomyopathy do every day.

Save the Date!

Cardiomyopathy UK Conference

Saturday 23rd October 2021

